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School of Medicine, Dentistry and Nursing
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Developing a Nurse-led Palliative Care Intervention for Adults with Cancer and their Family Caregivers in the Resource-challenged Context of Indonesia

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Thesis submitted in fulfilment of the requirements for the
Degree of Doctor of Philosophy

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Abstract

Background: Indonesia is the fourth largest country in the world. The prevalence of communicable and non-communicable diseases is high. Cancer diagnosis and treatment are often delayed for more than three months due to limited resources, thus delaying treatment and appropriate supportive care. Indonesia also lacks a formal policy on services to support adults with cancer who need palliative care. Meanwhile, there is a culture that the family has responsibility for caring for their family members. This role increases the burden on family caregivers. In addition, nurses have a pivotal role in palliative care. This doctoral study aimed to identify the need for and develop a nurse-led intervention for adults with cancer and their family caregivers in West Java Province, Indonesia, which will be tested and implemented in postdoctoral work.

Methods: This study is a mixed-methods study carried out in four stages. Stage 1 synthesised evidence on palliative care service development in the countries listed as being in levels 1-3 of palliative care development to justify the main components of the service and suggest the appropriate modes of operation in Indonesia. Stage 2 investigated the current structure of the service, patient access, as well as the type of services and how they work. Stage 3 surveyed the level of needs and the burdens on people and family caregivers. Stage 4 involved gathering participants' views and expectations of a nurse-led intervention via semi-structured interviews. Ethics approval was granted by the University of Glasgow College of Medicine, the veterinary and Life Sciences Ethics Committee (ref no. 200180198) and Hasan Sadikin Hospital. Data were collected using a search strategy for the systematic review, document observation for the audit, surveys using four questionnaires, and an interview topic guide for the interviews. Descriptive statistics were computed and reported for the quantitative data, while thematic analysis was used for the qualitative data analysis. Integrated findings from all four stages were used to map the main components of the proposed new intervention and suggest its mode of operation in Indonesia.

Results: The systematic review suggested a model of care that allows for easy access to palliative care to mitigate burdens and fulfil supportive care needs. The audit found that palliative care development in West Java province, Indonesia, was slow and served few people due to the limited resources in the hospital. In the survey, the participants reported high need supportive care needs in all domains except for sexuality. The top highly need was discussing treatment with staff. All participants experienced a high level of needs and burdens regarding their illness and struggled to balance their living costs and their budget for cancer treatment, which increased the burden on the family. The interviews found that all participants had high expectations of a nurse-led intervention, which they determined would provide easier access to palliative care to help them meet their needs. Overall, the findings demonstrated a need for a nurse-led intervention that focuses on the following issues: 1) greater access to the 'superhero nurse’, 2) extending out the service to the community, 3) providing a low-cost intervention, 4) greater access to pain management, 5) more systematic assessment using patient reports, 6) more training for the family so that they can be more involved in patient care, that is, shared care with the nurse.

Conclusions and implications: Overall, palliative care in West Java team is developing slowly, and most participants reported a high level of need for supportive care. The overarching theme was the barriers to and challenges of providing a nurse-led intervention in a resource-poor setting. The suggested palliative (cancer) care service model developed from this thesis supports the physical, psychological, spiritual and financial components. The hospital- and home-care-based model uses qualified healthcare staff and volunteers. The findings will be valuable for enhancing the status of supportive and palliative care provided in West Java Province, Indonesia. Flexible and comprehensive nurse-led interventions should be developed to support family caregivers to fulfil their roles and sustain their quality of life. Reinforcing the role of nurses as part of the local multidisciplinary palliative care team is valuable because nurses are available 24 hours a day for patients. These results significantly contribute to the emerging literature on palliative care initiatives in resource-challenged countries.

Keywords: cancer, palliative care, person-centred nursing care.

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I remember you, my late sister Fery Puspa Purba. You ended my research journey through my experience of doing palliative care for you. I felt like I was writing your life experiences. I witnessed the miracles in your life story. When you got cancer in your 30s, you begged our God to give you a long life to care for your four young children and He did. Sixteen years later, in my final year, your cancer returns. You believed, kept your faith and begged God to heal you again through two surgeries. But Covid-19 stopped all your efforts. I collected my data two years before your cancer recurred. But rereading my findings made me feel like I was reading your life story. All my research findings represent your voice as a person with cancer in Indonesia. The incredible feeling when you were in end-of-life care and nothing can I do to help you. I was hoping to be able to accompany you to die in peace and dignity. I was fasting, crying and did not take a bath for one week full when you died in the cold springtime. I had no energy; I flooded my bed with tears and patiently walked through my grieving time. All sprung flowers remind me of you, for your name is PUSPA, which means beautiful flowers. I will bring Scotland's flowers for you, to be sown on your grave. Rest in Peace, my dearest sister. Till we meet again.

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Author’s Declaration

I declare that except where explicit reference is made to the contribution of others, this thesis is the result of my own work and has not been submitted for any degree at the University of Glasgow or any other institution.

Printed name: Chandra Isabella Hostanida Purba, SKp., M.Kep.

List of publications/dissemination of research

The following is a list of my publications and conference presentations resulting from the work in this thesis:

Publications arising from this PhD study

1. Developing palliative care in resource-challenged countries context of Indonesia. Authors Chandra Isabella Hostanida Purba, Bridget Johnston, Grigorios Kotronoulas, Journal Palliative Medicine Vol 4 Issue 1 (Supl). https://journals.sagepub.com/doi/10.1177/0269216320958098

2. An Exploration of Family Caregivers' Health Care Needs When Caring for Patients with Cancer in the Resource-Challenged Context of West Java, Indonesia, Authors: Chandra Isabella Hostanida Purba, Bridget Johnston, Grigorios Kotronoulas, Journal Seminars in Oncology Nursing, Publication date 2022/11/21, https://www.sciencedirect.com/science/article/pii/S0749208122001474

2. Involving patients and the public in nursing PhD projects: practical guidance, potential benefits and points to consider
Authors:Chris McParland, Bridget Johnston, Bahaa Alassoud, Maria Drummond, Annabel Farnood, Chandra Isabella Hostanida Purba, Muzeyyen Seckin, Saengrawee Thanthong. Publication date 2023/9/7. Journal: Nurse Researcher Volume 31 Issue 3 Publisher RCN Publishing Company Limited. https://pubmed.ncbi.nlm.nih.gov/37731298/

Conference presentations arising from this PhD study

1. 2019, Oral presentation at Three Minutes of Thesis (3MT) University of Glasgow, Palliative Care Intervention Needs for Adults with cancer in the Resource-challenged Context of Indonesia

2. 2020, Oral presentation at Three Minutes of Thesis (3MT), University of Glasgow, The Needs of Adults with cancer in Indonesia.

3. 2020, Oral presentation at Padjadjaran International Nursing Conference UNPAD, Online, An Exploration of Burdens Level in Caregivers of People Living with Cancer in the Resource-challenged West Java Province, Indonesia
4. 2020, Oral presentation at 3rd Bandung International Conference on Collaborative Health Research (BICCHR), An exploration of the Needs of the Family Caregivers of Cancer Patients in the Resource-challenged West Java Province, Indonesia

5. 2020, Poster presentation at European Association for palliative care (EAPC) International Conference in Palliative Care, Palermo, Italy, Developing Palliative Care in Resource-challenged Countries Context of Indonesia

6. 2021, Poster presentation at School of Medicine, Dentistry and Nursing Day, University of Glasgow, Nurse-led Palliative Care Views and Expectations among Adults with cancer, Family Caregivers and Staff of Palliative Care in West Java Province, Indonesia

7. 2021, Oral presentation at Three Minutes of Thesis (3MT), University of Glasgow, What Do I Expect on My Last Breath? (Patient’s interview)

8. 2022, Oral presentation at Three Minutes of Thesis (3MT), University of Glasgow, I Might Have Died Soon; I Am Worried About My Family! (Psychological reported outcomes among adults with cancer in West Java, Indonesia)
9. 2022, Oral presentation at School of Medicine, Dentistry and Nursing Day, University of Glasgow, What Should I Do to My Patient at their End of life? (Staff’s interview on Nurse-led Palliative Care views and expectations in West *Java Province, Indonesia*

10. 2023, Oral presentation at The 2023 STTI Alpha Beta Lambda at-Large Chapter Annual Meeting In Conjunction With The 16th Annual Padjadjaran

Nursing Conference and The 3rd Universitas Indonesia International Nursing Scholar Congress: "Good Governance in Nursing Education and Practice Post COVID-19 Pandemic" Unpad Training Centre Bandung (Hybrid), June 16-17, 2023. An exploration of burden level in caregivers of people living with cancer in The Resource-challenged West Java Province, Indonesia.

11. 2023, Oral presentation at WEST JAVA INTERNATIONAL NURSING SYMPOSIUM (WIJNS) Indonesia, 19 August 2023 'I might have died soon; I am worried about my family! (The patient worried about their family).

Definitions/Abbreviations

ASCO	American Society of Clinical Oncology
Askeskin	Asuransi Kesehatan orang miskin (Indonesia health insurance for low income)
ASEAN	Association of Southeast Asian Nations
BPJS	Badan penyelenggara jaminan Kesehatan (Indonesia health insurance agency)
DPIA	Data Protection Impact Assessment
E-o-L care	End-of-life care
ESAS	Edmonton Symptom Assessment Scale
GDPR	The General Data Protection Regulation
ICS	Indonesian Cancer Society
INNA	Indonesia Nursing Association
VAI	Visual Acid inspection
IPOS	Integrated Palliative Care Outcome Scale
Jabar	Jawa Barat, West Java Province
LMIC	Low- and middle-income countries
MMAT	Mixed Methods Appraisal Tool
M.Kep.	Magister Keperawatan (Master of Nursing)
Menkes	Menteri Kesehatan (Ministry of health)
NVivo	Software to code, develop the themes and generate the themes
non-RCT	Non-randomised controlled trials
NNPC	Neighbourhood Networking Palliative Care
NGOs	Non-government organisations
NHS	National Health service
PC	Palliative care
PRISMA	Preferred Reporting Items for Systematic reviews and Meta-Analyses
PROSPERO	International Prospective Register of Systematic Reviews
Puskesmas	Pusat Kesehatan Masyarakat (primary healthcare providers)
PPI	Patient/public and Public Involvement
PICO	Population, intervention, comparison, output

PROs	Patient-reported outcomes
POS	Patient outcomes scale
QoL	Quality of life
RS	Rumah sakit (hospital)
RI	Republik Indonesia (Republic of Indonesia)
RCT	Randomised controlled trials
SIF	Singapore International Foundation
SKp.	Sarjana Keperawatan (Bachelor of Nursing)
SCNS	Supportive Care Needs Survey
SCNS-P&C	Supportive Care Needs Survey-Partners and Caregivers
SPSS	Statistical Package for the Social Sciences
SWiMs	Synthesis without meta-analysis guidelines
SWOT	Strengthen-weakness-opportunity-threatened
TBC	Tuberculous
UK	United Kingdom
VIP	Very important person
WHO	World Health Organisation
YKI	Yayasan Kanker Indonesia (Indonesian Cancer Society)
ZBI	Zarit burden interview

Chapter 1 Introduction

1.1 Palliative care for advanced cancer in Indonesia

Indonesia's population is the fourth largest globally, with a population of 270,203,917 in 2020 (BPS, 2020) and a high level of burden of communicable (33%) and non-communicable diseases (58%) (Tati et al., 2020, Mahendradhata et al., 2017). Cancer incidence is 14 cases per 1000 people; this meant 19.30 million new cancer cases in 2020, while cancer-related deaths reached 10 million (Sung et al., 2021). Notably, 70% of patients in Indonesia are diagnosed with advanced disease; nonetheless, only half of them go on to receive treatment and supportive and palliative care (Kemenkes, 2019). Patients usually have to wait up to three months for treatment to begin (Kemkes, 2022) due to long diagnostic and treatment delays (Dwijayanti, Samosir and Herawati, 2020). Therefore, access to palliative care is either denied or delayed considerably, leading to suboptimal care for a considerable portion of patients with advanced cancer in Indonesia.

Palliative care is an approach to improving the quality of life of patients and families with chronic illnesses (WHO, 2020a). The World Health Organisation (WHO) works to strengthen palliative care by building evidence of effective palliative care models in low- and middle-income settings (Connor et al., 2021).

In 2020, only 50 countries were classified as providing advanced palliative care (Connor et al., 2020a). In the mapping of levels of global palliative care at the end of life, most resource-challenged countries, including Indonesia, are categorised as being in group 1-3, i.e., having isolated palliative care provision (Connor et al., 2014). This category is characterised by palliative care that is still patchy in scope and not well supported; sources of funding are often heavily donor dependent; availability of morphine is limited; and palliative care services are disproportionately limited considering the size of the population in question (Connor et al., 2020a). In general, the implementation of palliative care services is hindered by barriers in policy, education and implementation and the availability of medicines.

The Economist Intelligence Unit provided a white paper about the provision of palliative care globally. They ranked the quality of death in 40 countries based on

20 indicators (EIU, 2010). In 2015, 80 countries were included with 20 quantitative and qualitative indicators across five categories. Indonesia was placed 53rd in the rankings with a score of 33.6/100 (EIU, 2015). While Indonesia has made significant improvements in palliative care, implementation is still challenging. An important step was integrating palliative care into the national cancer control programme between 2014 and 2019 (Effendy et al., 2015a). However, a recent study declared that Indonesia lacks formal institutions to support long-term illness, as shown in the absence of hospice care and lack of policy related to palliative care (Effendy et al., 2015b). Specialist palliative services are mainly available on Java Island and specialised staff are available only in two cities (EIU, 2015.) Furthermore, legal restrictions hinder access to opioids, while difficulty in medication transportation across 17,000 islands and isolated communities with limited facilities and low public awareness further aggravates the situation (EIU, 2015).

Several facilitators for and barriers to addressing the significant demand for palliative care in Indonesia have been identified (Rochmawati, 2016a). Facilitators include government and volunteering organisations’ policies and cultural beliefs about the role of the family in caring for the patient. Recommendations have been made for specialist training in palliative care for nurses and doctors, advances in academic curricula and provision of education to families and communities (Rochmawati, 2016a). Nevertheless, Indonesia still suffers from a lack of awareness of cancer and a lack of belief in treatment, financial and emotional burdens, people having severe side-effects, a paternalistic style of communication and unmet information needs (Iskandarsyah et al., 2014a). Consequently, the family caregiver in Indonesia needs information on how to care for the patient at home.

Owing to the limited access to palliative and hospice care, the family primarily cares for patients with advanced cancer in Indonesia. The quality of care provided depends on the caregiving capabilities of the family. Indonesia has a communal culture whereby family members belong to one another (Riany, Meredith and Cuskelly, 2017). As such, the family generally provides care on a 24/7 basis (Kristanti, Setiyarini and Effendy, 2017b). This task is perceived as an obligation deeply rooted in cultural beliefs (Kristanti et al., 2018). Even though the Indonesian government established a national health system in 2014 (BPJS, 2019a), the patient and family are responsible for meeting expenses related to managing advanced cancer. Furthermore, Indonesia does not have a national pension scheme. Thus, the caring capabilities of the family are affected by their finances.

The palliative care and hospice care system in Hasan Sadikin has yet to be well developed in terms of the concept, system and policy, nor has any systematic evaluation/publication of it been developed in the hospital. However, an improved service is essential owing to the sharp increase in the incidence of chronic illnesses. The best way to provide palliative care in West Java could be started by refining the existing palliative care clinic in Hasan Sadikin Hospital and extending it to all districts in West Java. Nurse-led intervention can begin with a nurse's ability to assess patient needs and manage collaboration with another healthcare provider. The conditions in the hospital gave the researcher insight into developing a nurse-led palliative care service intervention in Hasan Sadikin Hospital. Therefore, the programme should be evaluated first to provide data to help develop its services by reinforcing the nurse's role. Mapping the data from the audit, the survey, the interviews and the systematic review will help the researcher provide a model of the services as soon as possible despite the hospital’s poor resources.

1.2 Personal motivation

In my third year of my Bachelor of Nursing Studies in 1998, I cared for an adult woman with breast cancer. Her giant tumour was gaping open like a volcanic eruption, leaving bloody and mostly pus-filled furrows with a powerful odour that everybody could smell from 10 metres away. The nurse had put her at the end of the ward; it was an eight-bed room. However, because of the odour, nobody wanted to stay in the same room with the patient. The patient said she wanted the doctor to cut her breast off to reduce her isolated suffering. However, the doctor said the patient could not have surgery because the cancer had already metastasised to several organs. The doctor had still not decided what the cancer treatment for the patient should be. The patient was in constant pain, but the doctor only gave her paracetamol. It was immediately apparent that it did not reduce the pain. At the time, patients, families and health workers avoided discussing care for those who were dying, and the quality of death.

The patients and families focused on hoping that the patient could still recover by following the treatment protocol in the hospital. They wanted the patient to stay at the hospital because no one could care for them at home. Families were also worried that taking the patient to the hospital would be complicated if the patient was getting worse because of the limited transportation and the step-by-step process for getting a bed in the hospital. Thus, the patient and family chose to stay at the hospital until the patient died. Previously, I had heard about hospice care and palliative care in Australia. There was no such hospice service model in Indonesia or curricula about palliative care at that time. I thought palliative care was just like hospice care, that is, for helping patients die in peace and in less pain and only for patients at the end of life. Nevertheless, I hoped there would be a place like that in my country.

After finishing my Bachelor of Nursing, I worked in the surgical-medical ward. Almost every day, I cared for a patient with cancer in the same scenario as that of the lady previously described. Nonetheless, 20 years later (2018-present), the situation of the lady is unchanged. Patients were suffering from pain and odour and still hoped they could combat cancer through medical treatment; their family stayed close to them in the hospital. Moreover, after Indonesia issued a health insurance programme for the population in 2014, there was a sharp increase in adults with cancer arriving at the hospital. The significant numbers and limited resources meant there was a long wait to receive treatment in the hospital. However, people with chronic illnesses still cannot access palliative services. Consequently, people die without receiving palliative care.

Thus, as part of this PhD project, I wanted to develop a nurse-led intervention to enhance the palliative care service offered at the hospital. I wanted to see people with life-threatening conditions living in the present moment and dying with dignity. Dying with dignity is one of the aims of palliative care (Dönmez and Johnston, 2020). My experience of caring for that lady in 1998 has motivated me to conduct research to help change current practice around palliative care in Indonesia.

1.3 Aim and objectives of this research

1. The aim of this PhD project was to present a mixed-methods study to evaluate an existing palliative care service and develop a nurse-led intervention for adults with cancer and their families for use in the resource-challenged context of Indonesia.
2. Objectives of this research:
3. Outline and justify the main components of the new intervention and suggest a mode of operation to guide future research.
4. Investigate the current structure, patient access and services provided by an existing palliative care service in Hasan Sadikin Hospital, Indonesia.
5. Investigate patients' and family members' needs and the burden of those members when accessing palliative care in Hasan Sadikin Hospital, Indonesia.
6. Investigate the views of patients, family members, health professionals and managers and their expectations of a future nurse-led intervention to address the shortcomings of the current service: what would stakeholders want this new intervention to offer in addition to the current service?

1.4 Research questions

1. What should the main components of an enhanced palliative care service be and what is the suggested mode of operation for implementation in the West Java context, considering contextual socioeconomic factors.
2. What is the current structure and mode of operation of the existing palliative care service, what is the range of services it provides and what are the patient characteristics and access rates?
3. What is the level of need and burden of adults with cancer and their family caregivers who go to Hasan Sadikin hospital?
4. What are patients', family members' and healthcare providers' expectations of and preferences and priorities concerning an improved palliative care service, what should the system look like and how would an embedded nurse-led intervention improve the standard of the care provided?

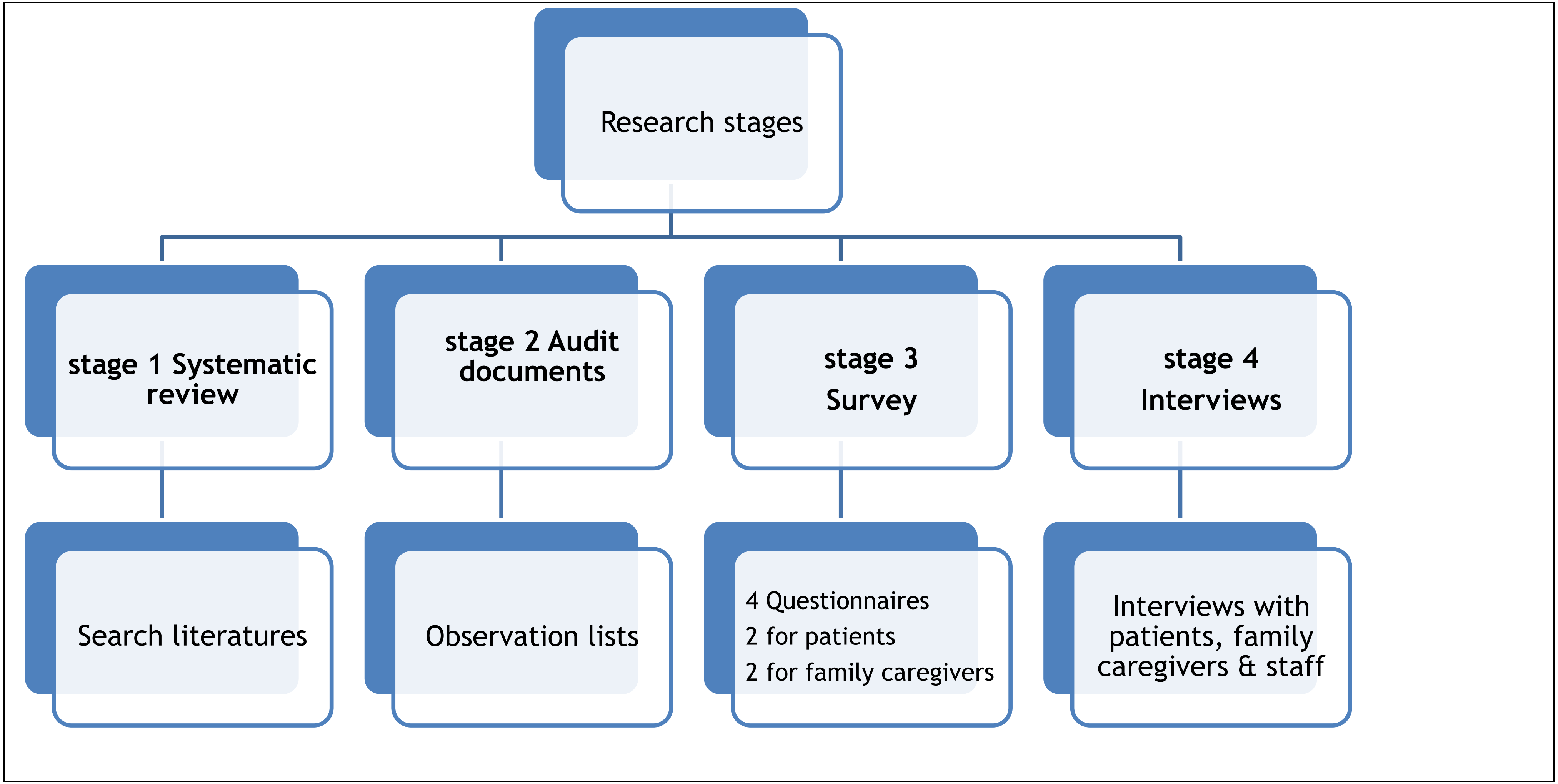


Figure 1-1 Research flow

1.5 Chapter summaries

This thesis is divided into eleven chapters, from the introduction to the conclusion — every chapter presents a detailed chronology of the research.

Chapter 1 introduces the Indonesian context, personal interest and motivation and scope of the research. The chapter describes why the researcher developed the research on the palliative care topic. The objective and research questions are presented in this chapter.

Chapter 2 presents details of the scope of palliative care both globally and in Indonesia. The literature examines the evidence concerning the development of palliative care, the quality of death and the action to push all countries to develop their palliative care service.

Chapter 3 outlines a systematic review using qualitative, quantitative and a mixed-methods study to find the organisational characteristics of palliative (cancer) care services developed for and implemented in level 1-3 of palliative care development.

Chapter 4 presents the approach to the literature on the selected methods, the reasoning paradigm and theory underpinning the research, and the background to implementing the theory.

Chapter 5 presents the findings from the audit documentation created by the palliative care team to describe how they run the service.

Chapter 6 describes the designs and methods used to answer the research questions, stage by stage. The rationale behind the methods used at every stage of the research are outlined in this chapter.

Chapter 7 presents the survey results and findings of stage two. The second stage presents the statistical level of the burdens and needs of supportive care of the patients and their family caregivers.

Chapter 8 presents the qualitative study. This details the interviews with the stakeholders about their views and expectations of palliative care.

Chapter 9 presents the qualitative study findings. The third stage presents the views and expectations of the palliative care stakeholders.

Chapter 10 synthesises each stage's results and discusses them in comparison to the relevant literature and research evidence, stage by stage.

Chapter 11 concludes with the major points and implications of this research for future research, practice and policy.

Chapter 2 Background to the Research Topic

This chapter provides a background from a broad literature review on palliative care. This literature examines evidence regarding developing palliative care for adults with cancer in emerging countries. The topic starts with palliative care, an overview of palliative care development in resource-challenged countries and developing palliative care in those countries. Then it moves to the need for palliative care in resource-challenged countries and for action regarding palliative care issues in Asia, emphasising the nurse role in resource-poor countries. Next there is an overview of Indonesia, including the demography of Indonesia, palliative care development in Indonesia, the palliative care service at Hasan Sadikin Hospital, the great demand for palliative care and support for and barriers to palliative care in Indonesia. It also includes an overview of palliative nursing, patient outcomes from nurse-led interventions and exceptional clinical care in palliative care.

2.1 Introduction to palliative care

The World Health Organisation (WHO) defined palliative care as 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' (WHO, 2020b).

In resource-challenged countries, the implementation of palliative care services can be hindered by barriers in policy, education and implementation and the availability of medicines (Yarney et al., 2013, Fadhil, Lyons and Payne, 2017, Qanungo et al., 2021). These barriers have a negative effect on patients and cause them to die with severe signs and symptoms (Setiabudy, Irawan and Sudoyo, 2015). The comfort level and needs fulfilment make people realise that death is a normal process (Gayoso et al., 2018). If their needs can be met at home, they will receive the option to die in peace at home (Hong et al., 2011). Nevertheless, people in resource-challenged countries still feel more comfortable dying in hospital because of the limited palliative care services in the community (Purba, Johnston and Kotronoulas, 2022).

2.1.1 Palliative care in countries with limited resources

Worldwide Hospice and Palliative Care reported that almost 53 million adults needed palliative care globally in 2020; most were aged 50-69 (27%) and 20-47 (26%) (Connor et al., 2020a). The proportion was relatively high in all regions; however, 76% of the 53 million adults were identified to be living in upper- and lower-middle-income countries, with the highest proportion living in low-income countries. The Lancet Commission on Palliative Care and Pain Relief noted that adults with cancer living in resource-challenged countries faced difficulty when accessing palliative care (Knaul, 2017). Therefore, they suffered from serious health complaints (Knaul et al., 2020). More than 90% of children who suffer from HIV AIDS living in Sub-Saharan Africa need palliative care (Harding et al., 2014). Around 97% of children who need palliative care live in low to middle-income countries, with a third of them living in low-income countries (Connor et al., 2020a).

Similarly, India, which has a population of over one billion, and where half of people live in poverty, needs more palliative care providers (McDermott et al., 2008). Although India already has several palliative care programmes, its programmes should adapt to the high demand for palliative services and lifestyle changes (Philip et al., 2018). Access to pain control was insufficient for 84.25% of the world population in 2010-2019, low- and middle-income countries only consumed 10% of global opioids, while 90% was available in high-income countries (Cleary et al., 2020). Therefore, their populations suffer from severe health problems (Knaul et al., 2018a). This data can be seen in the world map showing global distribution by WHO regions of rates for adults in need of palliative care below.

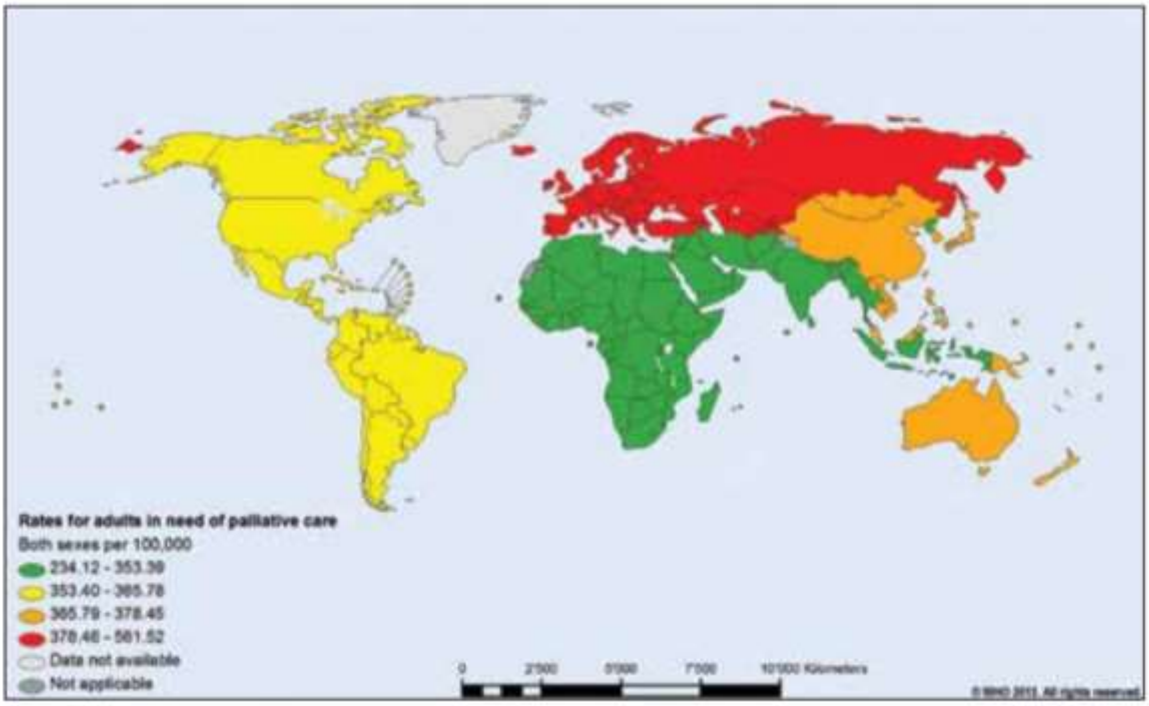


Figure 2-1 The global distribution by WHO regions of rates for adults in need of palliative care for progressive non-malignant disease at the end of life

Source: Distribution of adults in need of palliative care at the end of life by WHO regions. © 2014 Worldwide Palliative Care Alliance, All Rights Reserved.

The orange section of this map shows that in the Southeast Asian region, 36579-37845/ 10,000,000 people needed palliative care (WPCA, 2014). Furthermore, 22% of the worldwide population in need of palliative care, lived in this area as the second-largest population (29%) after the West Pacific Region (Keeling, 2015). Asian countries face issues such as having large populations, significant geographical variation such as having archipelagos, and ethnic, social and economic differences (Singh and Harding, 2015a). Natural disasters cause large numbers of deaths and injuries and the victims are forced to relocate or become refugees (Guo et al., 2021). These countries also need help with excessive health financing difficulties; the healthcare budget requirement competes with funding used to meet basic needs (Harding et al., 2013). Lack of professional health personnel, poor infrastructure, limited health research and data, lack of education and academic networks, the location of rural areas, mismanagement of resources (corruption) and false health myths together mean that health issues are only solved after other issues are solved (Singh and Harding, 2015b, Maharaj and Harding, 2016). Consequently, people suffer starvation and malnutrition and get limited treatment (Thomsen et al., 2013).

An evaluation is needed to find out what prevents countries with low resources from having effective palliative care interventions (Potts et al., 2018). Previous studies have suggested that healthcare providers and stakeholders should use the American Society of Clinical Oncology guidelines on palliative care service recommendations without replacing local guidelines (Osman et al., 2018). The local wisdom and guidance could help people feel in their comfort zone until they die with peace and dignity (Qanungo et al., 2021, Ibrahim et al., 2021).

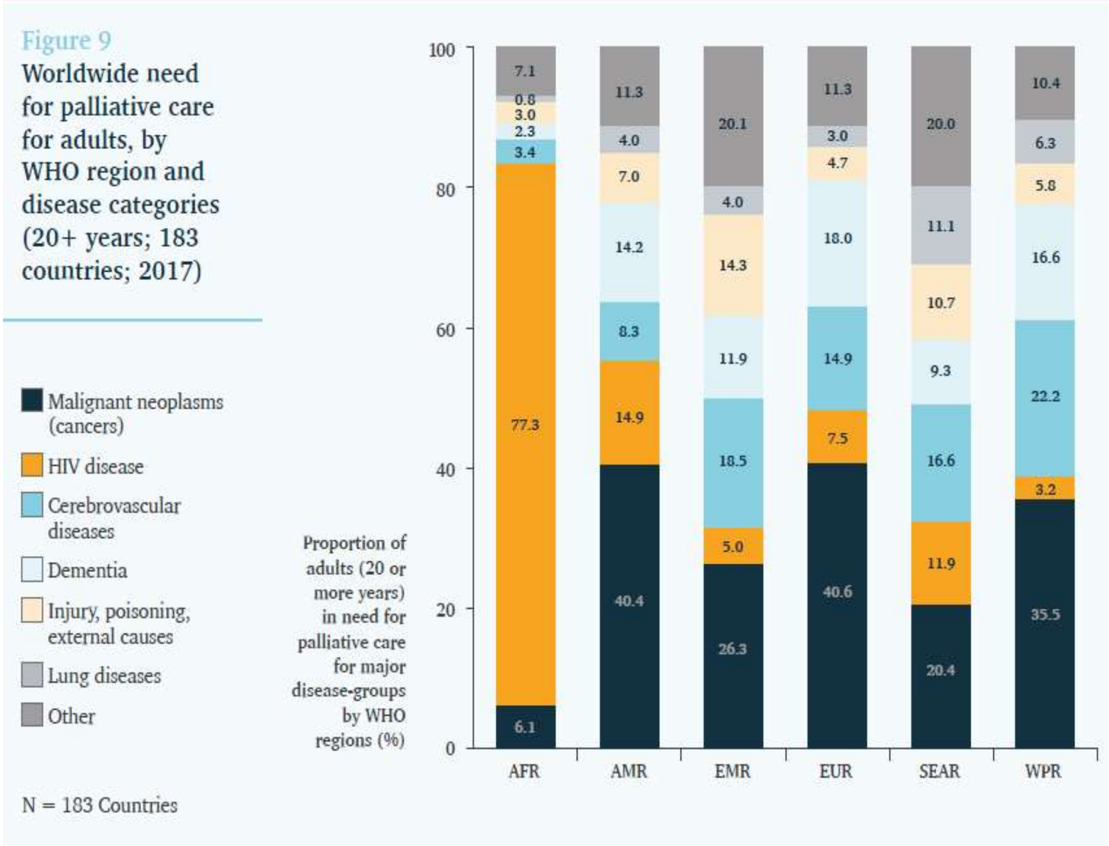
2.1.2 The need for palliative care

The need for palliative care services has increased sharply worldwide due to the incidence of chronic illnesses (Centeno and Arias-Casais, 2019). The Global Atlas of Palliative Care estimated that in 2014 over 20 million people needed palliative care; three-quarters of them lived in the Western Pacific, European and Southeast Asia regions and 78% of them lived in low- and middle-income countries **(Baxter et al., 2014, Connor et al., 2014)**. This number doubled to 56.8 million in 2020 with 25.7 million people in need of end-of-life care (Knaul et al., 2020). Furthermore, in 2020, the Worldwide Palliative Care Alliance reported that 76% of those people who need palliative care were living in upper- and lower-middle-income countries, mainly in Asia and Africa (Connor et al., 2020c).

In addition, the Lancet Commission on Palliative Care and Pain Relief noted that more than 12.2 million adults with cancer in resource-poor countries had difficulty accessing palliative care **(Connor et al., 2014)**. Hence, palliative programmes should adapt to the burden of and the high demand for palliative services and to population changes (Philip et al., 2018).

The highest ratio per 100,000 adult population who need palliative care can be seen in Figure 3-1, which shows the global distribution by WHO regions (Connor et al., 2020a). The need for palliative care is grouped based on seven diseases: cancer, HIV/AIDS, stroke, dementia, injuries and other malignant diseases. Most adults in all regions who need palliative care have non-malignant diseases, except in Africa, where HIV/AIDS dominates. ‘The proportion of adults needing palliative care for cancer is relatively high for all regions. It ranges from 6.1% in the African to 41.3% in the European and 40.8% in the American Region’ (Connor et al., 2020a).

This data could be used to indicate that there is a flawed healthcare system in those countries.



The regions of the World Health Organisation: AFR= Africa region, AMR=America region, EMR= Eastern Mediterranean Region, EUR=Europe region, SEAR=Southeast Asian region, WPR=Western Pacific region.
Source: (Connor et al., 2020a), p23. © 2020 Worldwide Palliative Care Alliance, All Rights Reserved

Figure 2-2 Worldwide need for palliative care for adults, by WHO region and disease categories (20 + years; 183 countries; 2017).

The Global Atlas of Palliative Care at the End of Life reported in 2014 that advanced integration of palliative care with broader health services had been achieved in 20 countries only (Baxter et al., 2014, Connor et al., 2014). These are categorised as group 4: Australia, Austria, Belgium, Canada, France, Germany, Hong Kong, Iceland, Ireland, Italy, Japan, Norway, Poland, Romania, Singapore, Sweden, Switzerland, Uganda, United Kingdom and the United States of America

(Baxter et al., 2014, Connor et al., 2014). In 2020, 50 countries made it to group 4, mostly European, with only six from Asia (Thailand, China, Singapore, Japan, South Korea, Mongolia) and five from Africa (Côte d'Ivoire, South Africa, Uganda, Zimbabwe, Malawi) (Connor et al., 2020a). The countries in groups 1-3 have barriers regarding policy, education, implementation and the availability of medicines in palliative care (Connor et al., 2020c). The way these countries develop their services for patients with cancer will help enhance the development in other countries with the same background (Singh and Harding, 2015a).

There was a slight improvement in palliative care in resource-challenged countries (Connor et al., 2020c). Some of them sharply developed but most are still in group 1. The countries that made significant progress in national policy were Colombia, Denmark, Ecuador, Finland, Italy, Japan, Panama, Portugal, Russia, Singapore, Spain, Sri Lanka, Sweden and Uruguay (EIU, 2015). They have successfully updated their guidelines, laws and national programmes. Their report showed that the government’s role is the most significant factor.

However, some countries with poor resources could improve their services with community support (Connor et al., 2020b), using its local resources and wisdom (Aditya, 2019). Similar reviews show that the community is also an important support regarding improving palliative (Aditya, 2018). However, not many reviews identify the main components and modes of the services or the background of staff. Little is known about the main components, the model of the service and the requirement for human resources in resource-challenged countries when they are developing their service. The way those countries develop their service with limited sources can be a model to the same background countries. Identifying problems when developing the services will help to find the components needed. The purpose of this review was to identify the organisational and operational characteristics of palliative (cancer) care services developed for and implemented in resource-challenged countries. It can be used as a recommendation for other resource-challenged countries that want to develop their palliative care. It will give clear directions about what steps should be taken and what factors must be considered, what seems to work and what does not, and what resources are necessary and at what cost.

2.1.3 Action to address palliative care issues in Asia

To overcome the lack of palliative care issue, the Association of Southeast Asian Nations (ASEAN) held a Jakarta Call for Cancer meeting in 2012, developing the 'Healthy Association of Southeast Asian Nations 2020 Vision' to push these countries to prioritise the cancer problem by developing programmes to prevent and control cancer, strengthening research, building strategic multi-sectors, investing in health insurance and promoting collaboration between the public and private sectors, and providing cancer databases (Woodward, 2014). The Jakarta Call realised that almost 500,000 patients with cancer died in Asia in 2008 without enough treatment and without enough preventive action and this figure has tended to increase. Asia also had a heavy cost burden and a lack of policymakers working in relation to cancer treatment (Connor et al., 2014).

Based on this fact, the Jakarta call developed the healthy ASEAN vision to push the countries' Ministers of Health to prioritise non-communicable diseases (Woodward, 2014). The vision also acts as a recommendation to the members to develop programmes to prevent and control cancer, strengthen the role of researchers, build strategic multi-sector organisations approaches, apply investment insurance health and encourage the private collaboration sector - civil societies - to provide a cancer database. The Association of Southeast Asian Nations countries at the time has no available data on cancers, except Singapore and the Philippines (Jan et al., 2012).

2.1.4 Overview of palliative development in countries with limited resources

Regarding the development of palliative care in resource-challenged countries, in 2008 the World Health Organisation called on its members to develop national cancer programmes, including early detection, prevention, quality of care and palliative care (WHO, 2020a). There is a prediction that cancer incidence in Asia will grow sharply, with 10.6 million cases in 2030 (Kemenkes, 2019). The American Cancer Society also predicted that in 2012 there were 786,400 cases and 528,500 deaths by cancer in Asia (Sankaranarayanan, Ramadas and Qiao, 2014).

Despite all problems, one grassroots community in Kerala, India, successfully created palliative care services in the 1980s with local people, called Neighbourhood Networking Palliative Care (NNPC) (McDermott et al., 2008). Although it gets little funding and there is a lack of policy and support from government, community volunteers and healthcare providers are active in the running of the programme (McDermott et al., 2008). This model grew from solid community support and can be replicated easily by other districts (Philip et al., 2018). In addition, one study noted that Namibia, Africa, had great success in dealing with the barriers to palliative care through community roles (Singh and Harding, 2015a). The Namibian community can support patients with tuberculosis to consume medicine by observing the patient directly. Palliative care in a low-income country can be improved with the input of local wisdom (Rochmawati, Wiechula and Cameron, 2018b), which shows that palliative care can be initiated by a community with minimum support from the government (Azeez and Anbuselvi, 2021). This is also evident because most people in Asian-African countries have strong community relationships (Singh and Harding, 2015a).

In contrast to the stagnant growth of palliative care in low- and middle-income countries, there are solutions for developing programmes and for enhancing the service (Cleary et al., 2020). The first step can begin by identifying important elements with consultation screening tools, and then appropriate palliative services can be provided, for example opening consultation services, inpatient units and clinic outpatient units (Smith, Coyne and Cassel, 2012). Various models of palliative care in low- and middle-income countries have been evaluated and gaps have been found that there is inadequate provision of care and interventions for the numbers of people in these countries that these kinds of evaluations needs (Potts et al., 2018). The strategy for enhancing palliative care includes identifying research priorities, funding, costs, training and mentorship programmes (Thomsen et al., 2013). A similar study in Sub-Saharan African described the barriers to enhancing palliative care: the impact of poverty on illness-related problems, a lack of funding, policy and strategy, customs, language, geography and the habit of seeking health via traditional healers (Taleb, 2018). Collaboration between resources and community readiness is a good preventive measure (Hannon et al., 2016a). Nevertheless, palliative care services should be sensitive to cultural and social norms (Alassoud, Johnston and Hogg, 2020).

Partnership with other organisations is one of the most effective strategies for educating people in improve palliative services (Partridge et al., 2014). Nurses can be leaders as professional health personnel in hospice care development to decrease the global burden (Downing et al., 2023). Nurses have a strategic role in supporting patients' palliative care to do their regular daily activities where possible and control their health problems for as long as possible (Johnston et al., 2014b). This strategic role is related to the fact that they are the person who spends the most time at the patient's bedside and they coordinate helping people fulfil their needs whenever they cannot do so alone (Keeling, 2015). In addition, the nurse serves people during the dying process until they die with peace and dignity (Östlund, Brown and Johnston, 2012).

2.2 Overview of palliative care development in Indonesia

2.2.1 Demography of Indonesia

Indonesia has the fourth largest population in the world and is the largest country in Southeast Asia, with people living on approximately 17,504 islands consisting of 514 districts, 8,480 sub-districts, 704,457 villages, 1200 tribes, 600 ethnic languages and seven different religions, with Muslim constituting the largest population (87%) (BPS, 2014). It has five of the biggest islands, Sumatra, Java, Borneo (Kalimantan), Sulawesi and Papua. Indonesia shares three islands with Malaysia and Brunei Darussalam in the northern part of Borneo Island, with Papua New Guinea in the eastern part of Papua Island and with Timor-Leste in the southeastern part of Nusa Tenggara Timur island. Indonesia is situated from 6°08′ N latitude to 11°15′ S latitude and from 94°45′ E to 141°05′ E longitude in the equatorial tropical horizon. It is also the most varied archipelago, covering 1,904,569 square km (735,358.202 square miles), and lies between the Pacific and Indian oceans; it is 3,200 miles from its easternmost point to its westernmost point and 1,100 miles from its northern-most point to its southernmost point'. It takes seven hours to fly from the western part to the eastern part, which affects the cost of getting treatment in a referral hospital (EIU, 2015).

Indonesia lies in the ring of fire of active volcanoes (Masum and Akbar, 2019, Blair, 2010) and has thousands of dense rainforest mountains. There were 77 active volcanoes in 2020; 27 had not erupted since 1600 and 21 had never erupted but still had volcanic activities (BPS, 2021). This situation causes several natural disasters for thousands of people who live nearest to the mountains. The evacuation caused by the volcanic eruption in 2020 affected 15,853 people (BPS, 2021). Others were affected by floods that caused 4,466,207 people to be evacuated, submerged 15,813 people and damaged 848,169 houses. The most notable natural disaster was the eruption of Mount Tambora, 8,930 feet high, in 1815 (Almanac, 2021). It was the largest in history and killed 71,000 people (Almanac, 2021, Cao, Li and Yang, 2012). Its explosion was heard as far as 2000 km away and made summer freezing in western countries, 1816 was known as the year without a summer (Brázdil et al., 2016). It also caused snow in summertime, between June and August in America, Europe and Asia, and affected crops, which failed to grow (Almanac, 2021, Britannica, 2019).

The happiness index is moderate, 65.98 (100 scales), with a score of 65.98 for the personal subdimension and 76.16 for the social subdimension (BPS, 2021). Aspects of the satisfaction level are health (69.7%), education (69.7%), family harmony (78.9%), leisure time (71.7%) and social relationships (74.3%). Figure 2-2 shows a map of Indonesia with a red arrow pointing to West Java Province.

Retrieved from https://www.worldatlas.com/maps/indonesia

Figure 2-3 Map of Indonesia.

According to Indonesian statistics, in 2020, the population was 270,200,000 with a population growth of 1.25%, an infant mortality rate of 17.6 per 1000 live births, a life expectancy of 73.4 years, a human development index of 71.9, a literacy age of aged 15 and above for 96% of the population, a gross domestic product of 15,434.2 trillion rupiah, (£8,334,468 billion or $1058.42 billion USD), and a percentage of poor people of 10.19% (BPS, 2021).

Indonesia faces an increase in HIV/AIDS, cancer and other chronic illnesses cases (Suryati, 2016). Cancer incidence is 14 per 1000 people, with 70% of patients found in the end stages; however, only half continue medical treatment (Menkes RI, 2017). Patients with cancer are often diagnosed at the end stage when symptoms such as large tumours, persistent bleeding, tumour ruptures, pus and various other complaints are present (Nuranna et al., 2012a).

The significant increase in the prevalence of cancer has led to a severe problem as cancer treatment centres can treat only 15% of patients (Kemenkes, 2019). Only three hospitals with a total of 434 beds are available to serve 3,676,463 patients with cancer (Kemenkes, 2020). Around 300 patients with cancer go to hospitals every day (Nursalikah, 2019) and wait three months for their first chemotherapy treatment due to the limited number of hospitals, which delays treatment and getting appropriate supportive and palliative care (Kemkes, 2018). Furthermore, 5.7% of the total mortality in Indonesia is related to cancer (Anggraeni, 2011).

2.2.2 Palliative care development in Indonesia

There is limited evidence about palliative and hospice care in Southeast Asian countries and the Asian continent, especially in Indonesia until 2014 (Woodward, 2014). A recent study declared that Indonesia lacks formal institutions to support long-term illness, as shown in the absence of hospice care and lack of policy related to palliative care (Kristanti, Setiyarini and Effendy, 2017a). People in Indonesia face limited palliative care services (Nuranna et al., 2012a). Indonesia is in the 3a group regarding the global mapping of levels of palliative care at the end of life (Connor et al., 2021) and was ranked 50 out of 80 countries in the quality of death ranking (EIU, 2015). The slow growth of palliative and hospice care in Indonesia contrasts with that in high-income countries (Rochmawati, Wiechula and Cameron, 2016) even though palliative care began in 1990 (Ibrahim et al., 2014).

The Indonesian population has also experienced a change in lifestyle factors such as increased tobacco consumption (57 million smokers), alcohol consumption (no fixed data), obesity (52.712 million people) and there are also poor levels of early detection, proven by data showing that only 1% of the female population did breast cancer and cervix cancer early detection (Kemenkes RI, 2018). Besides, many patients choose to try traditional healing methods first for several reasons, such as financial concerns and remoteness (Kemenkes, 2019). Moreover, some patients believe that sickness is created by evil spirits and can only be cured by shamans (Widiastutik, Winarni and Lestari, 2016). Lack of awareness, beliefs about cancer, beliefs about treatment, financial and emotional burdens, severe side-effects, a paternalistic style of communication and unmet information needs, all contribute to the situation (Iskandarsyah et al., 2014b). Consequently, people often arrive in clinics at the end stage with serious problems that need palliative rather than curative care (BPJS, 2019a).

Moreover, the annual consumption of morphine in Indonesia is 0.054 mg/per capita (Setiabudy, Irawan and Sudoyo, 2015). As a comparison, four-fifths of the 61 million patients live in low- and middle-income countries with limited access to palliative care (Knaul et al., 2018b). As shown in Figure 2-3, half of the global population received only 1% of available morphine, so they suffered from severe pain and health-related complaints (Knaul et al., 2018a).

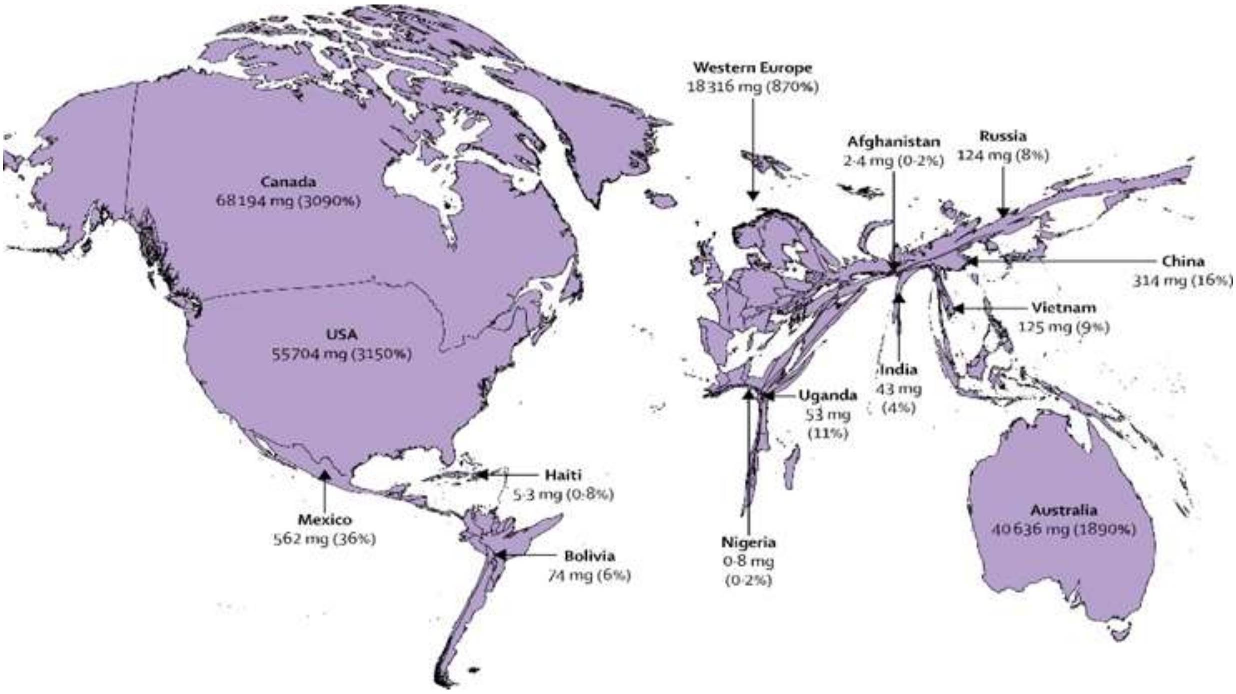


Figure 2-4 Distribution of morphine consumption for palliative care globally.

Source: Distribution of morphine consumption for palliative care in the world. © (Knaul et al., 2018a)

This map provides information about the suffering of patients who needed palliative care in Asia. In contrast to America and Canada, Vietnam consumed 9% of available global morphine, India 4% and China 16%, while the United States of America consumed 31.5% and Canada 30.9% (Knaul et al., 2018a). Furthermore, Knaul reported that around 10% of the poorest countries received only 10 mg of morphine per person, while wealthiest countries received >47,000 mg per patient. In addition, from 298.5 metric tonnes of morphine, only 10.8 metric tonnes were distributed to low- to middle-income countries. Hence, the low-income countries only received 13 mg per patient.

2.2.3 The hospital system in Indonesia

Indonesia's Ministry of Health provides health centres in every village/rural area which refer patients to district and provincial hospitals as final referrals (Kemenkes, 2019). Health centres provide primary health programmes run by nurses, midwives, dieticians, medical doctors, dentists and environmental health workers. District hospitals have several specialist doctors and provincial hospitals are complete healthcare providers. The Ministry of Health provides 10,479 primary public health centres, or Puskesmas, 25,104 Subsidiary Puskesmas and 13,356 pharmacies. There are 2,471 hospitals, 395 maternity hospitals and 8,858 polyclinics run by the government and private sectors. There are 1,550 type C hospitals (51.9%), 877 type D (29.4%), 436 type B (14.6%), 60 type A (2%) and others that remain uncategorised (2.1%) (Kemenkes, 2020). *Puskesmas* constitute the first level; referrals are then made to type D/C hospitals, then to B and finally to type A. A type A hospital is one that has complete facilities and services compared to other types of hospitals. There are 60 type A hospitals available in 16 provinces, commonly in the big cities (Kemenkes, 2020).

Of 1,463,452 healthcare providers, 73.3% are health workers and 26.7% are supporting personnel. The nurses constitute the biggest population, with 438,234 people (40.8%), while traditional health workers are the smallest (0.03%). There are only 67,916 physicians, and 55% of them are specialists. Every healthcare worker in Indonesia must have a Registration Certificate that is valid for five years; it can be renewed (PPNI, 2005). This policy is regulated by Article 44 of law number 36 from 2014 concerning Health Workers. The Labour Council issues a certificate when the applicant has met the requirements (Kemenkes, 2020).

The number of people who use health insurance is 74.27%, or around 195,273,540 people (BPS, 2021). In 2020, 78.3% of users accessed the first level outpatient referral but only 2.5% accessed the referral centre hospitals. However, the referrals received the most extensive financing, costing 53.3% of all health services costs. The lowest level of financing is for promotive and preventive programmes (0.3%). This data shows that the current insurance health financing still concentrates on curative elements or treatment, while promotive and preventive parts only receive a tiny portion of health financing (Kemenkes, 2020).

Furthermore, in December 2020, the Indonesia health insurance reported that they funded eight catastrophic diseases, that is, diseases with the highest costs (Kemenkes, 2020). Heart diseases are the highest in number (11,592,990 people) and cost the most (8.3 trillion rupiahs), while the lowest cost is for cirrhosis hepatitis (156,764 cases), which cost 243.5 billion rupiahs. The three diseases with the highest cost per case are blood disorders-related: haemophilia, leukaemia and thalassaemia. Among Indonesian women, breast and cervical cancer have the highest prevalence and have a high mortality rate due to delays in early detection (Kemenkes, 2020).

Early detection can reduce mortality and assist in health financing (Gakunga et al., 2019). Cervical cancer can be detected in the pre-cancerous stage using ana visual acid inspection (VAI) and Pap smear methods (Krishnan and Paing, 2020). Early detection of breast cancer can be achieved by self-assessment or be performed by trained health personnel (Tesfaw et al., 2021). Around 8.3% of women aged 30-50 years in Indonesia were detected as having cervical cancer earlier through the VAI method and through self-assessment nationally (BPJS, 2019a). Until 2020, staff had detected 50,171 positive VAI results and 5,847 suspected cervical cancers, while early breast cancer assessment detected 26,550 cases and 4,685 suspected breast cancers. Survivors are generally detected at an advanced stage. However, less than 1% of women use this service. A previous study in Bandung found that husbands perceived that cancer in a woman is a fatal disease, dangerous, scary and deadly (Widiasih, Nelson and Skinner, 2016). Notably, the husband was the patient's most significant emotional and mental support resource (Widiasih, 2021).

The province of West Java contains a significant proportion of the population of Indonesia, with about 48,497,827 people, or 19% of the total Indonesian population, living in 27 districts (Jabar, 2011). Hasan Sadikin Hospital in Bandung city is the referral centre for West Java Province, meaning that all hospital districts refer all patients with advanced cases to this hospital ((Kemenkes, 2019). The hospital is also the central referral location for other hospitals in Bornea Island region and the health consultation destination for areas outside Java Island (RSHS, 2019). The furthest island is 3,000 km away. The consultation cases include palliative cases that must be handled professionally. The researcher did the study in Bandung and found that in the last three years, this hospital received around

70,000 adults with cancer each year but can only provide 0.05% of them with palliative services.

The hospital system starts with the first level of primary health, or Puskesmas, in every village (BPJS, 2019a). The private general physician (GP) or clinics that have affiliations with the health insurance also provide primary health services. The patient accesses basic health needs here. The GP in the Puskesmas refers the patient to a type D or C hospital in the district’s capital city to receive more complex treatment from the specialist physician. The specialist will then refer the patient to a type B or A hospital, commonly in the province's capital city. However, health insurance does not cover palliative care services. If the patient wants a wider service or early treatment, they can also register to pay the private price. Complete advanced treatments are available at the referral centre. However, the referral causes a temporary migration of the patient and their family caregivers to a big city during the treatment, which adds extra cost and causes them to suffer (Dinillah, 2019).

2.2.4 The great demand for palliative care in West Java

Under the current hospital system, adults with cancer in West Java Province should be treated at Hasan Sadikin Hospital (Dewi, Machmud and Lestari, 2020). Because no palliative/hospice care is available, patients stay at shelters around the hospital while they wait for treatment (Personal communication with Non-Government Organisations and patients at shelters, 2017). Some patients have an appointment to receive chemotherapy but there is no bed, so their treatment is postponed for one or two weeks. As the top/provincial centre, the hospital cannot refuse any attending patient. They must be admitted even if there are no beds available. Sometimes patients will take a seat or wait in a wheelchair until a bed becomes available. Thus, even if a physician has made an appointment for a person with cancer for treatment, there may be no bed available when the patient arrives. This may cause the patient significant discomfort and concern. On top of this, having to stay in shelters without receiving primary or palliative care makes several patients stop their treatment.

On the other hand, many patients need palliative care, which is a medium-level burden for family caregivers (Sari, Warsini and Effendy, 2018). These conditions should force the government to provide palliative care services at the first level of healthcare services in villages as soon as possible. Also, the palliative care team at Hasan Sadikin Hospital should be forced to provide access to this service to the patients in the shelters around the hospital and spread their services to another district hospital. This is crucial to reduce the mortality rate and patient suffering, improve quality of life and patient satisfaction and reduce the burden of a referral hospital.

2.2.5 Palliative care service at Hasan Sadikin Hospital

The Indonesian Minister of Health announced the opening of palliative care services in 2007 and appointed five referral hospitals to provide them, excluding the Hasan Sadikin Hospital (Effendy et al., 2015a). A part of this study found that Hasan Sadikin Hospital's director formed the palliative team in 2007. However, this programme needs to be better developed. Since the government introduced national health insurance in 2015, the number of adults with cancer and other chronic illnesses who go to the hospital has escalated significantly. As a result, the palliative care team receive many requests, so they needed to improve their service.

The Hasan Sadikin Hospital was designated a National Referral Hospital following the Minister of Health Decree Number HK.02.02/ MENKES/390/2014, which manages regional hospitals outside West Java Province (RSHS, 2018). The hospital has 944 beds and 3,000 employees, with 395 physician specialists and subspecialists. They formed a team of multidisciplinary healthcare providers to achieve the relevant goals. The interprofessional team consists of physicians, nurses, psychiatrists, psychologists, dieticians and physiotherapists, but no chaplain. The aim is to provide a collaborative approach to palliative care treatment. The palliative team at Hasan Sadikin Hospital Bandung was formed on the order of the hospital director and based on the decree of the director, letter number HK.03.06/9250/VII/2012 from July 2012, and was running a clinic by 2012. They provide outpatient clinics for general palliative care patients and inpatient visits for hospitalised patients. Surprisingly, the palliative care service is underused. According to the chief of the hospital, 11,711 adults and 17,090 children with cancer were hospitalised in 2018, most strikingly, only 86 patients accessed the palliative care service (RSHS, 2019).

To date, the team has yet to measure the outcomes of the service; there is no hard evidence about the model of care over seven years: what is the need for the service, what are its outcomes and what are the barriers to using it? What are the levels of patient sickness and how satisfied are the patients and their families with the service? How does the service work and how is it being developed? Therefore, it is hard to evaluate the service. A future study is needed to find out why people did not access palliative care, how many people need palliative care, what the barriers are to accessing the service and what kind of service is needed to refine existing palliative care services.

2.2.6 Support for and barriers to palliative care in Indonesia

A recent study recognised the support for and barriers to the significantly extending demand palliative care in Indonesia (Effendy et al., 2015a). The support is in the form of government and volunteering organisation policies and a strong family culture of patient care. The barriers are a limited understanding of palliative care of different healthcare professions, poor infrastructure in remote areas and a lack of cancer painkillers (Rochmawati, Wiechula and Cameron, 2016). The study above recommends that stakeholders provide palliative care training for nurses and doctors, insert it into academic curricula and provide education for families and communities.

Similarly, a study in a hospital in Indonesia in 2018 found that the score for palliative care knowledge among 146 physicians and 377 nurses was low (7.8 ± 3.3 of a possible score of 20) (Nuzul et al., 2020). This needs to be improved soon because a lack of information and consistency in the health system is the most stressful issue for adults with cancer (Kotronoulas et al., 2017d). Nurses' perceptions of and knowledge about palliative care will ensure that nurses can optimise symptom relief, promote quality of life, maintain physical function and manage chronic disease (Omidi, Dehghan and Shahrbabaki, 2020, Silva et al., 2020, daSilva, Buscher and M.M., 2017, Silva et al., 2011). Future study is needed to describe the informal training on palliative care in Indonesia..

2.3 The role of nurses in palliative care

One of the first definitions of palliative nursing was provided by the Royal College of Nursing in the United Kingdom in 1989 (Finlay, 2001). However, Johnston provided one of the clearest definitions: ‘all life-threatening illnesses have implications for physical, social, psychological and spiritual health for both the individual and their family’ (Johnston and Smith, 2006). The role of palliative nursing is, therefore, to assess the needs in each of these areas and to plan, implement and evaluate appropriate interventions. ‘Palliative nursing aims to improve the quality of life and enable a dignified death’ (Kennedy and Connoly, 2018). Patients want palliative nurses to be there for them, to spend time with them, to provide comfort by meeting their needs and to listen to their fears (Johnston and Smith, 2006).

2.3.1 Nurse-led interventions in palliative care

The Cambridge Dictionary defines a nurse-led clinic as follows: ‘A nurse-led clinic is an outpatient clinic run or managed by registered nurses, usually nurse practitioners or clinical specialists in the UK’. Presently, every country requires a different level of education to be able to provide palliative nursing (Hansen-Turton et al., 2015). Some countries require a master’s, while others provide the general nurse with training skills and knowledge (Cameron and Johnston, 2015, Borland, Glackin and Jordan, 2014). However, even where nurses only have a basic level of education, they should have basic palliative care knowledge (Qanungo et al., 2021). The patient expects the professional to provide palliative care in the clinical and community areas (Cameron and Johnston, 2015). A nurse-led clinic can focus more on health status than illness and can manage lifestyle rather than diagnosis and intervention (Hansen-Turton et al., 2015). A recent study demonstrated that nurse-led care can enhance patients' self-management skills and self-efficacy; focusing on the patient's ability to manage life with an illness might improve their self-efficacy, while physicians seem more task oriented (deThurah et al., 2017).

Owing to the increased issues in palliative care, nurses should be educated by allowing them to continue their studies to become specialists in palliative care who collaborate with other healthcare providers and social care (Kennedy and Connoly, 2018). A nurse specialist in the clinic and community can provide better interventions with their advanced skills (Borland, Glackin and Jordan, 2014). A clinical nurse specialist is an advanced practice nurse with specialty-based knowledge (Delamaire and Lafortune, 2010). Their practices could decrease health resources use and cost because their high-quality care in the community will reduce hospital admission (Kilpatrick et al., 2014). One review reported that nurse-led clinics have an advantage regarding patient satisfaction, health outcomes, cost-effectiveness and care access (Sofer, 2018). Nonetheless, future research is required to evaluate the need to standardise the nurse-led clinical structure and the rationale behind such efforts (Randall et al., 2017).

2.3.2 Patient outcomes nurse-led palliative care interventions

According to the Cambridge Dictionary, nurse-led care is 'care of patients organised and done by nurses’. Nowadays, it is common to find palliative care services run by nurses (Schenker et al., 2021). Nurse-led care is 'principally task or role substitution in which well-defined protocols drive the delivery of high-quality patient care’. In nurse-led care, nurses have responsibility for the coordination, management and continuum of care for specific treatment alongside other teams that also serve the patients (Garner et al., 2017).

Nurse-led interventions in palliative care are one of the crucial achievements in countries with insufficient resources (McParland, Johnston and Cooper, 2022). This is because nurses can deliver interventions to address patients’ needs even with a minimal budget (Basu, Mittag-Leffler and Miller, 2013). Nurse-led interventions focusing on coordination and management can improve patient-centred and patient-reported outcomes (McParland and Johnston, 2021, McParland, Johnston and Cooper, 2022).

Therefore, in nurse-led palliative care, it is the responsibility of the nurse to care for the patient who needs palliative care and their family using a nursing care plan (Zhou et al., 2015a). Nurses in clinics are involved in patient assessment, admission, providing related education, treatment and monitoring, discharge, referrals to other healthcare providers and offering psychological support for the patient (Randall et al., 2017). The central role of nurses in supporting patients with palliative care needs is to maintain their independence for as long as possible (Johnston et al., 2014b). Nurse practitioners have been identified as healthcare providers who can serve a combination of needs (Keeling, 2015).

The outcomes of the nurse-led intervention can be seen in the patient satisfaction ratings, health status and health service utilisation rates (Groom, Kidd and Carey, 2018). To date, patients' and nurses' views of palliative care still vary (Nunes and Rodrigues, 2012, Gielen et al., 2011). However, several studies concluded that patients who received nurse-led interventions in clinics had positive experiences and outcomes, more affordable care and convenient and reduced waiting times (Randall et al., 2017). There was evidence that nurse-led interventions significantly reduced blood pressure in a patient with hypertension (Clark et al., 2010). Recent studies demonstrate that nurse-led care may enhance patients' self-management skills and level of self-sufficiency (deThurah et al., 2017). Nurse-led intervention also improves patients' quality of life and mood because it provides more holistic care to make patients feel more comfortable despite their symptoms (Groom, Kidd and Carey, 2018, Whitehead et al., 2017).

Nurse-led consultation was noted as an effective way of reducing patients' concerns about cancer treatment (Schofield et al., 2016). Other studies also demonstrated the positive effects of nurse-led educational interventions in improving cancer pain management (Zhou et al., 2015b). Notably, one qualitative study found that nurse-led intervention can be a conduit between the hospital and home, which could reduce the time spent at the hospital (Venkatasalu, Clarke and Atkinson, 2015).

2.3.3 Nurse role in Indonesia with limited resurces

In a resource-poor country like Indonesia, nurses can lead in developing palliative/hospice care because they have a good relationship with patients and their families (Effendy et al., 2015b). Nurses are also available in every village/rural area (Kemenkes, 2020); they have a good reputation for teaching families how to do daily activities for family members at home (Kristanti et al., 2019). Usually, family caregivers stay by patients' beds in the hospital 24 hours a day (Effendy et al., 2015b). A previous study in Indonesia also stated that nurses and physicians are essential for educating the family who is caring for the patient (Rochmawati, Wiechula and Cameron, 2016).

Indonesia has a communal culture with a high level of responsibility for caring for family members; they protect each other and demand loyalty throughout their lives, particularly in Java, where there is a proverb, Mangan ora Mangan waton kumpul, which means ‘even if there is no food to eat, being together is the most important thing’ (Subandi, 2011). In the scope of palliative care, this culture might benefit healthcare providers, patients and families (Effendy et al., 2015c), as almost all patients diagnosed as terminally ill need palliative care at home with family supervision (Kristanti, Setiyarini and Effendy, 2017a).

2.4 Chapter summary

The need for palliative care services has increased sharply worldwide due to the incidence of chronic illnesses. More than 12.2 million adults with cancer in resource-poor countries had difficulty accessing palliative care. The development of palliative care in resource-challenged countries urgently needs to be sped up, despite insufficient resources. However, some of these countries have made successful efforts to improve their services. A nurse-led intervention service reaches adults with cancer. In a resource-poor country like Indonesia, nurses can take the lead in developing palliative/hospice care because they have a good relationship with patients and their families. The palliative programmes should adapt to the burden of and the high demand for palliative services and to population changes.

Chapter 3 Provision of palliative care in countries listed as being in levels 1-3 of palliative care development: A systematic review.

This chapter provides an account of methods used in and findings from a mixed-methods systematic review of the international evidence on the provision of palliative care in countries listed as being in levels 1-3 of Palliative care development. This systematic review addresses the first research question of this PhD project. The first part concerns the systematic review findings regarding the suggested mode of operation of palliative care in those countries.

3.1 Methods

3.1.1 Objectives of the review

1. Identify the main components of palliative care services for adults with cancer and their family caregivers in level 1-3 of palliative care development.
2. Identify the mode of operation of palliative care services for adults with cancer and their family caregivers in level 1-3 of palliative care development.
3. Identify the requirement for palliative care staff and volunteers to provide palliative services in level 1-3 of palliative care development.

3.1.2 Review questions

1. What are the main components of palliative care services for adults with cancer and their family caregivers in level 1-3 of palliative care development?
2. What is the mode of operation of palliative care services for adults with cancer and their family caregivers in level 1-3 of palliative care development?
3. What is the requirement for palliative care staff and volunteers to provide palliative services in level 1-3 of palliative care development?

3.1.3 Ethical considerations and review registration

The researcher did not use any individual data. Therefore, no ethical approval was needed. The researcher looked at PROSPERO for reviews similar to the proposed study before starting a review to avoid doing work that someone else was doing already. After finding no similar study, the study protocol to PROSPERO with registration number *CRD42021220499* (Appendix 1) was used.

3.1.4 Methodological and reporting guidance

This review was informed by the Joanna Briggs Institute (JBI) methodological guidelines and structured according to the PRISMA reporting guidance (Aromataris and Munn, 2020). The first step included formulating the questions using PICO, developing criteria, searching through the literature, screening abstracts and selecting articles for further analyses (Linares-Espinós et al., 2018). Searching for, screening and identifying the studies included were reported using the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) Flowchart (Figure 3-2). The researcher screened the papers twice, first using titles and abstracts and then the full text. Then, the selected studies were exported into *Endnote* software, removed duplicate studies, screened potential articles and formatted the PRISMA flowchart (Page et al., 2021). The outcome was a suggested model for palliative care services in resource-challenged countries.

A systematic review aims to generate a complete, empirically derived answer to a focused research question **(Mallett et al., 2012)**. Qualitative and quantitative outcomes studies focus on palliative care service delivery for adults with cancer, family caregivers and staff were analysed together. The study used narrative data synthesis to interpret the data. The researcher chose to search all relevant literature including all the empirical articles using quantitative, qualitative and mixed-method research. The criteria was provided to prioritise results for summary and synthesis with supporting justification, selected the studies for the central synthesis and drew conclusions from the synthesis. The synthesis without meta-analysis (SWiMs) guidelines were also followed by grouping studies for synthesis to describe populations, interventions and outcomes. The results section describes and presents synthesised findings in graphics and tables. In the discussion section, the researcher reports synthesis methods' limitations and how these affect conclusions concerning the original review question (Campbell et al., 2020). The same steps in the interview analysis were followed to construct answers to the research questions.

3.1.5 Search parameters

A literature review was conducted using a PICO worksheet and search strategy protocol by identifying the patient/problem, intervention, comparison group and outcome (PICO) (Mallett et al., 2012). The PICO model is a tool for developing search strategies and focusing on clinical questions (Schardt et al., 2007). The tool is beneficial for achieving the best intervention and outcome in the nursing area (Hastings and Fisher, 2014). The PICO framework could develop search terms by asking PICO questions and using Medical Subject Headings (MeSH) and other terms (Eriksen and Frandsen, 2018). However, PICO needs more time is needed if PICO is being used to find the results of standard queries because it is necessary to include indexing terms in other relevant terms (Hoogendam, de Vries Robbé and Overbeke, 2012). The researcher used specific indexing terms to ensure homogeneity in search terms' databases by using the minor difference terminology in the MeSH. The main keywords of PICO (Appendix 2) determine applicable studies for review and help the researcher to see the variety of palliative care services developing globally. The PICO lists specific qualitative search terms or filters to identify relevant studies.

The types of studies/publications included in the search were original research, qualitative research (interviews, focus group discussions), quantitative research (surveys, RCTs, cohort studies, experiments, quasi-experiments). Secondary research/reviews included metanalysis, meta-synthesis and systematic reviews. The articles included original quantitative and qualitative studies done in low- and middle-income countries with massive populations, variety and difficulties regarding geographic areas, a low level of education, a small economy and limited transportation available to hospitals.

The researcher used five electronic databases to search for relevant articles, including Embase, CINAHL (Ebsco), Medline, Web of Science and Cochrane Library.

To ensure the search process was comprehensive, the researcher received advice from a librarian at the University of Glasgow. They discussed the search process intensively to reduce the risk of wrong steps or processes being undertaken and to avoid bias. The complete search strategy history can be seen in Appendix 3.

3.1.6 Inclusion and exclusion criteria

The criteria helped to find relevant articles (McKenzie et al., 2022). The researcher used purposive criteria to determine articles on relevant research topics to get helpful information. Original publications were included in the search. The criteria can be seen in table 3-1.

Table 3-1 Inclusion and exclusion criteria

Inclusion	**Exclusion**
Any research methodology and study design published in a peer-reviewed journal in English in the last 10 years (2011-present). Original research: Experiments, quasi experiments, interviews, surveys, RCTs, cohort studies. Secondary research/ Reviews: Metanalysis, meta-synthesis, systematic reviews.	Case series, case reports, case studies, clinical reports, letters to the editor, editorial letters, individual reviews, expert/non-expert opinions, congress abstracts, organisations' reports (WHO/NHS group), diaries, speeches, manuscripts, records, autobiographies, dissertations, theses, eyewitness accounts. Explanation: Researcher needed trusted articles which met the criteria for published articles.
Studies investigating the intervention, implementation and evaluation of palliative care services for adults with cancer in level 1-3 of palliative care development.	Studies investigating the palliative care approach for people with HIV/AIDS, Covid-19 and other chronic illnesses and studies in high-income countries. Explanation: Researcher is suggesting a mode of operation of services for adults with cancer, so evidence regarding cancer only is needed, not other chronic illnesses.
Participants: All types of research participants: adults with cancer, family caregivers, palliative care staff/healthcare providers, volunteers. Adults with cancer and their family caregivers who need/receive palliative care services/supportive care /end-of-life care treatments/interventions. Palliative care staff and volunteers who provide palliative care services/supportive care/end-of-life care treatments for adults with cancer. The researcher included all of the above in her search and also split the term 'adults with cancer' into two different searches, 'adult only' and 'cancer only'. The reason for this was that using the search term 'adult with cancer' found articles about the growth stages of cancer cells. These	Adults (>18 years old) without cancer. Participants receiving a non-palliative care approach/ services/supportive care/end-of-life care such as medicine, diagnostic procedure and those undergoing professional training. Staff/volunteers who do not provide a palliative care approach. Explanation: This study examines services for adults only.

Inclusion	Exclusion
contained more results about histopathological cancer than about individuals with cancer.	
English and Indonesian languages	Non-English and non-Indonesian
Full text available	Full text not available
Setting: The countries in the group categories 1-3 as used in *Global Atlas of Palliative Care at the End of Life* (Connor et al., 2014). There are 127 countries in this study: Brunei, Kiribati, Laos, Marshall Islands, Micronesia, Nauru, Palau, Solomon Islands, Tonga, Tuvalu, Vanuatu, Bhutan, Maldives, North Korea, Timor Leste, Andorra, Kosovo, Monaco, Montenegro, San Marino, Turkmenistan, Vatican City, Djibouti, Iraq, Somalia, Somaliland, Syria, Yemen, Antigua and Barbuda, Cuba, Dominica, Grenada, Guyana, Saint Lucia, St Kitts and Nevis, St Vincent and the Grenadines, Suriname, Cape Verde, Central African Republic, Chad, Comoro, Congo Republic, Guinea-Bissau, Lesotho, Mali, Seychelles, South Sudan, Uzbekistan, Samoa, United Arab Emirates, Bahamas, Haiti, Algeria, Benin, Botswana, Cameroon, Congo, Ethiopia, Ghana, Guinea, Madagascar, Mauretania, Mauritius, Mozambique, Namibia, Niger, Nigeria, Rwanda, Senegal, Sierra Leone, Tanzania, Togo, Bolivia, Dominican Republic, Ecuador, Guatemala, Honduras, Jamaica, Nicaragua, Paraguay, Peru, Trinidad and Tobago, Venezuela, Armenia, Azerbaijan, Bosnia and Herzegovina, Croatia, Estonia, Greece, Kyrgyzstan, Moldova, Tajikistan, Turkey, Bangladesh, India, Indonesia, Myanmar, Nepal, Sri Lanka, Cambodia, Fiji, Malaysia, Papua New Guinea, Philippines, Vietnam, Gambia, Kenya, Zambia, Belize, Brazil, Colombia, El Salvador, Panama, Jordan, Oman, Qatar, Saudi Arabia, Albania, Belarus, Bulgaria, Cyprus, Finland, Luxembourg, Macedonia, Malta, Serbia and Slovenia.	Palliative services for adults with cancer in Australia, Austria, Belgium, Canada, France, Germany, Hong Kong, Iceland, Ireland, Italy, Japan, Norway, Poland, Romania, Singapore, Sweden, Switzerland, Uganda, United Kingdom, and the United States of America. Explanation: The countries on the map of palliative care with the same background as 'in level 1-3 of palliative care development' (which I refer to as resource-challenged countries or 'low- and middle-income countries in this thesis) will have the most similar conditions. The term 'developing countries' has a broad meaning and there are differences in the number of such countries mentioned in the low and middle-income filter here: https://epoc.cochrane.org/lmic-filters (Cochrane, 2020). The researcher decided to use the countries that the *Global Atlas of Palliative Care* lists as 'developing countries' in relation to palliative care as defined above. The resource-challenged countries in this study are in the group categories 1-3 as used in the *Global Atlas of Palliative Care at the End of Life* (Connor et al., 2014). • Group 1: No known hospice-palliative care activity; current work has not been recognised. • Group 2: Capacity-building activity: There is evidence of wide-ranging initiatives designed to create the organisational, workforce and policy capacity for hospice palliative care services to develop, but no service yet. • Group 3: Isolated palliative care provision and generalised palliative care provision. These groups do not have advanced palliative care yet. Thus, the studies included all the palliative care settings in countries in groups 1-3. There are 127 countries in groups 1-3 and only 20 countries in group 4, which are high-income countries (Cochrane, 2020, Connor et al., 2021, Connor et al., 2014).
Time: 2011-2021	Before 2010 Explanation: Up-to-date articles will include reliable information.

3.1.7 Quality appraisal

Quality appraisal is an essential aspect of a review. An appraisal tool aims to evaluate empirical studies' quality by appraising the most common study methodologies and designs (Hong, Gonzalez-Reyes and Pluye, 2018). The researcher used the Mixed Methods Appraisal Tool (MMAT), version 2018, to assess the risk of bias. 'The MMAT is a critical appraisal tool designed for the appraisal stage of systematic mixed studies reviews, i.e. reviews that include qualitative, quantitative (randomised controlled trials (RCTs) and non-randomised controlled trials (non-RCTs), quantitative descriptive) and mixed-methods studies. This tool has an algorithm for selecting the study categories to rate quantitative, qualitative or mixed-methods studies (Hong, Gonzalez-Reyes and Pluye, 2018). The tool proved to be quite effective in locating pertinent information from a wide range of published studies including quantitative, qualitative and mixed-methods studies.

This algorithm has five different question sets. There is a set of questions for qualitative and quantitative studies (RCT and non-RCT), and mixed-methods studies. Every question has three options, *Yes, No, Can't tell*, and a reason for choosing one of those three options. The maximum score for every set is 5 and the minimum is 0. For a mixed-methods study, the author needs to answer the quantitative and qualitative sets first, then answer the mixed-methods set with the last score from the mixed-methods scores. After completing question sets, the scores determine the quality of the articles: scores of 4 and 5 mean it is high quality, 3 means moderate quality and 1 and 2 mean low quality. Two reviewers (CP and GK) did critical appraisals to reach the final papers' final scores. All articles met the quality appraisal criteria, with scores ranging from 3 to 5.

3.1.8 Data analysis

The researcher used thematic analysis to synthesise critical findings across studies. *NVivo* version 12 software was used to code, develop and generate themes. Data interpretation was performed using a narrative synthesis approach. While the quantitative works with numbers, the qualitative works with words

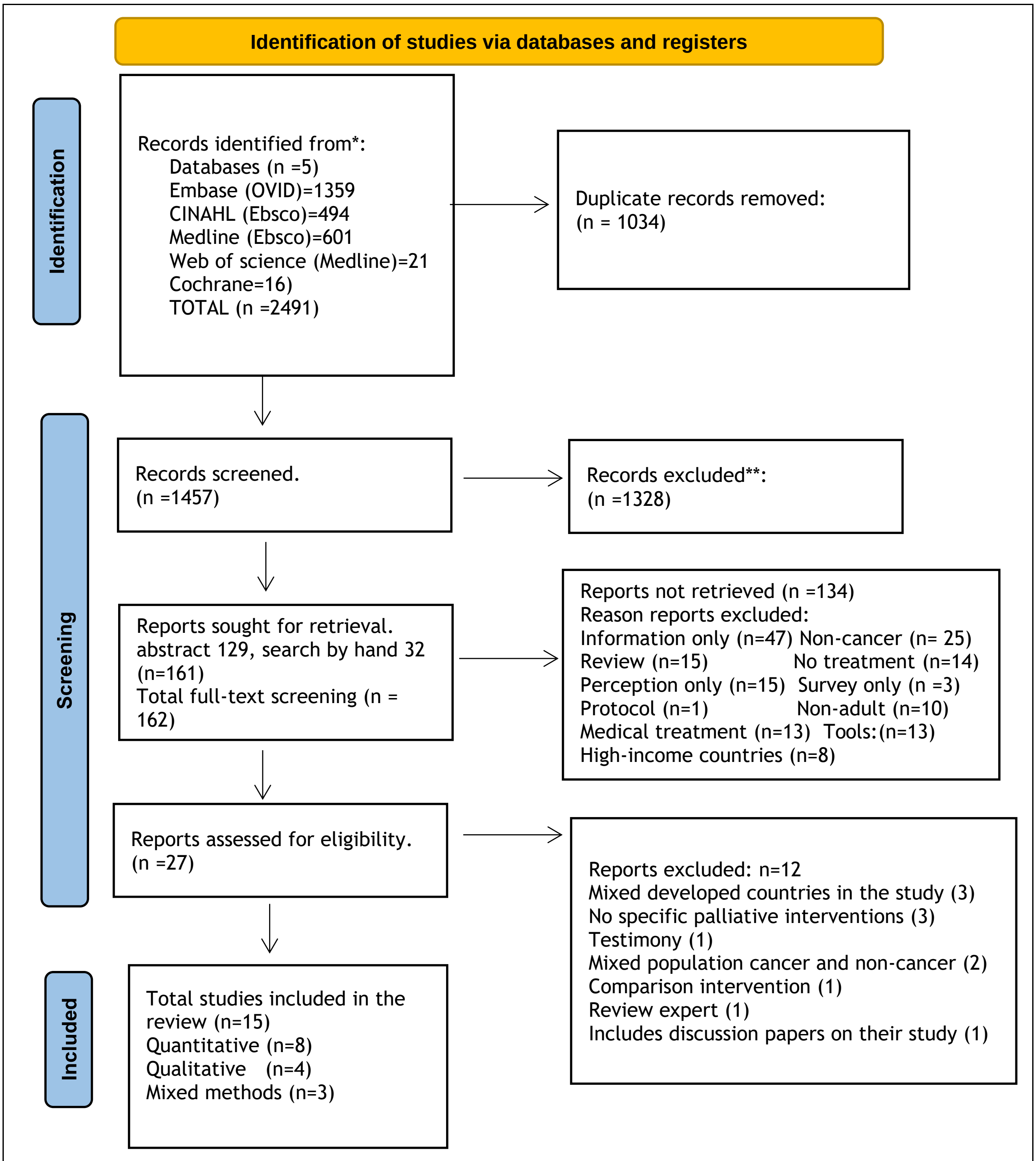
(Houghton, Hunter and Meskell, 2012). The researcher followed Braun and Clarke's six steps for analysing data (Braun and Clarke, 2006, Braun and Clarke, 2012).

1) Familiarisation with the data: the researcher read and reread the articles until an answer was found and made it into a code.
2) Coding: the researcher created a code for the same answers from different articles.
3) Searching for themes: the researcher clustered the same coding into the same sub-subthemes, then grouped the same sub-subthemes into the same subthemes then into the same theme. All codes were grouped into similar themes. The same themes were then grouped until the researcher had the final themes. Headings were used that were direct answers to the research questions, then similar findings were grouped under each heading so that identify the initial subthemes and themes could be identified.
4) Reviewing themes: the researcher found several themes for the first time; after reviewing them, some themes were merged, so these are the final themes.
5) Defining and naming themes: the researcher changed the name of the themes several times until the final names of the themes were decided on, which identified the answers to the research questions.
6) Writing up: writing up is an integral element of the analytic process in thematic analysis. The researcher wrote down all the processes used for building the themes.

3.2 Findings

3.2.1 Search results

The initial searches identified 2491 records from five databases: Embase (OVID=1359, CINAHL (Ebsco)=494, Medline (Ebsco)=601, Web of Science (Medline)=21, Cochrane=16). After de-duplication, 1034 records were removed so that there were 1457 articles left. Titles and abstracts were screened from those 1457. At this stage, the researcher eliminated 1328 irrelevant titles because they fitted exclusion criteria: studies on children/elderly people, protocol studies, non-English language studies and review or conference papers. Next, the researcher screened 129 full texts. During the full-text screening process, 32 abstracts were found by using a hand search method. In total, there was a full-text screening of 161 abstracts of eligible studies. This excluded papers that were not conducted in a resource-challenged country, did not use palliative care services and did not involve adults, which resulted in 27 papers. Two researchers (CP, BJ) assessed and read all titles, abstracts and full-text screening thoroughly and independently. Studies were selected if they met the inclusion criteria. The full-text screening eliminated 12 papers. After reassessment by the second reviewer, the researcher obtained 15 eligible studies for synthesis. A further screening added zero papers. Any disagreement was decided between the researchers. The steps can be seen in Figure 3-1.



Source: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. (2020), The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/

Figure 3-2. The PRISMA flowchart

3.2.2 Data extraction and synthesis

The researcher screened the papers and extracted the data. Two researchers extracted data to promote reliability and avoid data entry errors. Reviewer one

(CP) extracted data from each study and verified it with a second (BJ). They then decided which paper to select and displayed the results. The reviewers agreed to define the most appropriate term. The researcher read the reviewed studies several times and extracted data using piloted data extraction forms on an Excel spreadsheet. Next, the researcher used a custom-made data extraction template for further synthesis by reading the data extraction twice, and then extracted the data for further synthesis. The data extracted were author (year), country/region, study design, description of the study, sample, objectives, mode of operation of palliative care service, main components of an enhanced palliative care service, and requirements for the staff and quality appraisal, as set out in **Appendix 1 Data extraction.**

3.2.3 Characteristics of the included studies

Study origin. Eight of the included studies were from Asia, 4 India, 2 Malaysia, 1 Indonesia and 1 from Bangladesh (Shabnam et al., 2018, Kristanti, Setiyarini and Effendy, 2017c, Abdulla et al., 2021, Rajah et al., 2021b, Chacko et al., 2014b, Kapoor et al., 2017b, Krishnan et al., 2018b, Damani et al., 2020a). Four studies were conducted in Africa, in Tanzania, Rwanda and Nigeria, and one was conducted across Nigeria, Rwanda and Zimbabwe (Hartwig et al., 2014, Ndiok and Ncama, 2021, Tapela et al., 2016b, Adejoh et al., 2021). Meanwhile, two studies were conducted in the Middle East: in Jordan and across 15 countries in the Middle East (Shamieh et al., 2017, Silbermann et al., 2014). Only one study was done in Brazil, Latin America (Rozman et al., 2021a). Regarding the institutions, two were palliative care centres in India (Krishnan et al., 2018b, Damani et al., 2020a), two were NGOs in Africa (Tapela et al., 2016c, Hartwig et al., 2014), four were hospitals (Shabnam et al., 2018, Kapoor et al., 2017b, Shamieh et al., 2017, Ndiok and Ncama, 2021), two were patients' home (Kristanti, Setiyarini and Effendy, 2017c, Hartwig et al., 2014), three were not in a specific place (Abdulla et al., 2021, Rajah et al., 2021b, Silbermann et al., 2015), one was a school of medicine (Chacko et al., 2014b) and one was a teaching hospital (Rozman et al., 2021a).

Publication date. The studies included were published between 2011 and 2021. Three studies were published between 2011 and 2016, six between 2017 and 2020 and six in 2021. All studies used purposive sampling and all papers answered the research questions.

Study design. There were three mixed-methods studies: one surveyed patients and interviewed nurses (Hartwig et al., 2014), one surveyed the activities of palliative care services then interviewed the staff (Shabnam et al., 2018) and the third surveyed the patients and staff and then interviewed the staff (Chacko et al., 2014b). There were four qualitative studies: the first accessed nurses' roles in making palliative care decisions (Abdulla et al., 2021), the second accessed informal caregivers' role in palliative care (Adejoh et al., 2021), the third examined the barriers to and benefits (Ndiok and Ncama, 2021) and the fourth explored the emotional state of patients with limited supportive care (Rajah et al., 2021b). The researcher included eight quantitative studies: one experimental pre-post intervention study (Rajah et al., 2021b), three surveys (Tapela et al., 2016a, Shamieh et al., 2017, Damani et al., 2020a), one randomised controlled study (Kristanti, Setiyarini and Effendy, 2017a), one retrospective study (Rozman et al., 2021a), one study describing the palliative centre (Krishnan et al., 2018a) and one study evaluating the cancer centre (Silbermann et al., 2015). The mean age of the participants was 53.57 years for the patients, 44 for the family caregivers and 46.89 years old for the staff. Most participants were female (52.46%).

Interventions tested. Of the 15 studies, the majority evaluated palliative care services (n=7) (Adejoh et al., 2021, Silbermann et al., 2015, Tapela et al., 2016c, Damani et al., 2020a, Krishnan et al., 2018b, Rozman et al., 2021a, Kapoor et al., 2017b). Four studies did an assessment (Rajah et al., 2021b, Ndiok and Ncama, 2021, Abdulla et al., 2021, Chacko et al., 2014b). Two studies did interventions (Hartwig et al., 2014, Shamieh et al., 2017) and two others did implementation plus evaluation (Kristanti, Setiyarini and Effendy, 2017c, Shabnam et al., 2018).

Across the 15 studies, eight studies were conducted on patients. There were two surveys, one by Hartwig et al. and one by Shabnam et al. to 145 adults with cancer and six nurses across 13 hospitals. (Hartwig et al., 2014, Shabnam et al., 2018). Another study was an intervention to 66 patients with cancer (Kapoor et al., 2017b), surveying 140 patients and interviewing 40 healthcare professionals, which also interviewed 66 adult female patients with advanced cancer. Two studies counted the cost evaluations of palliative care by Rozman to 2,985 adult patients with cancer, and Damani to 80 of the 102 PC centres providing information about PC services (Rozman et al., 2021a, Damani et al., 2020a). Three studies were conducted with family caregivers: one provided an intervention by training 41 family caregivers of patients with cancer (Kristanti, Setiyarini and Effendy, 2017a), one explored 48 unpaid adult caregivers (Adejoh et al., 2021) and one analysed the family's phone calls to the palliative care telephone services 4,195 calls to the palliative centre (Shabnam et al., 2018). Five studies involved health professionals, three involved mixed healthcare professionals, one involved a nurse and one involved a physician.

One study highlighted patterns of pain symptoms of patients in Asia and Africa (Hartwig et al., 2014). Specific interventions by nurses were reported in Africa (Hartwig et al., 2014), where nurses treated pain only with visits and consultations because of the absence of morphine. These treatments can decrease the patient's pain level. Another specific intervention was reported in Indonesia; nurses trained family caregivers to deliver primary care to patients at home, which increased patients' quality of life (Kristanti, Setiyarini and Effendy, 2017a). The specific intervention needed for the Middle East was the cultural and religious approach (Silbermann et al., 2015). And specific palliative care needs in Africa and Asia were physical support (Kristanti, Setiyarini and Effendy, 2017a), psychological support (Adejoh et al., 2021), financial support (Rozman et al., 2021a) and information support (Shabnam et al., 2018). The psychological need for family caregivers was emotional support in their role as caregivers (Adejoh et al., 2021) and information about treatment (Shabnam et al., 2018).

3.2.4 Methodology quality

The evidence is deemed trustworthy given that 13 studies scored 5, which means they are very high quality 5 (2 are mixed-methods, 6 are quantitative descriptive and 5 are qualitative studies). Eleven studies had scored 5 (Hartwig et al., 2014, Shabnam et al., 2018, Rozman et al., 2021a, Shamieh et al., 2017, Tapela et al., 2016b, Damani et al., 2020a, Silbermann et al., 2014, Abdulla et al., 2021, Adejoh et al., 2021, Ndiok and Ncama, 2021, Rajah et al., 2021b, Krishnan et al., 2018b).

Kristanti et al’s study scored 4 (Kristanti, Setiyarini and Effendy, 2017a) and the study of Kapoor (Kapoor et al., 2017a) and Chacko (Chacko et al., 2014a) scored 3. No meta-analysis or meta-synthesis was possible across the 15 studies due to heterogeneity (McKenzie and Brennan, 2019). All quantitative studies used relevant statistical tests to answer their questions. The studies were up-to-date; 10 were published between 2020 and the present day.

3.3 Discussion

To the researcher’s knowledge, this study is unique in that it is the first to synthesise evidence concerning the development of palliative care services in countries classified as groups 1-3 in the Global Atlas of Palliative Care at the End-of-Life 2014. The evidence points towards the implementation of a multicomponent approach to palliative care services, a multimodal operation of palliative care services and diverse roles of palliative care staff and volunteers. The findings can be seen in this picture below.

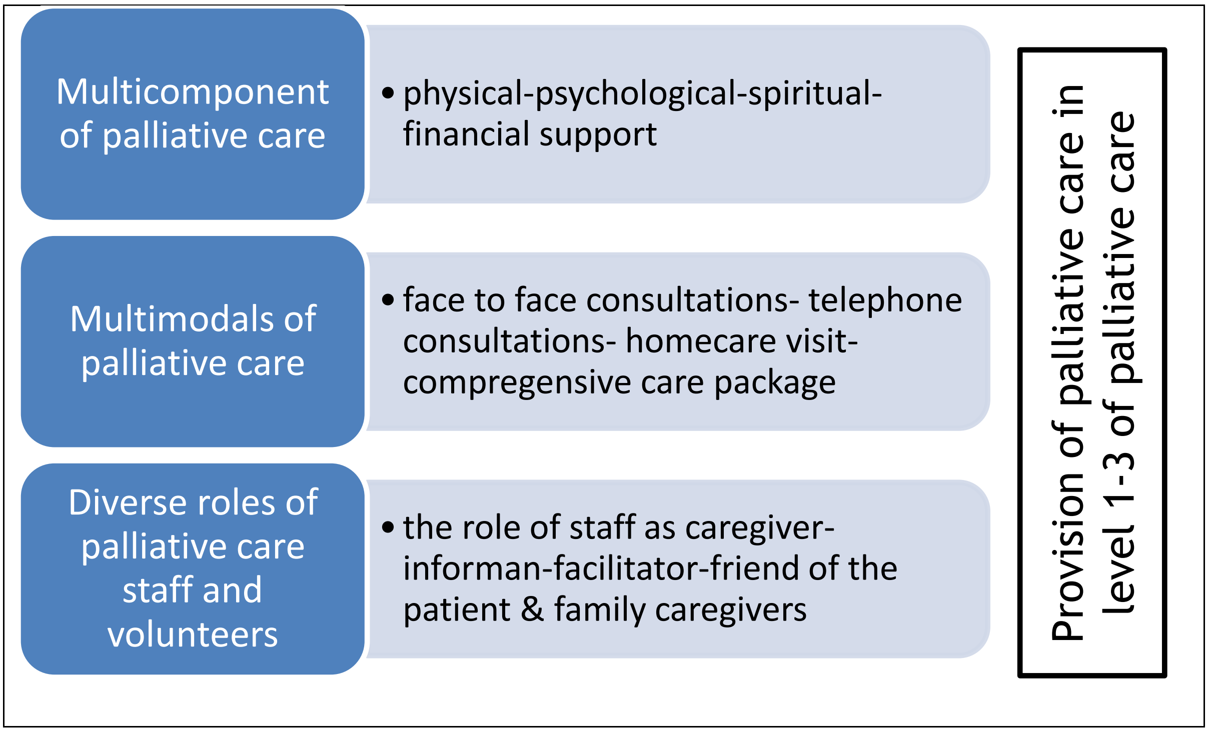


Figure 3-1 Provision of palliative care in level 1-3 of palliative care development.

3.3.1 Identified themes

The purpose and process of identifying themes can be based on the research question (Braun and Clarke, 2006, Braun and Clarke, 2012), where thematic analysis can help to identify common patterns (Mishra and Dey, 2022). Braun and Clarke's thematic analysis method started when coding the text to develop the initial subtheme (Thomas and Harden, 2008). This method could help keep the result in line with the research questions because every step ensures the result sticks to the questions. The Nvivo tools help the synthesis process and keep the nodes representing every sub-subtheme until the final themes are generated. All the verbatim is transferred to the NVivo for analysis. Then, the word is read line by line to see the respondent's answer (Tark et al., 2023). The researcher interpreted the data by grouping the answer to the research questions. The researcher made coding for every answer, grouping the coding into the same subthemes and then to the final themes to construct answers to the questions. The codes and nodes were coded one by one to build subthemes and themes.

A minimum of two answers from different articles supported every subtheme. There are many tools that can be used for coding reviews. The researcher used the *Nvivo* tools in coding and constructing the themes because it can help in coding and generating the sub-subthemes, subthemes and themes. Moreover, the researcher has experience in using this tool in the previous study. Therefore, the researcher is able to do it successfully and in less time compared to other tools.

Three main themes and sixteen subthemes constructed from the analysis and synthesis. These generated themes represent suggested modes of operation for nurse-led intervention in level 1-3 of palliative care development palliative care. The first theme is the main service components for adults with cancer and their family caregivers in level 1-3 of palliative care development, with four subthemes: physical support, psychological support, spiritual support and financial support. The second theme is the mode of operation of palliative care services for adults with cancer and their family caregivers in level 1-3 of palliative care development, with four subthemes: face-to-face consultation, telephone consultation, home-care visits and comprehensive care packages. The third theme is the requirement for palliative care staff and volunteers to provide palliative services in level 1-3 of palliative care development, with four subthemes: caregiver, informant/educator, facilitator and friend (Table 3-2).

Table 3-2 Themes, subthemes and corresponding review questions.

Themes	Subthemes	Review questions
1. Main components of palliative care services for cancer in resource-challenged countries	1. Physical support 2. Psychological support 3. Spiritual support 4. Financial support	What are the palliative care service's main components for adults with cancer and their family caregivers in level 1-3 of palliative care development?
2. Mode of operation of palliative care services for cancer in resource-challenged countries	1. Face-to-face consultations 2. Telephone consultations 3. Home-care visits 4. Comprehensive care packages	What is the mode of operation of palliative care services for adults with cancer and their family caregivers in level 1-3 of palliative care development?
3. Required roles for palliative care staff and volunteers to provide palliative care for cancer in resource-challenged countries.	1. Caregiver 2. Informant/Educator 3. Facilitator 4. Friend	What are the role requirements for palliative care staff and volunteers to provide palliative services in level 1-3 of palliative care development?

3.3.1.1 Main components of palliative care services for cancer in level 1-3 of palliative care development.

The main components were represented by four subthemes: physical support, psychological support, spiritual support and financial support. These components could address the patient's physical, psychological and financial burdens and the policy and information barriers.

a. Physical support.

Ten studies showed that participants experienced physical burdens that need physical support as the main component of palliative care (Hartwig et al., 2014, Damani et al., 2020a, Kapoor et al., 2017b, Shabnam et al., 2018, Chacko et al., 2014b, Shamieh et al., 2017, Kristanti, Setiyarini and Effendy, 2017a, Adejoh et al., 2021, Ndiok and Ncama, 2021, Rozman et al., 2021b). The following key symptoms were reported; 5 studies reported issues around pain management (Ndiok and Ncama, 2021, Kristanti, Setiyarini and Effendy, 2017a, Damani et al., 2020a, Shamieh et al., 2017, Rozman et al., 2021b), 1 reported the use of non-pharmacologic to treat mild cancer pain (Silbermann et al., 2015), 1 reported the needs to integrate all treatment to ensure the patient has enough support for physical needs (Tapela et al., 2016b) and 2 reported needs support for food-related problemmas (Shabnam et al., 2018, Kapoor et al., 2017b).

For 5 studies that reported pain management as a key symptom, Shamieh et al (2017) who conducted interviews with 182 patients to find out about the symptom changes among adults with cancer at a palliative care clinic in Jordan and using ESAS, found that symptom change can be prevented by palliative care physical support. Similar findings were reported by (Damani et al., 2020a), whose research aimed to identify gaps in palliative care provision across National Cancer Grid centres in India, who also found that the essence of the symptom pain decrease was the integrated palliative care services. However, (Hartwig et al., 2014) found that the difficulty of patients' accessing morphine also caused a psychological burden to the staff. They saw patients’ suffering but could not provide painkillers, so that physical support is needed as the main component of palliative care services (Hartwig et al., 2014).

b. Psychological support

Seven studies showed that participants experienced psychological burdens, so that they need psychological support as the main component of palliative care (Krishnan et al., 2018b, Shamieh et al., 2017, Chacko et al., 2014b, Silbermann et al., 2015, Shabnam et al., 2018, Hartwig et al., 2014). The following key components were reported: 4 studies reported issues around pain management, and 3 studies reported the need for the staff to provide psychological support.

For the 4 studies that reported issues around pain management as a main component, (Shamieh et al., 2017) conducted interviews with 182 adult patients with advanced cancer in Jordan and found that nurses are trained to manage the pain symptoms. Similar findings were reported by (Chacko et al., 2014b), whose research aimed to explore the end-of-life care perspectives of 140 patients and

40 healthcare professionals in India, using mixed-methods quantitative, self-administered questionnaires and qualitative interviews that also found the patients need support about their emotional, social, physical, and spiritual dimensions on end-of-life preference to help patients pain free. Krishnan et al., 2018b described that the Trivandrum Institute of Palliative Sciences is a WHO collaborating centre for training and policy regarding access to pain relief, conducted interviews on 3,270 patients with cancer in India to find out about care settings (Krishnan et al., 2018b). However, (Silbermann et al., 2015) who conducted 15 Middle Eastern countries, found that services related to pain management using non-pharmacologic therapy, multimodal therapy, nonsteroidal anti-inflammatory drugs, opioids, and complementary alternative medicine were the staff's palliative care ability to offer.

For the 3 studies that reported the need for the staff to provide psychological support as a main component, Rajah et al. (Rajah et al., 2021b) researched 102 patients in Malaysia to explore the sources of emotional distress of cancer survivors in Malaysia using interviews. They found that this main component resulted from a lack of staffing, monitoring and supervision of funds and programmes. The participant also experienced the fear of losing their reproductive organs. Similar findings were reported by Shabnam et al (Shabnam et al., 2018) in Bangladesh; the purpose of the research was to analyse the calls to palliative care services, which also found that psychological support is delivered by the staff using telephone services. However, (Hartwig et al., 2014) found that the fear of pain can decrease by the nurse’s presence even when no morphine was administered.

c. Spiritual support

Six studies reported that participant experienced spiritual needs so that expected the spiritual support as the main component of palliative care (Rajah et al., 2021b, Ndiok and Ncama, 2021, Adejoh et al., 2021, Abdulla et al., 2021, Hartwig et al., 2014, Chacko et al., 2014b). The following key symptoms were reported: 5 studies that reported spiritual support as a key component: 1 study reported that patients received spiritual support from the unpaid family caregivers (Adejoh et al., 2021).

For the five studies that reported spiritual support as a key component, (Rajah et al., 2021a), found that the lack of spiritual support was the result of rejection by patient or family of cancer diagnosis and inadequate knowledge or inappropriate attitude of nurses. Similar findings were reported by (Abdulla et al., 2021), whose purpose of research was to explore the perspectives of palliative care decision-making for palliative patients and families in Indonesia and Malaysia who also found that palliative care service includes a good death concept for their patients' care management with the Muslim concept, which is related to the palliative care goals of care. However, Chacko et al. (2014a) found that nurses and physicians should be proactive in offering key support services to ensure patient autonomy and facilitate a good death (Chacko et al., 2014b). Similar findings were reported by (Ndiok and Ncama, 2021), whose purpose of research was to identify barriers to and benefits of establishing a model for integration of palliative care 19 nurse managers in two hospitals in Nigeria who also found that social supports play a pertinent role in buffering emotional distress and need investment to ramp up mental health. Similar findings were reported by, Hartwig et all, 2014 conducted mixed methods to 145 adults with cancer across 13 hospitals and 6 nurses in Tanzania also reported the patients' emotional and spiritual conditions improved when a nurse visited them at home (Hartwig et al., 2014). Rajah et al. (2021b) conducted interviews with 102 patients with cancer in Malaysia to explore the sources of emotional distress, reported that the patients felt satisfied when they received spiritual support from nurses (Rajah et al., 2021b).

However, (Adejoh et al., 2021) explored 48 adult unpaid caregivers in Nigeria, Uganda, and Zimbabwe, reported that the family taking care of the majority of patients' medical, physical, financial (fundraising for treatment), emotional and spiritual (prayer) needs.

d. Financial support

Seven studies reported that participants experienced financial support needs as the main component of palliative care. Patients felt satisfied when they received financial support from palliative services (Rozman et al., 2021a, Krishnan et al., 2018b, Damani et al., 2020a, Tapela et al., 2016b, Adejoh et al., 2021, Ndiok and Ncama, 2021, Rajah et al., 2021b).

The following key symptoms were reported: four studies reported that the cost can be addressed by providing early palliative care, and three studies reported that the monthly income is too small to cover the treatment cost. For the four studies that reported the cost can be reduced as a critical component (Rozman et al., 2021a); conducted interviews on 2,985 adult patients in Brasilia, mentioned that they could address the cost by providing early palliative intervention (Rozman et al., 2021a); (Tapela et al., 2016b) surveyed on to describe the programme-level experience of implementing palliative care in Rwanda to find out about providing infrastructure, staff and non-specialised consumables in oncology can deceased the financial burden. (Krishnan et al., 2018b) surveyed 3,270 patients with cancer who visited the palliative service and can predict the estimated cost per clinical expenditure. Similar findings were reported by (Damani et al., 2020a) in India who also found that developing community-based palliative care (neighbourhood palliative care network) in Kerala, which was an exemplary model for resource-poor countries around the world to provide services with community's service.

However, (Adejoh et al., 2021, Ndiok and Ncama, 2021) found that providing transport to palliative services and having financial support before establishing any service was the key to keeping the service on the budget. Adejoh et al. reported that more than 60% of patients in Asia had a monthly income of less than $100, whereas, the cost of cancer treatment for six weeks was £2800 in Africa and similar in Asia (Ndiok and Ncama, 2021). In Brazil, the cost of palliative care per patient was $325.50 (Rozman et al., 2021b), while the basic wage per day was about $1.651, or 300 times minimum pay per day. This cost reflected the need for uninterrupted funds (Abdulla et al., 2021). Study participants mainly experienced a double burden of finances after illness (Abdulla et al., 2021). Support services in this area are still underdeveloped (Rajah et al., 2021b). Food, childcare and study competed with patients' hospital costs. As a result, patients chose to die rather than add an economic burden to their families (Rajah et al., 2021b).

Despite problems with costs, several institutions or organisations started palliative care services at a low price. The most significant result regarding a cheap service was found in Kerala's palliative care (Krishnan et al., 2018b). There was significant development in the palliative care service in India when it was run through the community fund (Damani et al., 2020b); there was collaboration between NGOs and the government regarding funding for buildings and human resources (Hartwig et al., 2014). A free telephone call service was an excellent deal for patients because they could access more information about their condition without cost (Shabnam et al., 2018). Electronic medical record technology also reduced providers' budgets (Tapela et al., 2016a). Routine screening using patient-reported outcomes was recommended to reduce costs through an earlier physician's visit and treatment (Rozman et al., 2021a). Early palliative care gives patients enough time for discussion and to make decisions (Abdulla et al., 2021). Government health insurance was recommended as the first system for reducing costs in India because around 90% of patients were under an extreme financial burden, which meant they died without enough support (Damani et al., 2020a).

3.3.1.2 Main mode of operation of palliative care services for cancer in level 1-3 of palliative care development

Palliative care interventions in level 1-3 of palliative care development were offered in various ways, including face-to-face consultations, telephone consultations, home-care visits and comprehensive care packages.

a. Face-to-face consultations

Six studies stated that participants expected face-to-face consultations as the mode of operation (Krishnan et al., 2018b, Ndiok and Ncama, 2021, Rozman et al., 2021b, Kapoor et al., 2017b, Hartwig et al., 2014, Shamieh et al., 2017). The following key modes were reported: 3 studies reported consultations outside the hospitals, and 3 studies reported in the hospital. For the three studies that reported the need for face-to-face consultation outside the hospital as a mode of operation, Shamieh et al. conducted interviews used the ESAS questionnaire, which found improvement with moderate-severe symptoms as a result of providing medical and surgical specialty consultations (Shamieh et al., 2017). Similar findings were reported by (Hartwig et al., 2014) in Tanzania; found that consultation by visiting145 adults with cancer at home could decrease their pain and unmet needs. In line with (Kapoor et al., 2017b), who delivered nutrition plus counselling for 30 patients to assess the efficacy of nutritional addition in India, found that the participants showed the improve of the anthropometric status as well as the quality of life.

However, (Rozman et al., 2021a) with the study purpose of identifying the sociodemographic and clinical variables that could explain the cost per day of palliative care for 2,985 adult patients with cancer in Brazil, found that consultation services in the clinic are less costly compared to other treatment. Similarly, (Ndiok and Ncama, 2021) conducted interviews with 19 nurse managers in two hospitals in Nigeria. They used focus group discussions to identify barriers to and benefits of establishing a model for integration of palliative care of adults with cancer. They found that the patients wanted providers to reduce the number of administration systems for accessing cancer treatment and morphine, as well as having consultations about their sickness. Likewise, findings were endorsed by (Krishnan et al., 2018b), who surveyed 3,270 patients with cancer who visited the Trivandrum Institute of Palliative Sciences to describe the delivery of care in India. These results found that giving consultations for inpatients in general wards, which are community-based, also benefit the continuity of care (Krishnan et al., 2018b).

b. Telephone consultations

Only two studies showed that participants experienced the usefulness of telephone consultations. One study showed that participants experienced the usefulness of telephone consultations (Shabnam et al., 2018). Shabnam et al. conducted a mixed-methods study with the purpose to analyse the calls to the services. Nonetheless, it was challenging for physicians who provided telephone consultations to sort out all problems quickly without touching patients or seeing their medical records. Tapela et al conducted a quantitative study to illustrate the program-level experience of implementing patient care at Butaro Hospital, a specialised palliative care facility for cancer patients. Despite the absence of on-site oncology specialists, the study found that care was successfully delivered through strategic task-shifting, structured twinning, and long-term collaboration between organizations. This was facilitated by regular communication through weekly tumor board-like conference calls and emails (Tapela et al., 2016b).

c. Home-care visits

Six studies showed that participants expected the home care visits as the main mode of operation (Krishnan et al., 2018b, Chacko et al., 2014b, Hartwig et al., 2014, Shabnam et al., 2018, Adejoh et al., 2021, Kristanti, Setiyarini and Effendy, 2017a). The following key symptoms were reported: four studies expected homecare visits, two studies reported community based palliative care. For the four studies that reported home visits as a mode operation, in a study conducted by (Adejoh et al., 2021), interviews were conducted with 48 unpaid adult caregivers in Nigeria, Uganda, and Zimbabwe. The findings revealed that caregiving for adults with cancer in these countries comes with unique challenges that are specific to the context. These challenges include financial constraints and difficulties with transportation for informal caregivers in Sub-Saharan Africa. As a result, delivering home-based services is the most practical option for providing care (Adejoh et al., 2021). Similar findings were reported by (Kristanti, Setiyarini and Effendy, 2017a) with study conducted in Indonesia aimed to assess the impact of basic skills training for family caregivers on the quality of life (QoL) of adults with cancer. The results showed that home-based services can be facilitated by equipping family caregivers with necessary skills (Kristanti, Setiyarini and Effendy, 2017a).

(Krishnan et al., 2018b) with purpose to describe the delivery of care including care setting, did research into 3,270 patients with cancer in India, reported that home-based is one of the care setting for the patient. Similar findings reported by (Damani et al., 2020a) conducted research to 80 of the 102 PC centres provide with study purpose to identify gaps in palliative care provision across National Cancer Grid centres in India, found out that integration of palliative care and cancer rehabilitation between physicians & nurses can be done at home based services. However, (Chacko et al., 2014b) did mixed-methods study to explore the end-of-life care perspectives both of patients with advanced carcinoma and of healthcare professionals in a tertiary healthcare setting in India, found that patient outcomes reported is increased with the community based palliative care and healthcare professional treatment. Similar findings with (Rajah et al., 2021a), in Malaysia to find out about a compassionate and holistic care approach in an integrated system can be delivered through community based methods to overcome the financial problem.

Nevertheless, some authors noted that hospital based palliative care also provides home visits as the main mode of operation. (Hartwig et al., 2014) in Malaysia to

find out about a compassionate and holistic care approach in an integrated system can be delivered through community based methods to overcome the financial problem.
Nevertheless, some authors noted that hospital based palliative care also provides home visits as the main mode of operation (Hartwig et al., 2014). Hartwig et al., 2014). Similar findings were found by (Silbermann et al., 2015) who conducted a study in 15 Middle Eastern countries. The study found that most satisfied service was hospital based services to delivery of pain and symptom management; and to have discussion with palliative care staff.

Of the seven studies which reported hospital based palliative care as the mode operation, (Shabnam et al., 2018) did a literature scoping review to find out what is the existing literature on 24/7 telephone palliative consultation for patients and their careers, to found out that hospital based palliative care can provide 24 hours free call services. However, partially needed home visits were successfully mitigated by 24/7 inpatient access in one hospital (Shabnam et al., 2018). (Kapoor et al., 2017b) conducted RCT on two group patients with cancer in India to assess the efficacy of nutritional addition with counselling, also found that hospital-based modes can deliver these services to the patient. A similar study was conducted by (Abdulla et al., 2021) with a purpose to explore the perspectives of palliative care decision-making for palliative patients and families in Indonesia and Malaysia, conducted study to 12 staff in the hospital, also found that the nurse played a supportive role in ensuring that the patients’ and families' care was effective and efficient through hospital based (Abdulla et al., 2021). Other modes of palliative care services that allowed staff to visit patients at home were hospital-based and patients’ home-based (Abdulla et al., 2021).

(Shamieh et al., 2017), who conducted research in Jordan to examine the symptom changes among adults with cancer at a palliative care clinic using questionnaire, reported that outpatient palliative care consultation associated with improvement on ESAS, is done in the hospital service. (Rozman et al., 2021a) measured the cost of treatment for patients with cancer during hospitalisation cancer in Brazil using quantitative study, noted that their palliative care service is hospital-based provided by a multidisciplinary team organised for outpatient, inpatient and hospice care (Rozman et al., 2021a). Tapela et al aim to describe programme-level experience of implementing, patient characteristics and challenges encountered of Butaro hospital, using quantitative research, reported their service was done via hospital-based service (Tapela et al., 2016b).

Similar findings were reported by (Ndiok and Ncama, 2021), who interviewed 19 nurse managers in two hospitals to identify barriers to and benefits of establishing a model for integration of palliative care of adults with cancer in Nigeria, found that an economic burden and vulnerability make it more difficult for some patients to visit the hospital, so they need home-care visits (Ndiok and Ncama, 2021). Home-care visits give staff an opportunity to see the patient's condition at home and give the patient and family a chance to talk deeply about cancer and treatment (Ndiok and Ncama, 2021).

e. Comprehensive care packages

Seven studies reported needing comprehensive care packages and the continuum of care as the key modes of palliative care (Tapela et al., 2016b, Rozman et al., 2021b, Damani et al., 2020a, Shamieh et al., 2017, Krishnan et al., 2018b, Silbermann et al., 2015). For the seven studies above, (Tapela et al., 2016a) conducted a quantitative study on one hospital oncology model in Rwanda to find out about programme-level experience of implementing integration of care in one hospital. The result showed that the hospital has integration of palliative care needs support delivered by a multidisciplinary team. Moreover, many patients are undiagnosed because of limited diagnostic capacity, hence, paying attention to cancer nationally to integrate the service is needed to reduce this problem (Tapela et al., 2016a). The comprehensive cancer treatment provided a service for diagnosing and curing by a multidisciplinary team through task-shifting and structured twinning with no on-site oncology specialists (Tapela et al., 2016b).

Similar findings were reported by (Silbermann et al., 2015), the purpose of the research is to find data to inform the future educational and training activities. Researchers found that integration of palliative care including consultation, symptoms management and discharge planning is needed to ensure sustainable service. Similar findings were reported by Silbermann et al across 15 countries in the Middle East with research aiming to determine knowledge, beliefs, barriers, and resources regarding palliative care services in the Middle Eastern countries. Furthermore, they found the comprehensive package of the palliative service providing pain management consultation and delivered by an interdisciplinary care programme for dying patients (Silbermann et al., 2015). The same findings were reported by Rozman et al. (2021b) in Brazil. The purpose of the research was to analyse the prospective healthcare facility of 2,985 adult patients (Rozman et al., 2021b). They noted that the people who received care in the hospital needed comprehensive services related to inpatient-outpatient and home care: clinical and interdisciplinary consultations, hospital supplies and hospice care for adults in Brazil (Rozman et al., 2021b).

Moreover, a study conducted by Shamieh et al. (2017) in Jordan, whose data analysis of 182 adult patients with advanced cancer; reported that the hospital provides a palliative care programme consisting of an outpatient clinic, inpatient consultation, a palliative care unit and a home-based palliative care programme for adults with cancer in The King Hussein Cancer Centre, Jordan (Shamieh et al., 2017). In line with a study in India, with the purpose to describe data on palliative care provision across the National Cancer Grid centres. Of 102 centres, 80 reported that they provide comprehensive palliative services such as pain services and home-based palliative services; hospice referrals offered concurrent cancer therapy alongside palliative care and a licence to procure, store and dispense opioids (Damani et al., 2020a).

Another quantitative study aims to describe programme-level experience of implementing palliative care in hospital in Rwanda, reported that Rwanda had a hospital that provided integrated palliative care service with 152 beds, a 27-bed cancer ward and a weekly cancer outpatient clinic (Tapela et al., 2016b). Similar findings were reported by Krishnan et al., who conducted a study with aims to describe the delivery of care by the palliative care centre in India, who also found that The Pallium India centre provided a comprehensive service (Krishnan et al., 2018b). The Pallium India centre provides an inpatient, outpatient and home-based community-oriented palliative care service which has adopted the palliative care policy of the government of Kerala (Krishnan et al., 2018b).

3.3.1.3 Required roles for palliative care staff and volunteers to provide palliative care for cancer in level 1-3 of palliative care development

Nine studies described the required roles for palliative care staff and volunteers as the central part of the palliative team (Shabnam et al., 2018, Tapela et al., 2016b, Krishnan et al., 2018b, Silbermann et al., 2015, Rozman et al., 2021b, Damani et al., 2020a, Abdullah et al., 2021, Kristanti, Setiyarini and Effendy, 2017a).

a. Caregiver

One of the studies that reported nurses helping caregivers (Hartwig et al., 2014), who conducted mixed-methods on 145 adults with cancer across 13 hospitals and six nurses to find out the nurses who visited patients at home, did consultation, measured the patient outcomes and found out that the pain reduced even without morphine as a result of the nurses' visit. Similar findings were reported by Kristanti et.al, 2017c in Indonesia, whose study aimed to evaluate how basic skills training given to family caregivers could enhance the quality of life of the patient with cancer. This included training family at hospital and home visits by nurses (Kristanti, Setiyarini and Effendy, 2017a).

Similar findings were reported by Tapela et al., 2016a in Brazil. Similar findings were reported by Tapela et al., 2016a in Brazil. The research purpose was to describe the programme-level experience of a hospital model of an oncology centre. The Butaro Cancer Centre in Rwanda demonstrated that complex cancer care can be delivered in resource-constrained settings with significant support. Key attributes were partnerships, innovative tasks, infrastructure-shifting, solid leadership with the public sector and the priority being to serve those most in need (Tapela et al., 2016b). However, Rozman et al. (2021a) found that the staff should organise care support regarding providing palliative services (Rozman et al., 2021a). (Abdullah et al., 2021) interviewed 6 nurses and 6 physicians who have palliative care experience, to explore the perspectives of palliative care decision-making for palliative patients and families in Indonesia and Malaysia, also found that nurses played a supportive role in ensuring that the patients' and families' care was effective and efficient.

Of the four studies which mentioned the clinicians as the health care providers, Silbermann et al. (2015), who conducted surveys on palliative care teams to find out about resources regarding palliative care services, found that in many Middle Eastern countries, staff controlled mild pain with nonpharmacologic therapy as a result of limited painkillers (Silbermann et al., 2015). Similar findings were reported by Damani et al. (2015) in India. For the most part, the palliative care team have no dedicated funds nor support from the hospital, a staff shortage: no social workers, no counsellors and no volunteers. However, the physician and nurses can provide inpatient and hospice care by doing their role as health care providers. They found the need for collaboration between oncologists, PC specialists, executives from the public and private sectors, and the government to enhance the delivery of high care (Damani et al., 2015).

Shabnam et al., (2018) did semi-structured group interviews with the physicians, whose purpose of the research was to explore the staff's feelings when delivering the services, also found that the staff provided direct care work via telephone, which could make the patients feel they had someone to talk to (Shabnam et al., 2018). However, Tapela et al. (2016b), who conducted research on Rwanda, found that as health care providers, complex cancer care can be delivered by staff using non-specialised consumables (Tapela et al., 2016b). Krishnan et al. (2018) who conducted surveys on 3,270 patients with cancer, find out about the provider need fund for training staff and providing interventions via policies (Krishnan et al., 2018b).

b. Informant/educator

Four studies showed that the required roles for palliative care staff and volunteers is the Informant/educator (Shabnam et al., 2018, Ndiok and Ncama, 2021, Silbermann et al., 2015, Abdullah et al., 2021). The following key requirements were reported: three studies reported information needed to educate them on prognosis, care, end-of-life care, grief and bereavement, pain symptoms, medication and nutrition. One study reported the need to have nurses as barriers to re-explain the physician’s words. For the three studies that reported educating needs on prognosis as a key requirement, (Ndiok and Ncama, 2021) find out about barriers to and benefits of establishing a model for integration of palliative care of adults with cancer in daily clinical practice, found that the patients need information. For instance, the patients and families needed the staff to educate them on prognosis, care, end-of-life care, grief and bereavement, pain symptoms, medication and nutrition. Similar findings were reported by (Shabnam et al., 2018) who conducted descriptive analysis on 4,195 calls to palliative care centres in Bangladesh to find out that patients asked about medication usage, symptom management, psychologist support, anxiety, admission, ambulances, food and other problems. This requirement was as a result of limited palliative care support in Bangladesh.

Similar findings were reported by Silbermann et al., 2014. The participants assumed that staff were informants who could answer their concerns within 24 hours. Information needs related to support for an end of life without pain and help performing daily activities, follow-up and painkillers. The questions were about the prognosis, care, programme development, financial issues, death and dying, end-of-life care, grief, bereavement, pain/symptom management, complementary alternative therapy and medication (Silbermann et al., 2014).

However, the purpose of research for (Abdulla et al., 2021) found that the nurse is required to give suggestions to doctors during discussions about patients’ care management. One contradiction was that patients thought that the physician was the crucial information resource and the nurse supplied supporting information to explain what the doctor had said (Abdulla et al., 2021).

c. Facilitator

Seven studies showed that required roles for palliative care staff and volunteers is the facilitator (Hartwig et al., 2014, Shabnam et al., 2018, Chacko et al., 2014b, Abdullah et al., 2021, Silbermann et al., 2015, Ndiok and Ncama, 2021, Kapoor et al., 2017b). The following key required roles were reported: five studies reported practical interventions, two studies reported having someone to talk to. As for the five studies that reported practical interventions as a key requirement, Hartwig et al. (2014) who conducted surveys across 13 hospitals and 6 nurses, found out about the psychological burden of clinical providers. This research found that patients expected staff to facilitate all patient-related matters as the result of an absence of morphine (Hartwig et al., 2014). Similar findings were reported by (Shabnam et al., 2018), also found the callers need the staff to provide direct care work about medication usage, symptom management, psychologist support, anxiety, admission, ambulances, food and other problems (Shabnam et al., 2018).

Similar findings were reported by Chacko et al. (2014a). In India, the purpose of the research was to explore the end-of-life care perspectives of both patients with advanced cancer and of healthcare professionals. They found the nurse facilitated supportive services and facilitated a good death (Chacko et al., 2014b).

Likewise, (Kapoor et al., 2017b) in India who did a randomised controlled trial with 66 women to see the effect of nutrition and counselling to improve the anthropometric status and quality of life of adults with cancer and cachexia, found that providing a nutritional supply; and offering counselling is the nurse's role as facilitator. Similar findings were reported by (Abdulla et al., 2021) who interviewed 12 staff & six nurses to find out decision-making for palliative patients and families. It is reported that nurses played supportive roles to ensure they managed patient care effectively. Meanwhile, (Silbermann et al., 2015) found out that staff's ability to offer unidisciplinary and interdisciplinary services were the required skill of the staff as facilitator regarding palliative care (Ndiok and Ncama, 2021).

d. Friend

Three studies showed that required roles for palliative care staff and volunteers is friendship. Patients and families favoured friendship with healthcare staff (Shabnam et al., 2018, Hartwig et al., 2014, Rajah et al., 2021a). The following key symptoms were reported: need to be visited and listened to, need of having someone to talk to, and to cope with emotional issues. For the study that reported being listened to as a key requirement, Hartwig et al. (2014) who conducted surveys on 145 adults with cancer in Tanzania to find out the effectiveness of palliative care teams in reducing, found that the patients were happy to be visited and listened to as they addressed their problems at home (Hartwig et al., 2014).

Similar findings were reported by (Shabnam et al., 2018); the study aims to analyse the calls to palliative teams in Bangladesh, who also found the callers need to have someone to talk to if there were any problems (Shabnam et al., 2018). Some families even invited staff to the funeral to show their appreciation as friends (Shabnam et al., 2018). Similar findings were reported by (Rajah et al., 2021a), who explored the sources of emotional distress of 102 cancer survivors in Malaysia, also found that patients needed friendship-level support from their friends, spouses, children and other family members to help them cope emotionally and to support for emotional distress along the cancer journey (Rajah et al., 2021b).

3.3.2 Multicomponent palliative care services

The reviewed studies primarily reported on palliative care services aiming to address advanced cancer's physical, psychological, spiritual and financial consequences. Notably, concern regarding access to painkillers was reported in the physical need support theme. This finding is in line with many previous studies. One study in low-income countries reported that 26% of participants with cancer had a poor quality of life, with physical symptoms the most prevalent ones (Molassiotis et al., 2017b). Around 95.4% of patients experienced some physical symptoms, with pain being the greatest (Tan et al., 2020). Similarly, data from the Eastern Mediterranean region reported that global opioid consumption was 0.384 mg per person, while in other countries it was 6.24 mg per person (Fadhil, Lyons and Payne, 2017). Eighty percent of the global population was in low- and middle-income countries and 70% had limited access to opioids (Hannon et al., 2016b). Around 10% of the poorest countries received 10 mg of morphine per person, while the wealthiest countries received >47,000 mg/patient (Knaul et al., 2018b). Pain management challenges staff to be more proficient in using existing analgesics (Hartwig et al., 2014). For example, they may need to make a home visit, collaborate with NGOs to fund painkillers, reduce the number of steps needed to access painkillers and ask the government to support palliative care services. The nurse's capability to deliver care in the patient’s home is the main component of palliative care (Kristanti, Setiyarini and Effendy, 2017a).

One of the palliative care targets is reducing the psychological burden. The nurse should integrate psychological screening tools to assess psychological problems and release burdens on all parties (Krakauer et al., 2021). As nurses were constantly with patients, it was understandable why patients and other healthcare providers thought nurses should deliver psychological support. The intervention should be planned by multidisciplinary staff because it might need a mixed pharmacological, behavioural and psychological approach. Moreover, patients at the end of life commonly experience anxiety, uncertainty and a lack of confidence (Dönmez, Alici and Borman, 2021). Psychotherapy helps patients find their meaning in life, enjoy events while they are ill and maintain their dignity (Abdel-Razeq, Attiga and Mansour, 2015). Psychotherapy also resulted in positive criteria outcomes among patients and families, such as less depression, anxiety, worry and grief (Weru, Gatehi and Musibi, 2020).

Despite patients’ difficulty accessing the service, one fascinating fact and pattern from resource-challenged countries was the importance of spirituality in daily life. Commonly, religious people use their religion to reduce their symptoms and anxiety. Spirituality supports quality of life, and eases psychological distress (Pérez-Cruz et al., 2019). Nurses can ensure that patients can practise their religious ritual by providing emotional and spiritual support in hospitals (Abdel-Razeq, Attiga and Mansour, 2015). Palliative care alleviates physical, psychosocial and spiritual aspects of chronic illnesses for patients and families (Fernando and Hughes, 2019). Thus, spiritual support should also has an enormous effect on family caregivers because family provides the most significant support for patients.

Economic difficulties can be challenging; it is recommended that governments provide services at minimum cost. Some resource-challenged countries successfully provided integrated palliative care and maintained a continuum of care (Basu, Mittag-Leffler and Miller, 2013). This could lead palliative care staff in such countries to adopt and adapt sufficient services using their existing sources. Their funding sources were, commonly, religious organisations, non-government organisations or local donations (Azeez and Anbuselvi, 2021). The people who accessed their services also had the same funding difficulties and wanted a lower-cost service (Abdel-Malek et al., 2019). The team could focus on outpatient clinics and community-based services to reduce cost (Aditya, 2019).

Nevertheless, high-income countries reported needing a mixed-payer system for insurance payments, community payments and charitable donations (Groeneveld et al., 2017). The financial crisis negatively affected the poorer group (Johnston et al., 2019). This evidence shows that mixed financial support is still needed for palliative care costs in high-income countries.

Providing palliative care services puts a considerable burden on patients and families, staff and countries. Patients need social support such as food, housing and transport (Krakauer et al., 2021). Some patients perceived finances as a sensitive topic. Hence, communication skills are essential to address sensitive issues in palliative care (Papadopoulou et al., 2019). Families are crucial partners in palliative care because they care for patients' physical, financial, emotional and spiritual needs (Adejoh et al., 2021). They sacrifice their finances, work and social life, their own health and need for social support. Thus, it is recommended that stakeholders work together to support caregivers (Drummond, Johnston and Quinn, 2019b). Volunteers' involvement in palliative care in middle-income countries can decrease the cost and economic burden (Abu-Odah, Molassiotis and Liu, 2020). Their involvement in death and the dying process, end-of-life care, grief and bereavement would be the starting point to reduce the cost (Ndiok and Ncama, 2021). Training volunteers might be a good component of palliative services.

Within high-income countries, a nursing at home programme has been established and has met this need to a moderate degree. For instance, Cicely Saunders in the United Kingdom helped to begin nurse-led interventions in global palliative care (Johnston et al., 2014a). Macmillan, another specialist in palliative care at home, added to the services by providing end-of-life good-quality care at home and options for the place of death (Johnston, 2018). Communication among staff is helpful to ensure patients have dignity during their illness and die with dignity; they should respect patients' privacy and treat patients as people (Johnston et al., 2015b). Nurses could use partnerships with other institutions to increase their skills and to develop management and practical skills in palliative care and extend these across countries (Downing, Leng and Grant, 2016).

3.3.3 Multi-modal operation of palliative care services

The strong culture in resource-challenged countries where families were the unpaid caregivers is the decisive reason for providing home-visit services (Harding, 2013). This systematic review recommends easily accessible services for patients and families. For instance, for consultations about their illness and other issues regarding their life-changing cancer. Most consultations are delivered in inpatient wards and are about end-of-life care (77%) (Roeland et al., 2016). One study found that most patients lack confidence regarding their decisions and need surgeons' opinions (Lally et al., 2021). The nurse can navigate the patient's questions during a consultation (Gilbert et al., 2011) via a video call (Barsom et al., 2021). Another study reported that an early consultation prolonged patient death by 11 days in 2003 and 33 days in 2008 (Arif et al., 2011) and improved pain control (Yennurajalingam et al., 2012). The consultation also improved quality of life and made cost savings because early recommendations can be made for intervention (Scibetta et al., 2016) and helping patients to cope with and understand their illness (Jacobsen et al., 2011).

No country has optimal palliative care delivery (Zeinah, Al-Kindi and Hassan, 2013). Therefore, palliative care teams should try several programmes to help patients access services earlier. Access to palliative services should encompass patients, carers, different health populations, commissioning, funding models and integration into existing services (Johnston et al., 2021). India has seen a sharp growth in palliative care services. This country provides inpatient services in hospices or hospitals and outpatient clinics in hospitals or other settings and they are run by hospitals and volunteers (McDermott et al., 2008). The Jamaica Hope Institute also started providing small hospitals for cancer patients (Connor et al., 2020b).

However, the sharp growth of palliative care services in Asia and Africa cannot serve all those needing palliative services (Knaul et al., 2020). Patients in severe pain still wait months to start treatments. Hence, telemedicine is recommended as an alternative to help patients fulfil their needs. Telemedicine by free telephone consultation could be an alternative palliative service in resource-challenged countries (Chávarri-Guerra et al., 2020). Some countries reported that telehealth could remotely assess patients and provide interventions (Grewal, Terauchi and Beg, 2020), be useful for bereavement support (Fadul, Elsayem and Bruera, 2021) and help the family to make care decisions (Wu et al., 2020). Telehealth palliative care is another option for patients and stakeholders to reduce emergency care needs (Johnston et al., 2012b, Johnston, 2011). Technology development resulted in good palliative telehealth outcomes; for example, phone and video calls improved patient and clinician engagement (Lally et al., 2021). This trend pushed the staff to change their service through online consultations to ensure they were involved in medical interventions (Farnood, Johnston and Mair, 2020). Thus, the team could offer many services through telehealth (Johnston, 2011).

It is more difficult for patients with economic burdens and vulnerabilities to travel to hospital, and they are prevented from visiting hospital earlier (Maharaj and Harding, 2016). Consequently, they need home-care visits. Home-based palliative care services need qualified staff with good knowledge, skills and attitudes (Johnston, 2014). The staff also require training to ensure they provide high-quality services. The American Society of Clinical Oncology (ASCO) stated that the essential services which palliative care models needed were home-care- and community-based, hospital-based for consultations and home-based for inpatient wards (Hibah et al., 2018). Home care was the most palliative model (Brereton et al., 2017).

In 2020, the Worldwide Hospice and Palliative Care Alliance reported on models of palliative care development in different resource settings (Connor et al., 2021). A prior systematic review had noted five models of palliative care delivery worldwide. They were outpatient clinics, inpatient consultations, acute care units, and community-based and hospice care (Hui and Bruera, 2020). For example, Hospis Malaysia provides a charitable community service based in the community (Connor et al., 2020b). These models reduce the cost of the services (Harding and Higginson, 2005). Rachel House, a pioneer in palliative care in Indonesia, provides nurse-led pain and symptom management services for children with life-threatening illnesses (Connor et al., 2020b). They collaborate with primary and tertiary hospitals regarding giving painkillers. Meanwhile, Australia has created collaborative cultures in end-of-life (Connor et al., 2020b). These collaborations aim to help people accept their care with cultural dignity. Another provider, the Island Hospice and Healthcare in Zimbabwe, parks a vehicle next to patients who need palliative care (Connor et al., 2020b). This car helps to shorten the long queues in hospital clinics. They assess the patient and provide them with medication and medical equipment. This service might be useful in countries with limited cancer treatment where hundreds of patients from long queues in the clinics. Another benefit in Panama included palliative care in the existing primary health system to help people access the service (Connor et al., 2020b). Regarding providers, having an interdisciplinary staff led by a physician or nurse has positive outcomes (Connor et al., 2020b)

A family caregiver can sometimes exacerbate a patient’s suffering regarding sensitive issues like social distress and sexual dysfunction (Krakauer et al., 2021). The spouse is the busiest caregiver and source of joy for the patients, however, the situation got worse if the spouses were jobless (Govina et al., 2015). To reduce stress on patients and families, community nurses could use Dignity Care Intervention guidance 'to identify and provide appropriate care, regarding key physical, emotional, spiritual or social concerns' (Johnston et al., 2015a). The patient-reported outcome could alleviate the burden on patient and family by monitoring and evaluating symptoms and burdens and providing sufficient interventions at home (Kotronoulas, 2021).

Palliative care in Mongolia includes palliative services in the national cancer programme and provides beds for inpatients (Connor et al., 2020b). In Oman, the palliative care association provides cheaper beds for palliative care in the hospital (Connor et al., 2020b). A successful programme integrating palliative care in hospital settings has been reported in Kenya, Uganda, Rwanda and Zambia (Grant et al., 2017). From the explanation above it is clear that home-care visits constitute a rational service and are less costly in resource-challenged countries. The critical success of these services lay in the integration of the government health system, advocacy, staff training, mentorship partnerships and mutual learning.

Community-based care for elderly people with a chronic illness and life-limiting condition in Bangladesh adopted Kerala’s community system (Connor et al., 2020b). Medical and nursing university students visit the patient at home with a package of oral morphine. Their visits involve the family caregivers at home. This programme is sustainable if the campus can continue this service. This palliative care could be extended beyond the university. However, for people in remote areas, this system seems impractical, and collaboration between stakeholder groups seems more practical to ensure the continuity of the programmes.

3.3.4 Diverse roles of palliative care staff and volunteers

The suggestions for providers' roles were their expertise and ability to act as health care professionals, informants, educators and facilitators and to be a friend to patients and their family caregivers. Patients expected staff to respect their autonomy and listen to their concerns (Silbermann et al., 2012). This finding showed that patients believed staff to be a source of correct information. This was similar to other studies in resource-challenged countries where people commonly have less literacy and lack information about their illness and treatment (Purba, Johnston and Kotronoulas, 2022). As care providers, nurses provide cures and advice on illness prevention and health and rehabilitation for patients. Patients mentioned that nurses' goals were to prevent pain and suffering, cure any symptoms, promote comfort and encourage rehabilitation to help patients perform their daily activities (Abdulla et al., 2021). Moreover, nurses also played a specific role in unique challenges, for example they could serve patients in different places, including prisons (McParland and Johnston, 2021). In line with previous studies, patient suffering was reduced when they received attention and friendliness from staff during their treatments (Tan et al., 2020). Adults with cancer need support from friends, family, employers and religious and support groups to keep a positive outlook (Gakunga et al., 2019).

Research is needed regarding the best intervention depending on participants' backgrounds (Drummond, Johnston and Quinn, 2019a). Staff could decide on a system that supported their decision-making (McParland, Cooper and Johnston, 2019). Their experience and skills enabled them formulate a care programme for patients, if possible until they die (Elcigil, 2011). Staff in Middle Eastern countries reported that their work increased palliative services, legislation, negotiation, self-awareness and policies via training and education and helped to integrate hospital services (Bingley and Clark, 2009). Essential outcomes for patients with other chronic diseases were a functional status, reducing the burden on caregivers, symptom management and survival (Johnston, 2018). One study reported that most patients perceived that their needs were already well identified by nurses and they had a high-level of satisfaction (Meegoda., Fernando. and Sivayogan., 2017).

Patients required scientific information on whether to follow up on their medical treatment (Kotronoulas, Cooper and Johnston, 2019) or delay their therapies (Kotronoulas et al., 2017b). Evidence from one study found that adequate information could be delivered orally or in written form (Kotronoulas et al., 2017c). Clear communication is essential to reduce confusion between patients and staff. Specific information, such as that relating to sexual wellbeing, should be accessible through an e-library (Maguire et al., 2021) to maintain patient dignity (O'Connor et al., 2019). Staff could give information and mitigate measures to prevent insufficient responses from patients and families (Meegoda., Fernando. and Sivayogan., 2017). They could explain the rationale of all treatments so that families understand why the staff give or do not give treatment. Staff could identify and address supportive care by asking patients to measure their outcomes (Kotronoulas et al., 2017a) and provide information to identify their needs.

To bridge cultural barriers, staff should consider patients' values and beliefs, language, social context and family role (Alassoud, Johnston and Hogg, 2020). The staff, especially nurses, should ensure the patient's family receive the correct information and can handle unwelcome news and should show empathy, support the patient, trace a patient who refused an intervention, reschedule visits and improve access to palliative care and health insurance. Patients need information from trusted sources like the healthcare staff (Farnood, Johnston and Mair, 2020, Farnood, Johnston and Mair). The staff should perform self-management by educating patients to take control of their health (Molassiotis et al., 2017a). Thus, the staff should provide understandable information to patients and families according to their cultural backgrounds. Similarly, staff also need to have a close relationship with patients (Gakunga et al., 2019). This relationship enables nurses to improve their ability to encourage adults with cancer as well as help their families to perform self-management and seek information (Cheng and

Kotronoulas, 2020). The nurse’s role when delivering person-centred care is to focus on living healthily today or living in the moment. If patients recognise and understand the concept of living in the moment, it will be easy for them to reach the goal of dying in peace and dignity (Dönmez and Johnston, 2020).

3.4 Strengths and limitations of this review

This synthesis considers that all the research answers to identify organisational characteristics of the services developed in level 1-3 of palliative care development. The researcher followed the JBI guidance when identifying and selecting all articles relevant to our eligibility criteria and reporting the review in PRISMA flowchart (Page et al., 2021). The Mixed Methods Appraisal Tool version 2018 was used to assess the risk of bias in high-quality articles (Hong, Gonzalez-Reyes and Pluye, 2018). The strength of this appraisal tool is its capability in assessing the quantitative, qualitative and mixed-methods study at a time. The researcher promoted reproducibility by synthesising evidence unbiasedly following synthesis without meta-analysis guidelines in the methods and the reporting in discussions and conclusions (Campbell et al., 2020).

The search strategies involved 172 countries representing three continents; Asia, Africa and Latin America. Some papers may not reflect all countries and some may reflect more about India than another geographical area. Even though Europe is well-known for having high-quality palliative care, some countries are still on the map of resource-challenged countries for global palliative care. Nevertheless, almost 80% of resource-challenged countries lie in Africa, Asia and the Middle East, so it is appropriate to compare their organisational palliative care service with that of Indonesia. Some services may be limited. The researcher grouped the interventions to reflect the main components, the mode of operation and the requirement for palliative care staff and volunteers to provide palliative services in resource-challenged countries. Hence, this synthesis reflects the benefits in all continents and could answer all research questions.

The researcher used version 2014 of the Global Atlas of Palliative Care and the End-of-life care when searching for the countries; in 2020, a new atlas was published. 20 countries were excluded in this search, but in the new atlas, there are 51 countries. However, the results retrieved no articles from those additional countries. Thus, the researcher could still use those articles for this study. The first search excludes 20 countries as map 2014. The updated map in 2020 excludes 51 countries. However, none of the articles included in this study come from additional 31 countries. The literature review did not include clinical trials to do meta-analysis due to the diversity of the outcomes and study designs.

3.5 Conclusion

The researcher conducted a systematic literature review to identify the main components of the service and the mode of operation of palliative care services in level 1-3 of palliative care development. The study presented robust evidence about the suggested organisational and operational characteristics of palliative (cancer) care services developed for and implemented in resource-challenged countries. They were a multicomponent model of palliative care services, a multi-modal operation of palliative care services and diverse roles of palliative care staff and volunteers. This evidence could lead palliative care staff in resource-challenged countries to adopt and adapt the component services with their existing sources. Those components could address patients' physical, psychological, spiritual and financial burdens, as well as policy and information barriers. Hence, component services relating to these areas were the most successful in low- and middle-income countries.

Based on this review, the mode of operation of palliative care in level 1-3 of palliative care development should be more concerned with physical services, information and financial distress. Teams could develop their service by opening an outpatient clinic for all adults with cancer and extending their service to community-based palliative care by strengthening the family caregivers' role in delivering primary care. Until the staff can provide and develop a comprehensive service, family caregivers' presence and involvement in patient care is the most reasonable option; it is less costly and more comfortable for patients, families and the country/government/healthcare provider/volunteer.

A future study to identify a lower-cost service with family involvement is needed to provide more evidence on how to run accessible palliative services. It is also important to prevent financial burdens and an information gap through policy restructuring.

Chapter 4 Theoretical framework; Literature Pertaining to the Selected Methods

4.1 Introduction

This chapter discusses the literature pertaining to the selected methods and explains the rationale for choosing the research methods and designs. It explains the chosen paradigms which shaped this research. It also discusses the use of mixed methods in this study. The chapter explains the person-centred theory approach in research methodology when collecting, analysing and interpreting data. Table 4-1 shows the summary of the research paradigm.

Table 4-1 The research overview of this PhD

Paradigm	**Critical realism**
The ontological position	I believe that there is an actual, real universe; the reality is that patients with advanced cancer are dying without access to quality palliative care in West Java. Their needs, burdens, views and expectations are understood as social and personal self-worlds. I accept that the quality of palliative care might mean something different for different people. This reality cannot always be objective. I may be wrong in my observations and knowledge, so there is subjectivity in my perception.
The epistemological position	I believe that a study cannot always be done objectively. A researcher may make mistakes when making observations or have incorrect knowledge. Hence, there is a degree of subjectivity in a researcher's perception.
The chosen methodology	Mixed methods is considered the best way to help gather evidence of palliative care interventions needed in resource-challenged countries. I wanted to know the relationship between what would-be knowers and what can be known about adults with cancer needs: their burdens, views and expectations of supportive care needs. Truth from numeric data is needed to predict their outcomes, needs and burden, along with the truth concerning how people experienced the services.
Conceptual and theoretical underpinnings	The truth and knowledge from this research have come from participants, not from the researcher's interpretations. Patients believe that healthcare providers always know the best solution for them and that they make the best decision depending on their circumstances. In addition, autonomy is not possible for people in resource-challenged countries because the patients belong to their families. Thus, a shared decision between patients, families and healthcare providers is common for patients. A person-centred nursing approach will allow patient to choose what is good for him/herself.

Methods	I argue that mixed methods can be used to collect data to answer my questions, that is, to explain what people think about the interventions that they are told are reasonable for them. The quantitative data provided numeric data and the qualitative data provided the meanings of participants' life experiences.

I chose critical realism as the paradigm for this study because I believe that the world is constructed from perspectives and experiences that can be observed. Patients with advanced cancer die without access to quality palliative care and there is a need for cancer palliative care in West Java. Their needs, burdens, views and expectations are understood as social and personal self-worlds. According to critical realism, adults with cancer face a drastic change in their body, mind and soul and in financial respects. These changes create burdens for them and their family caregivers. Therefore, they need comprehensive supportive care from a multidisciplinary team.

I chose the person-centred care theory as a theory for this study because it suits Indonesian culture's health-seeking behaviour. People in Indonesia want to be treated as pleasantly as a friend with culturally and locally relevant dignity and wisdom during their illness. The cultural impact has the most significant effect on their life. Staff should work with the patient's beliefs and values, engage with their values authentically, share decision-making, be sympathetic and provide holistic care. What is suitable for each patient is unique. The person-centred approach allows the patient to participate in their care planning. Patient outcomes and the nurse's care plan can be discussed together. They can also evaluate it to see whether there is room for better interventions. Furthermore, Indonesia has a paternalistic culture: patients believe healthcare providers always know the best solutions for patients. As a result, patients and families will choose the best decision depending on their circumstances. They might refuse the suggested healthcare treatment because they cannot pay for it. So the physician's final decision regarding a drug prescription considers factors such as the drug type, medication guidelines and patients' buying power (Hartono et al., 2014). Thus, the person-centred theory was used to underpin this study.

4.2 The philosophy of knowledge

The axiology of this study is exploring suggested nurse-led interventions in palliative care for people with insufficient resources in West Java, Indonesia. It aims to help stakeholders understand the experiences of patients with cancer, family caregivers, and stakeholders in palliative care during patients' illness and treatment and to suggest a nurse-led intervention in palliative care services.

4.2.1 Ontology

Ontology is concerned with reality, a starting point from which researchers imagine and construct a theoretical framework or paradigm for any significant research (Scotland, 2012). The reality of what participants say about their life experiences can be used to predict their future needs and the milestones for improving existing services (Martinez-Posada, Hernandez-Molina and Hernandez-Molina, 2019). Participants' knowledge is their truth and can be used to improve their satisfaction level with nursing services (Min et al., 2013). In nursing, ontology is what nurses know about patients and interactions between patients, families, communities, environments and illnesses (Lake, West and Rudge, 2021). When patients report their data, it is the truth for them because it reflects their existing condition. Thus, ontology potentially influences the problem-solving process (Bender, 2018). The construction of nursing knowledge is well-known in nursing theories such as Orem's self-care theory and Roy's adaptation model (Flaming, 2004). The standard values in nursing, like showing respect, dignity, sensitivity and spirituality, should be defined in a complex practice context (Pesut, 2010). Hence, ontology enables nurses, staff and interprofessional teams to explore the best options for patient (Kessler, 2019). To enhance this, nurses could explore what they want to know and take action to elevate the better approach. This is a must, because what nurses think is better for patients might not be better from patients' viewpoints (Benedik, Rajkovič and Šušteršič, 2014).

The ontology of this study was to find out the true lived experience of adults with cancer and their family caregivers during their life experiences while they have cancer that was diagnosed in West Java. I believe they experienced disruptive changes during their sickness and need palliative care to reduce their burdens.

There might be different views on whether existing palliative care services can reduce their burdens. What is best for them should have come from themselves. The best care for them can be found by exploring how they evaluate their experiences and what convenient palliative care intervention should be carried out.

4.2.2 Epistemology

Epistemology is a philosophical theory concerning the nature of knowledge through which knowledge can be validated (Guba and Lincoln, 1994). It questions what people can know, how they can know it and how they can study knowledge to find out the extent to which theories are true. Together, epistemological and ontological assumptions make up a paradigm (Houghton, Hunter and Meskell, 2012). In other words, the epistemology of a paradigm relates to the question of what the nature of a relationship between individual is, who has the potency to hold knowledge and what can be known to that individual (Bender, 2018). Therefore, where ontology refers to what exists, epistemology contemplates how people can come to know what exists and can seek to know what they know and how they come to know about it.

Research on humans should involve participants to seek the truth about them. Furthermore, researchers should not treat humans as objects like in natural science. Instead, humans should be involved in understanding phenomena from their context. The researcher believes that this study cannot always be carried out objectively. A researcher may make mistakes in making observations or in knowledge, so there is a degree of subjectivity in a researcher's perception: how a researcher perceives situations, events and reality depends on what theory they use. The researcher accepted that good-quality palliative care might mean something different to other people and that as a researcher, it was fundamental to investigate what adults with cancer and their family know about palliative care, their views and expectations and how they know about it. Thus, reality and knowledge come from the participants.

4.2.3 Methodology

Scientists follow specific procedures to ensure verifiable, accurate and consistent observations (Guba and Lincoln, 1994). Research methodology is '[t]he general approach for conducting research' (Thomas, 2021). The methodology is the specific procedures or techniques used to identify, select, process and analyse information. It is a guide for selecting methods used to gather knowledge to answer research questions (Williams, Rycroft-Malone and Burton, 2017).

The methodology includes the purpose, location, time, population, sample, sample size, sampling technique, inclusion and exclusion criteria, data collection instruments, method, outcomes and data analysis. This project aims to find data concerning how to develop a nurse-led intervention in palliative care in resource-challenged countries. The mixed-methods study collected data using observation, surveys, interviews and systematic review during 2019-2020 in one hospital in Indonesia. The population was patients with cancer, their family caregivers and palliative care staff. The sample was recruited using purposive and convenience sampling techniques. Data were collected using audit, questionnaires, interview topic guides and search engine criteria for the systematic review. Outcomes were participants' level of needs and burdens, their views and expectations and suggestions regarding palliative care services in resource-poor countries. Qualitative data were analysed using statistics and qualitative data were analysed using thematic descriptions.

4.2.4 Methods

Methods are procedures for accomplishing what people want to know by following specific steps (Thomas, 2021). Research methods can be qualitative, quantitative or mixed (Ryan, 2019). Quantitative research is collecting numerical data and analysing it to find the statistical averages, patterns, relationships and predictions and generalising data for different population (Haig, 2018). Qualitative study is the process of collecting data through what participants said and analysing words to find the meaning of the words (Sandelowski, 2000). This method can produce thematic findings to describe a patterned response to research questions. Qualitative data provide evidence that contains insights, values and meaning

(McKinnon, 2018). Mixed-methods research collects and analyses data using both quantitative and qualitative methods (Creswell, 2009). Hence, this method can aggregate qualitative descriptive and quantitative data (Sandelowski, Barroso and Voils, 2007).

This project used mixed methods to gather data needed to answer the research questions. The qualitative method is needed to deliver participants' life experiences and expectations about good palliative care. The quantitative method is also needed to seek information about the level of needs and burdens and the reported outcomes.

4.3 Research paradigms

Philosophers believe that people can only understand human behaviour in a specific place and context (Russell, 1945). A research paradigm is an integrated cluster of substantive concepts or thought patterns, including theories, variables and problems attached to complementary methodological approaches, research methods, postulates and tools, distinct sets of concepts and standards for legitimate contributions to a research field (Thomas, 2021, Houghton, Hunter and Meskell, 2012, Nairn, 2019). A paradigm is an abstract, logical structure of meaning that guides a study's development and enables the findings to be linked to a body of knowledge (Younas, 2020). There are several research paradigms. Each paradigm can use specific research methods to find answers to its questions (Allmark and Machaczek, 2018). The research philosophy of this research can be seen in Figure 4-1.

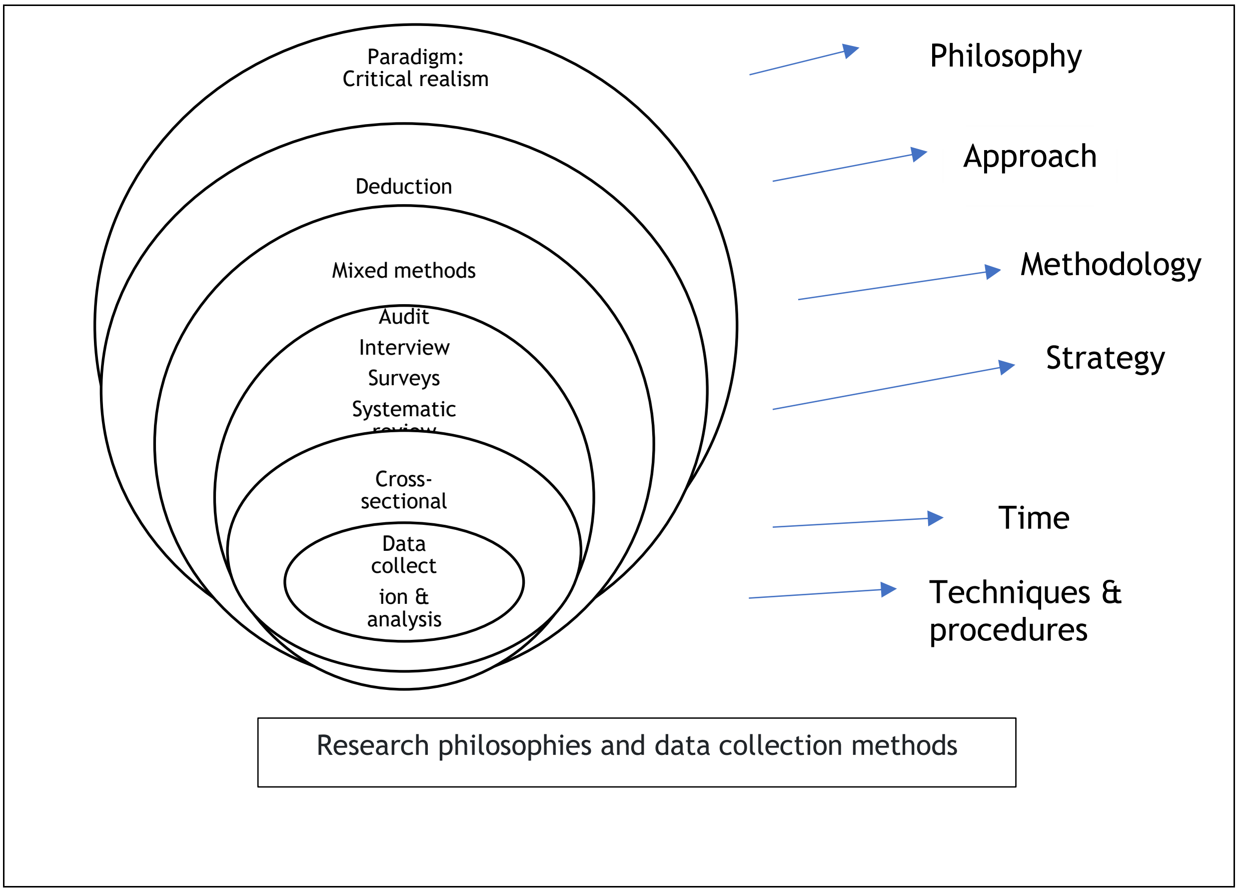


Figure 4-1 Overall research philosophy chosen for this study

4.3.1 The paradigms in research

a. Positivism

Positivism believes in the unity of sciences; scientific methods used in natural sciences should be equally appropriate for studying social phenomena (Park, Konge and Artino, 2020b). There are five basic principles of positivism: the logic of inquiry is the same across sciences; science aims to explain, predict and discover the truth; scientific knowledge is testable; science is not equal to common sense; science should remain free of values and should be judged by logic. Positivism dominates nursing research history through quantitative research (Ryan, 2019). The reason for this is that the nature of nursing is to test exact numbers or effects of implementation (Houghton, Hunter and Meskell, 2012). Testing actual scores or values of body measurements can help to find out about the cause and effect of implementation of a treatment or interactions between drugs (Polit and Beck, 2012, Vashishth and Chakraborty, 2019). For example, using numerical data is the best approach to calculating nursing quality of care and patients' quality of life during illness or treatment (Tanlaka, Ewashen and King-Shier, 2019).

However, regarding nursing care, it is realised that exact statistical numbers do not adequately represent a patient's condition because people are unique (Vashishth and Chakraborty, 2019). Thus, a mix between qualitative and quantitative research has become common in nursing research (Vashishth and Chakraborty, 2019). How patients live their experience and interpret their signs and symptoms also needs to be explored to help stakeholders choose appropriate action. This research needs both quantitative and qualitative data. It also needs to consider the meaning people give to their life experiences, which can only be measured by words, as well as numerical data about their outcomes, needs and burdens. Thus, researchers cannot use a positivist paradigm to answer this research questions.

b. Post-positivism

Post-positivism is a wholesale rejection of the central tenets of positivism (Manjikian, 2013). Post-positivism recognises that all observation is fallible, can be wrong and that all theory is revisable (Panhwar, Ansari and Shah, 2017). Post-positivism is more realistic and acknowledges the probable nature of prediction in social science (Park, Konge and Artino, 2020a). What can be observed by human senses (sight, hearing, touch, taste and smell) can be called social facts (Alharahsheh and Pius, 2020). This paradigm excludes studying concepts such as anxiety, wellbeing and life satisfaction (Manjikian, 2013).

While positivists emphasise quantitative methods, post-positivists consider both quantitative and qualitative methods valid (Taylor and Lindlof, 2011). Science is not simply a detached product of methods, but it is not simply cultural either (Corry, Porter and McKenna, 2018). Post-positivism believes all observations are theory-laden and scientists are inherently biased by their cultural worldviews (Groff, 2004). Post-positivism rejects relativist ideas concerning different perspectives that we can understand because we come from different experiences and cultures and rejects the idea that any individual can see the world perfectly as it is (Panhwar, Ansari and Shah, 2017).

This project aims to measure patient outcomes and participants' views and expectations that cannot be measured by human senses. The researcher needs to understand the meaning of palliative care needs from participants’ point of view and needs data measured by human senses and people's life experiences to answer the research questions. Thus, post-positivism cannot be used to deal with this project.

c. Pragmatism

Pragmatism was framed by Charles Peirce (Peirce, 1877, Peirce and Hetzel, 1878) and then refined by William James (James, 1975) and John Dewey (Dewey, 2018, Dewey, 1981). Pragmatism’s premise is that ‘[t]he meaning and truth of any thought or idea are determined somehow by criteria of practical usefulness, the value of an idea or proposition is to be found in the practical consequences of accepting it’ (Hannes and Lockwood, 2011). Pragmatism believes that reality is constantly renegotiated, debated, interpreted and directed to seek practical and useful answers or to provide direction for addressing concrete problems (Patton, 2015b, Morgan, 2007). Furthermore, pragmatism focuses on the outcomes of action (Morgan, 2014). Pragmatism can be used to research human experience based on a researcher's beliefs (Kelly and Cordeiro, 2020). Thus, it can be involved in grounded theory, ethnomethodology and conversational analysis (Denscombe, 2008).

After James (James, 1975) replicated pragmatics in academia from around 1904 to 1909, most nursing research and practice used the pragmatism approach (McCready, 2010). It is also used in nursing trials because it offers critical thinking and advocacy in research designs (Devos et al., 2019). The pragmatic approach could explore nurses’ complex interplay because it could link the variation of nursing interventions and multifactor outcomes (O'Reilly et al., 2018). Pragmatism could inform patients’ experiences and personal perspectives, particularly for people with mental health issues (Deering et al., 2021). T The most well-known research design in nursing studies is positivist studies using qualitative and quantitative methods (Ryan, 2018).

Commonly, the questions considered concern practical understanding and wisdom about concrete culture (Braithwaite, 1959) and real-world issues, and seek practical and valuable insights to inform action (Russel, 1959 in (Patton, 2015a). Pragmatic studies focus on individual decision-makers and try to understand multiple factors in people's experiences to understand better and to solve problems (Patton, 1990, Patton, 2015a). Because pragmatism is based on the human experience, the absolute truth in the pragmatic study should not be generalised to other populations because one truth in one population might be different from that in another (Russel, 1959 in (Patton, 2015a). Pragmatism also seeks to decrease problematic situations rather than test hypotheses (Salkind, 2010).

This study sought to understand the truth about adults with cancer. The researcher believes that the truth in one population is based on their experience and the truth can be the same for other populations with the same background. The researcher was trying to interpret the truth for different populations without creating theories. Because pragmatism believes a truth in one population might be different from that in another population, this paradigm does not fit this project.

d. Constructivism-interpretivism

Constructivism-interpretivism was formed and developed by Jean Piaget via his cognitive development theory through the process of child development (van der Walt, 2020). 'The first step is to acknowledge a social world(s) that is reflected in the natural habits of daily life and exists independent of either positivist or constructivist analysis; hence realism' (Cupchik, 2001). Quantitative and qualitative studies could measure these phenomena and describe them using rich information.

The interpretivism paradigm rejects this paradigm. Interpretivism believes that the 'social world is constructed by the human being and continuously involved in interpreting social environments' (Parahoo, 2014). Interpretivism focuses on subjective experience, perception and language to understand intention and motivation to explain behaviour (Parahoo, 2014). This paradigm believes that a person is active in process interaction to construct the truth. Knowledge is not part of the natural world but merely a scheme created through conception. For example, people are constructing their lives when they choose activities (Antlová et al., 2015). Constructivism believes that the truth is relative to individuals and communities and that the social world is constructed by humans and continuously involved in interpreting social environments.

This research needs to explore the truth through the participant-researcher's deep reflections on how people construct their truth. The project seeks to interpret the realism among the participants by not involving their social environment. The researcher believes that knowledge can be found through communities without involving their social environment. Thus, constructivism-interpretivism does not fit this research paradigm.

e. Interpretivism

Interpretivism is a more qualitative approach to social research; it is the view that individuals are complex and intricate people, not just puppets reacting to external social forces (Alharahsheh and Pius, 2020). Individuals experience the same reality in different ways and often have different ways of behaving (Thanh, 2015). Interpretivism is a sociological approach that say it is crucial to understand or interpret individuals' beliefs, motives and actions to understand social reality (Potrac, Jones and Nelson, 2014). In other words, while positivists treat sociology as a science dealing with numbers and experiments, interpretivism criticises this approach and says that sociology is not a science and human behaviour cannot be explained through quantification (Potrac, Jones and Nelson, 2014).

While positivists believe that social norms can explain human behaviour, interpretivism believes that humans are complex creatures whose behaviour cannot be explained by social norms (Streubert and Carpenter, 2011). Interpretivism focuses on subjective experience, perception and language to understand intention and motivation to explain behaviour. Interpretivism can deal with both quantitative and qualitative approaches (van der Walt, 2020).. Positivism uses quantitative methods such as statistics, surveys and questionnaires, whereas interpretivism uses qualitative methods such as participant observations and unstructured interviews to analyse human behaviour and society. The data collected are mainly in conversations and narratives, which is applicable for mixed-methods research. Interpretivism believes there is no actual realism out there, which the researcher believes exists in the population. Thus, this paradigm does not suit the aims of this research.

f. Critical realism

One of the most common forms of post-positivism is a philosophy called critical realism (Bhaskar, 1979). Critical realism constructed from Bhaskar's work in the 1970s as an alternative to positivism and constructivism (Denzin and Lincoln, 2011). Critical realism is a branch of philosophy that distinguishes the real and observable worlds. It believes there is a reality independent of our thinking about what science can study, contrary to subjectivists, who believe there is no external reality (Bhaskar et al., 1998). The reality and existence independent of human perceptions, theories and constructions cannot be observed (Parlour and McCormack, 2012a). Therefore, the best way to achieve objectivity is to triangulate multiple fallible perspectives (Patomäki and Wight, 2000).

Critical realism believes that the truth is realist-subjective (Bhaskar, 1979). The world, as people know and understand it, is constructed from their perspectives and experiences through what is observable (Fletcher, 2017a). According to critical realists, unobservable events and the social world can be understood if people understand the structures which generate the events (Gorski, 2013). Thus, research among humans should be used to promote action as the solution (Schiller, 2016b). The action could be the policy or guidance as concrete problem-solving (Deering et al., 2021). Critical realists assume that there is a real world out there (McEvoy and Richards, 2003). They acknowledge that social phenomena are intrinsically meaningful and that meaning is not only externally descriptive but also constitutively descriptive (Collier, 1994). They acknowledge that social phenomena are intrinsically meaningful and that meaning is not only externally descriptive but also constitutively descriptive (Sayer, 2010). The fundamental tenet of critical realism is that people can being the causal of language to describe the world (Bhaskar et al., 1998).

Critical realist philosophy has borne new and alternative ways of seeing, questioning and researching (Bhaskar et al., 1998). It holds that there is a deeper underpinning reality that can be observed, experienced or interpreted (Schiller, 2016b).

Interpreting how people expressed their needs and burdens will be valuable. The researcher accepted that quality of care might mean different things to different people and that reality cannot always be objective. A researcher may be wrong regarding observations and knowledge, so her perception is subjective. The research aim is to find out about the actual, real universe of patients with advanced cancer in West Java who die without access to good-quality palliative care. What do patients with cancer, their family caregivers and palliative care staff need to develop nurse-led interventions in palliative care? Their needs include numerical and word-related data. The researcher wanted to know how patients measure their need for supportive care and their signs and symptoms from numerical data and to know how family caregivers measure their supportive care needs and burdens. The views and expectations of palliative care and how the staff run their services were also sought for qualitative data. Hence, critical realism can fit this research.

4.3.2 Critical realism, the paradigm chosen for this study

This PhD project used a critical realism study, which combines quantitative and qualitative paradigms (Streubert and Carpenter, 2011). Critical realism is a theory that tries to bridge interpretivism and post-positivism (Holloway and Wheeler, 2010). The long human experience is the basis for decision-making. Critical realism reasserts truth criteria and suggests that one form of knowledge may be more valid than others. Therefore, the task of health, human and nursing sciences is to use theory to interpret how structures operate in an open system (Cruickshank, 2012). Some knowledge may be closer to reality than other theories that help researchers get closer to reality to explain and analyse more data. Complex problems in nursing practice require the creation of knowledge that can be gained through collaboration with researchers, policymakers, practitioners and the public (Streubert and Carpenter, 2011).

The researcher needs qualitative data concerning participants' views to help them understand participants' expectations and quantitative data regarding what they sense about their needs and burdens. I searched for the truth about how people interpret palliative care needs, whether they really need it, and if they do, how much they need it. The data I retrieved using mixed methods can access reality. However, participants have their own truth about their reality. Each participant is unique and can decide on the service they expect. What nurses perceive as best might be different from their point of view.

Furthermore, their cultural experience influences their decision-making. What is seen as truth in their society might affect their view. So, sharing decisions with their society is also common.

Person-centred theory is used as the theoretical framework for this research. The theory consists of an integrated set of defined concepts, existence statements and relational statements that can be used to describe, explain, predict or control the discussed phenomenon (McCormack et al., 2010). The needs, burdens, views and expectations are understood as social and personal self-worlds. Critical realism believes there is a real universe out there. The researcher found that patients with advanced cancer in West Java died without access to good-quality palliative care. Adults with cancer face a drastic change in their bodies, minds and souls and in their finances. These changes are a burden for them and their family caregivers as well.

In order to answer the researcher's questions, the researcher chose to investigate events, experiences and mechanisms to better understand the reality of patients with advanced cancer in West Java and to enable us to enhance reasonable care. Several methods were used to answer the questions: an audit, surveys, interviews and a systematic review. A more expansive view, both qualitative and quantitative, was needed to give the researcher better results. Data were gained from studying documents and from questionnaires, interviews and a systematic literature review by using mixed quantitative and qualitative methods, which is where the critical realism paradigm can fit in.

4.4 Theory underpinning the research

In philosophy there are many perspectives on a person. According to McCormack, people should explore health, social care, nursing policy and strategy to locate person-centred practice in broader health and social care (McCarmock, 2010). 'The complex relationship between nurses, patients, their families and other healthcare works as the complexity of health and social care decision making and internal and external constraining factor has been shown to prevent such a concept of autonomy being a viable option' (McCormack and McCance, 2010a). Person-centred nursing for elderly people develops from the patient's view that a nurse will be with them for their whole life, while staff generally view patients as demanding. Nowadays, patients have the autonomy to decide on their healthcare process frameworks (McCormack and McCance, 2006).

McCormack stated that four core modes of 'being' are at the heart of person-centred theory. They are 'being in relation, being in the social world, being in place and being with self' (McCormack and McCance, 2016). McCormack developed person-centred theory and constructed it using four original frameworks (McCormack and McCance, 2006). The frameworks are prerequisites, care environments, person-centred processes and expected outcomes, which are the results of practical person-centred nursing.

4.4.1 Person-centred theory

The participants in this study thought about and expected palliative care during their illness and treatment. Their needs and burdens, symptoms and outcomes should be addressed together with their autonomy. They should have an opportunity to choose and evaluate the interventions they have. Their person-centred outcome should result in satisfaction with care, involvement with care, a feeling of wellbeing and the creation of a therapeutic culture. On the other hand, palliative care staff should provide a service that satisfies the patient. Prerequisites and the care environment should be considered so that adequate care is given to satisfy the patient and to deliver person-centred outcomes (McCormack, 2020).

‘Person-centred nursing practice is about developing, coordinating and providing healthcare services that respect the uniqueness of individuals by focusing on their beliefs, values, desires and wishes, independent of age, gender, social status, economy, faith, ethnicity and cultural background and in a context that includes collaborative and inclusive practices and frameworks’ (McCormack and McCance, 2006) (Appendix 5). In addition, person-centred nursing practice aims to plan and deliver care that considers a person's context, including their social context, community networks, cultural norms and material supports (McCormack et al., 2017). The patient and family have the right to receive interventions that fit with the patient's culture. Good palliative care in high-income countries might be different from that in low- and middle-income countries. Respecting individuals’ values is also the task of healthcare providers. Matching needs and values should be done by coordination between stakeholders and patients. Person-centred theory is rooted in this nature of nursing and has a long relationship with nursing because the main nursing principles involve treating people as unique (McCormack and McCance, 2010a).

The principle of palliative care is treating all persons as individuals, respecting their rights, building mutual trust and understanding and developing healthy relationships. Evaluation of nursing-specific outcomes can start by adopting a person-centred approach. Providing a caring environment is a critical influencing factor experienced by patients, families and care teams. Thus, healthcare providers, including nurses, should ensure the patient feels comfortable, safe and happy when receiving treatments. Effective teamwork, workload management, time management and staff relationships are essential to creating a democratic culture in person-centred relationships (McCormack et al., 2010). Care environment elements are an appropriate skill mix, shared decision-making systems, effective staff relationships, supportive organisational systems, power-sharing, the potential for innovation and risk-taking and the physical environment.

4.4.2 The background to using person-centred theory

Caring is a human instinct that involves an emotional approach in the care process. Humans are not seen as machines that need physical repair and a psychological approach. Thus, all interventions should be person-centred. 'Many aspects of an individual reality may be shared so that common understanding can form a sense of community' (McCormack and McCance, 2010a). This definition emphasises that nurses see a patient as a whole person with all their bio-psycho-socio-spiritual elements. In other words, nursing's purpose is to treat the body, soul, mind and other elements. Hence, human research should include comprehensive physical and psychological value measurements. Body measurements could be measured using quantitative methods, while how patients perceive the quality of care or their life experience during their sickness journey could be measured by qualitative data.

The promotion of person-centredness is consistent with the healthcare policy direction internationally. This person-centred approach was endorsed by WHO in 2015; it set out a comprehensive framework of people-centred health services. This theory has been developed well in several countries and works effectively. In Australia, 'the person-centred supportive intervention has enabled more direct support to family carers rather than just enabling them to provide care' (Aoun et al., 2018). Many countries are embracing this challenge; healthcare policy and strategy initiatives are focused on reorganising to be people-centred (McCormack and McCance, 2017). The challenges are a lack of adequate tools for handling the complexity of individual illness and evidence and the need for a more flexible method, specialist multidisciplinary staff, a basic understanding of bio-psycho-biomedical aspects, phronesis, judgment and clinical experience evaluation, and personal experience. It is also essential to know how often an intervention works, how and why it works, and which interventions work, their methods and criteria for success (McCormack and McCance, 2017).

This research sought to understand how the participants feel about their physical, psychological and spiritual symptoms and signs, their finances, their burdens and needs levels regarding supportive care needs, and their experience while providing or receiving treatments during illness. The truth and knowledge arising from this research have not come from the researcher's interpretations but from those of the participants, and so have the implications of the results, which will enhance people’s views and expectations. A person-centred framework, which represents the process by the person-centred, starts working with the patient's beliefs and values, engages them authentically, shares decision-making, is sympathetically present and provides holistic care. Person-centred outcomes arise from a good care experience, involvement in care, the feeling of wellbeing and the existence of a healthful culture.

4.5 Mixed methods in nursing research

Nursing research can use the positivist paradigm and mixed methods as its approach. This is because research in nursing needs quantitative data to predict health problems, to find average scores for or likelihoods of health problems, and to reveal what living a healthy or sick experience means (van der Steen et al., 2017a).

The researcher chose mixed-methods research to collect data to fulfil the research aims. The quantitative approach provides numerical results about needs and burdens, while the qualitative approach explores the rich context of the meaning of life experience from the individual perspective. Qualitative data give deeper information about a small population or limited cases (Maarouf, 2019). For example, when Covid-19 first began, there was no literature about it. Hence, qualitative data such as case reviews are valuable for informing others about the nature of the virus and its effects on people.

4.5.1 Justification for the mixed methods used in this project

The researcher wanted to ascertain the relationship between what is currently known and what can be known about the needs and burdens of adults with cancer and their views and expectations of supportive care needs. It can also be said that mixed methods can be used to collect data to answer the research questions, that is, to explain what people think are suited interventions for them. Data were collected by multiple methods via a mixed-methods approach (van der Steen et al., 2017b).

This study aims to find how to develop palliative care interventions for adults with cancer and their family caregivers in resource-challenged countries. The researcher needed data about the structure of the existing palliative care services in resource-poor countries, how they provide the services and patient access. This data can be found using mixed-methods research. A qualitative study can be done by reading palliative care related documentation, interviewing the participants to explore their views and expectations and doing a systematic review to understand the mode of operation of palliative care. A quantitative study will describe the participants' outcomes and the levels of their needs and burdens. Thus, mixed methods can be used to find critical phenomena regarding adults with cancer in Indonesia.

4.5.2 Stage 1 The qualitative study: systematic review

The researcher wanted to find data about the suggested mode of operation of palliative care in resource-challenged countries through qualitative methods and a systematic review. A mixed-methods systematic review directly answered the research questions about the main components, mode of operation and the requirements for the palliative staff and volunteers. A systematic review can test whether existing research can address future study and appraise the evidence objectively (Higgins et al., 2022). The systematic review starts by formulating the problem, intervention, comparison and outcomes (PICO). Next, a study protocol is made, the data is exported and the results are discussed (Higgins et al., 2022). This project's recommendations will help formulate suggested outcomes and suggested interventions for participants based on the suggested interventions from previous studies.

4.5.3 Stage 2 The qualitative descriptive study: observation

The researcher needed data about the structure of the existing palliative care services in resource-challenged countries, how they provide their service and how patients access it. An in-depth understanding of how they provide their services can be found using qualitative descriptive observation. There are two kinds of observation: structured and unstructured. The positivist paradigm generally uses structured observation, while the interpretivist paradigm uses unstructured observation (Mulhall, 2003). Observation is a convenient way to view the course, behaviour, interaction and process of a disease (Mays and Pope, 1995). Through this method, the researcher used her sense of sight to describe or analyse what they have seen (Bloomer et al., 2012). The audit of documents helps to describe what happened in the past and to see the change process, the development, the barriers and other findings so that they can be used as evaluations or predictions of future action and to encourage the stakeholders to make policies or decisions (Raadschelders and Kwang-Hoon, 2011).

First, the researcher wanted to observe how staff provided the outpatient palliative service, what they did, what patients needed and how they accessed the service. However, the outpatient clinic was closed owing to some technical issues. The hospital had provided a new integrated room for outpatient clinics. However, it remained closed when the researcher was collecting the data. Since the observation could be done by observing documents related to the work, the researcher decided to do so. The documents observation method is a method of finding data in notes, books, transcripts, newspapers, inscriptions, magazines, meeting notes, agendas and photos of activities (Busetto, Wick and Gumbinger, 2020). The material can also be documents like annual reports, documents, policy documents, diaries, letters, notes and guidelines. Data from such sources is commonly used to complete data collected from interviews and observations (Alastalo et al., 2017).

The data from the documents observed form a description of the existing palliative services. The findings give a better understanding of the structure of services, so we can picture what services need to be improved or evaluated.

4.5.4 Stage 3 The quantitative descriptive study: survey

This project needed quantitative data about the level of needs of patients and their family caregivers, patients' reported outcomes and the family burden during treatment and the illness. The data were collected using a quantitative method, a survey of participants conducted through four questionnaires. The results show the level of their needs, their outcomes and the burdens caused by the illness. The survey is famous for collecting quantitative data (such as percentages and total numbers) and qualitative data (such as opinions, perceptions and attitudes). Data from health surveys can help to understand the trend of diseases, provide an exact number of interventions needed and to predict the number of resources needed to cover it (Courbier, Dimond and Bros-Facer, 2019). The survey can use questionnaires to collect data (Dawson, 2017). The surveyed data is shared in clinical settings (Weir et al., 2022). This project aims to understand what participants need to ensure the healthcare providers can provide or produce proper future interventions. The survey gathers information systematically from the population. However, for a large population, the data can be collected from the sample with various sampling techniques (Magill et al., 2014). The findings also can be used to judge the effect of activity on the population (Chaudhuri and Pal, 2022).

4.5.5 Stage 4 The qualitative study: one-to-one interviews

The researcher collected qualitative data about stakeholders' views and expectations of palliative care services in Indonesia from the interviews. Qualitative data can be collected from interviews and focus group discussions that explore participants' depth of understanding (Malterud, Siersma and Guassora, 2016). A one-to-one interview is an effective method of uncovering health problems (Singh et al., 2023). The data findings constructed the meaning of participants' life experiences and identified what they needed to shape the palliative service to fit with their outcomes, needs and burdens. Interviews help to find data about people's thoughts, experiences or knowledge about something.

The interview data should be transcribed rather than analysed to construct themes for participants' thoughts (Wemette et al., 2020). While quantitative research needs a fixed number of samples depending on the sampling technique, qualitative research does not require an exact number. As long as questions reach saturation, a few samples are enough (Heaslip et al., 2021).

4.6 Reflexivity

The researcher made a note containing every research step, from recruiting the participants to the writing process. Reflexivity ensures that the research is rigorous and trustworthy (Johnston, Pringle and Buchanan, 2016). To prevent unbiased data, the researcher kept a diary to write down all collected and analysed data (Busetto, Wick and Gumbinger, 2020). In doing systematic reviews (stage 1), the researcher used theoretical frameworks to help the study design, guide, investigate and ensure that they align with the research pathway (Tark et al., 2023). The PICO, criteria, and Prisma framework ensure that the researcher finds the relevant articles for the study, and the quality appraisal helps to find a high-quality study for further analysis. Meanwhile, Nvivo tools help to make coding and themes. Finally, the thematic analysis helps in constructing the themes from the verbatim.

For the audit process (stage 2), the researcher used simple observation to collect the data as the research questions. The staff members understood that I was a nurse lecturer, which made some of them worried that I would judge them about what they had done as the palliative care team was not in line with the national guidance in palliative care. However, I ensured that I would not intervene in their roles as the palliative team; all my data will be used to improve their service only. All the data provided by the team is read several times and grouped to describe their structure, the patient's access, the development of the team and their achievement since they opened the services. No data were added to make up the data, and we checked the data description with the team after the data analyses were finished.

In stage 3 surveys, some of the patients and family caregivers were worried that their care would impact their treatment if they joined as participants; hence, I ensured that all the surveys to the patients would not affect their treatment. The researcher checked all the questionnaires from the participants to ensure they filled out all the questions. I also checked the data entry and clearance to avoid missing data. SPSS tools help researchers find statistical data that describes the frequency, rate, mean, and percentage of the participant's needs, burden, and outcomes. The researcher checked every result to ensure the date analysis was done correctly.

Finally, in stage 4, I kept the interview process and analysis with minimum mistakes using thematic synthesis preserve principles (Thomas and Harden, 2008). All verbatim is written line per line to see the codes and nodus, and then the final themes are constructed. The Braun & Clarke 6 data analysis steps (Braun and Clarke, 2012) helped the researcher construct the themes. The researchers also made a table of research questions and the answer (constructed themes) to see their consistency. Three people helped as people and public involvement (PPI) to read the data and give their thoughts on the result. All of them agreed that the data reflected their experiences as people with cancer, as nurses who care for people with palliative care needs and as an unpaid caregiver of her mother, who had cancer.

4.7 Chapter summary

This chapter discussed literature pertaining to the selected methods. The chapter started with the methodology and paradigms, in general, in the search for an applicable design for the research. Then it moved to a discussion of research paradigms in nursing research to consider the relevant paradigms for this study. The critical realism paradigm chosen was justified in terms of scope and its relevance to this study. The chapter highlighted the ontology and epistemology of the thesis. Then it moved to the importance of the person-centred theory when gathering the information needed from the stakeholders. Justification for using mixed methods in this project was presented step by step, from qualitative research to quantitative research. The qualitative research includes observations and interviews while the quantitative study includes surveys and audit. The researcher mitigates the potential bias in data by making all the research steps transparent.

Chapter 5 The Audit

5.1 Introduction

This chapter presents the findings from the audit documentation created by the palliative care team to describe how they run the service. The chapter provides the answer to the second question about audit and the palliative services.

5.2 Research aims and methods of audit

This study aims to investigate the current structure, patient access and services provided by an existing palliative care service in Hasan Sadikin Hospital, Indonesia. The purpose of this study is to describe the palliative services provided by the hospital so that it is able to give information about the suggestions to improve their services.

5.2.1 Design and setting

This research was qualitative descriptive to describe the structure of the service, the patient access and how they serve the patients. This study is done in Hasan Sadikin Hospital, West Java Indonesia.

5.2.2 Audit considerations

The researcher receives consent from the hospital to audit their services and report the audit to the team in order to improve their service. Before doing data collection, the researcher presented the proposal to the team leader. The team understood what data they would share with the researcher. The researcher also had a written permit from the director of the hospital and the palliative leader to access all documents needed.

5.2.3 Data collections

The researcher used the total sampling technique when collecting data, which means all documents provided by the team were used as the sample. Public documents available from the hospital were examined in order to get an overview of its services but did not access the patients' medical records. Information was extracted from the hospital documents regarding the structure of the hospital, including the palliative team, patient access and the services. Data were compiled to provide a descriptive explanation of information. Inclusion and exclusion criteria were all documents about palliative care services. Data collection instruments study list: organisation's structure exists, and communication and task performance.

5.2.4 Ethics

The researcher gained ethics approval from the University of Glasgow and the hospital. The process was started by applying to the hospital ethics board for ethics approval (**Appendix 6 Ethics approval**). Two weeks later, the researcher was invited to present the proposal to the members of the ethics board. After ethics clearance was received, a request was submitted for permission to the director of the hospital. The researcher supplied them with the proposal, the ethics clearance from the University of Glasgow and the Ethics Board of Hasan Sadikin, along with the recommendation from the Indonesia Ministry of Research and High Education. The whole process took two months. The researcher conducted stage 1, observation of the palliative services, by contacting the palliative care team. The research aims were explained to the palliative care team leader, Doctor Gatot Nyarumenteng, and provided a questions-and-answers session. Next, the researcher organised a coordination meeting between members to discuss our research. Data collection began after the researcher received confirmation of permission on the 23rd of January 2020. The researcher observed the palliative care team's services, structure and patient access by accessing hospital documents and discussions with team members. The services from hospital documents were examined, then information about the structure of the hospital was extracted, including the work of the team, patient access and the services themselves. Data were compiled in a descriptive explanation of information.

5.2.5 Inclusion/exclusion criteria

As the research aims are to describe the services, the researcher did not have the inclusion/exclusion criteria. All the data about the services is included in this research.

5.3 Population and sample

The population for this part of the study was the organisation’s structure and communication between staff and other departments. The sample were documents, clinical pathway, medical records, letters confirming tasks/work orders.

5.4 Participant eligibility criteria

This involved the investigation of the current service via an audit of existing hospital documents. The researcher used the documents which were provided by the team and public information on the hospital website. The documents only include information about the palliative care team's structure, patient access, the services and patient characteristics. This data gives a better understanding of the services, such as how they function, the structure, the process, and aggregated data on the numbers of patients accessing the services as outpatients and those accessing them as inpatients over a particular period.

5.5 Data collection process

5.5.1 Data collection tools

The researcher used existing records to collect data. This was guided by what data were needed, including the palliative team's current structure and work, and patient access. All relevant documents provided by the team were collected.

5.5.2 Data collection flow

There is no pilot study at this stage. All the data sources were identified at Hasan Sadikin Hospital. At first, the researcher had discussions with Doctor Gatot, the palliative care team leader, to identify potential documents and activities for the study. Data were required about the service's current structure, patient access, the type of services and how they work. The researcher only observed public documents available from the hospital and did not access patients' medical records. The outcome was a description of the service structure. The researcher received documents relevant to palliative care team activities; the structure, the process of their services.

5.6 Instrumentation

The researcher made a list of what information was expected to have regarding aspects such as the structure of palliative care, patient access, the mode of operation and service resources.

5.7 Data analyses

The researcher used *NVivo* software tools to analyse the qualitative data. The purpose of qualitative data analysis is to describe and explain a pattern of experience. There are four stages for finding a pattern in qualitative research: collecting data, reduction, display and conclusion (Braun and Clarke, 2012). The purpose of qualitative data analysis in this study is to describe the current service, to find people's view on existing palliative care services and to find suggestions for future services. The data collected from document observation and interviews was joined with other information from this study and used to search for a suggested mode of improving palliative care in resource-poor countries. All data from the interviews was transcribed and analysed using NVivo, software that supports qualitative and mixed-methods research (Butler, 2017). The researcher did qualitative content analysis and thematic analysis by coding then generating the themes.

The researcher analysed documents to describe all services, including the goals of the palliative care team, the structure of the service, patient access to the palliative care team, outpatient service access, mode of operation, the range of services provided by the palliative team and actions taken to improve the service. The outcomes were descriptions of the current service, patient access and services provided by existing palliative care services.

5.8 Result: The palliative care team at Hasan Sadikin Hospital

This part will describe findings from an audit of the current structure, patient access and services provided by the existing palliative care team. The palliative care team refers to the team that provides palliative care services in the hospital.

5.8.1 The goals of the palliative care team

The palliative care team has set out both general and specific goals. The general purpose of the team is to improve sustainability and enhance the continuum of care of palliative services for all patients by developing the programme. The specific goals are a) to increase the staff's knowledge, skills and competence through formal and informal education. b) to provide infrastructure, facilities and equipment for the clinic, inpatient rooms and home care, c) to complete palliative management guidelines and operational standard for procedures and improve patient access to palliative team services, d) to improve inpatient and outpatient services, e) to collaborate with provincial government, local government, health services, community and non-government organisations, and f) to provide a monitoring and evaluation system for palliative care services.

5.8.2 The structure of the service

The current team was formed in 2016 and worked under the hospital director's control. It consists of 15 multidisciplinary staff including nurses, general physicians, physician specialists, psychiatrists, psychologists, pharmacists and nutritionists. Fifteen nurses from the wound and stoma care team were added to the team, plus one member of the clergy to do administrative jobs, so there are 36 people. The team leader is a physician specialising in obstetrics and gynaecology. To support their work, they were given a room at the outpatient clinic in 2019.

The palliative team’s work is based on the physicians’ referrals, and the team is called out whenever physicians refer a patient to the team. The general physicians or specialists can screen patients, decide whether they need palliative or not, then send them to the palliative team. Only physicians can refer patients to the team or to another hospital.

Besides their job in the palliative team, the staff also have primary responsibilities in their department. They can serve patients who need palliative care when they have finished their primary job. They do these jobs as part of their shift/regular working hours. The staff have to work two jobs in their regular hours, without any amount paid by the employer. Only physicians receive a fee for doing their extra job. The team has served a limited number of people since they started their services three years ago.

To increase the knowledge and skills of the palliative staff, the hospital supports their training. Currently, they are taking palliative care courses facilitated by the Indonesian Cancer Society (YKI) and the Singapore International Foundation (SIF). The courses contain six modules, one module per semester since March 2019. Currently, all the palliative care team members have undergone palliative training. This reshapes palliative staff's skills regarding delivering palliative care to reach some goals. For instance, they have improved the palliative services in the outpatient clinic and inpatient ward and collaborate with government and NGOs regarding cancer-related concerns.

5.8.3 Patient access to the palliative care team

The palliative care team provides two services, one for inpatients and one for outpatients in clinics and those who are receiving home care. There is no specific room or equipment for inpatients who need palliative care in wards.

5.8.3.1 Outpatient service access in palliative care

The palliative team runs an outpatient clinic and offers home-care visits. The team only provides one specific service in the outpatient clinic, which does not address all problems. To access the clinic, the patient should access the general clinic first by registering at counters between Monday to Friday. Here the patient receives services from a physician regarding their signs and symptoms. The physician screens everyone with a chronic illness using a palliative screening tool. This tool has been adapted from several instruments related to palliative care. If the physician finds that the patient needs palliative care, he/she will refer the patient to the palliative care team. However, the palliative team does not have staff that can be standing by at the clinic. They can only provide wound care, specifically only for people who have serious wounds, commonly people with stomas, burn injuries, or cancerous wounds. However, the patient has to pay for this service because it is not covered by national health insurance.

The national health insurance categorises palliative care as a specific treatment that can only be accessed by paying privately. Therefore, only people who need wound and stoma care and who can pay the fee will be sent to the palliative team. At the time of this study, they served on average 5-7 patients a week in the clinic. Stoma and wound care are provided by 15 nurses, members of the palliative team who have a certificate in wound dressing. The nurses also have primary duties in their ward. When the outpatient clinic needs wound care, the physician will call them. In addition, there is no room or equipment for palliative treatment for outpatient clinics and home-care patients. The home-care service can be accessed after the patient has had contact with the palliative team in the clinic or ward. When the patient goes home, the palliative team will offer a home-care visit. This can be done if the patient agrees to receive services at home and agrees to pay for them. Between 2017 and 2018 they only did ten home-care visits in Bandung city.

5.8.3.2 Inpatient service access

In contrast to outpatient services, all inpatients’ wards can access palliative services using the national health insurance scheme. The inpatient ward services are divided into class 1, 2 and 3 and very important person (VIP) categories. The VIP category is the most expensive, then class 1, 2 and 3. Class 3 is the cheapest and it is associated with poor people, whose access to medicine, equipment and specialist physicians is limited. The government finances poor people who cannot buy their benefits with class 3 insurance with a tariff of 25,500 rupiah/ person/month (£1=19,000 rupiah). In terms of service, the VIP class will receive an earlier scheduled appointment than those in class 3. Some patients thought that this meant the national insurance and the hospital had discriminated against them. The internship student practices caring for patients in this class, which made some patients assume the student is using them as a 'guinea pig'. The patients also perceived services in this class to be the worst.

Getting a bed in the hospital for poor people or people from rural areas is a significant achievement because hundreds of people experience a long wait to access the hospital. The patients have no other choices because of the limited cancer treatment in Indonesia. Hasan Sadikin is the central referral location for cancer in West Java Province for around 46 million residents. In 2019, 207 patients with chronic illnesses were referred to the palliative team. Half were diagnosed with cancer. Only 86 of them received palliative services because staff could only visit patients after finishing their primary tasks. Table 5-1 shows an overview of the number of patients who accessed palliative service.

Table 5-1 The number of people who received the services in the hospital.

Total patients	2016	2017	2018	2019
a. With cancer Adult total - Inpatient - Outpatient - Children	* 13,918 * 2,381	61,808 13,381 48,428 2,102	60,139 11,711 48,428 17,090	* 14,156 * *
b. Number of referrals	*	*	*	207
c. Number of patients receiving the palliative service	*	32	34	86
d. Gender - Female - Male - Unidentified	*	12 (39%) 20 (61%)	17 (50%) 17 (50%)	99 (47.8%) 93 (44.9%) 15 (7.3%)
e. Age - ≤ 50 years - > 50 years - Children - No data about their age	*	22 (68%) 9 (29%) 1 (3%) *	11(32.3%) 11(32.3%) 4 (11.8%) 8 (23.6%)	75 (36.2%) 68 (32.8%) 14 (6.8%) 50 (24.2%)
f. The diagnosis - Cancer - Non-cancer	*	28 (86%) 4 (14%)	16 (47%) 18 (53)	100 (48.3%) 107 (51.6%)
c/a1 (total patient going to the hospital)	*/*	32/61,808 =0.05%	34/60,139 =0.05%	86/*
c/a2 (total adults inpatients ward)	*/13.918	32/13,381=0.23%	34/11,711= 0.29% =0.05%	86/14,156= 0.6%
b/a	*	*/13,381	*/11,711	207/14,156 =1.46%
c/b		32/*	34/*	86/207=41.54%

*No data

It is apparent from the table that very few people received palliative care services. A significant number of adults with cancer went to the hospital every year. Most of them were males, aged 55 years and under. Half of them were diagnosed with cancer. The number of adults with cancer in 2017 and 2018 remains stable, at around 61,000, while the number of children with cancer increased sharply from 2,102 in 2017 to 17,090 in 2018.

The number of patients receiving the palliative service compared to total inpatient adults with cancer is only 0.05% in 2017 and 2018. Moreover, the number of patients receiving the palliative service compared to total adults with cancer is only 0.23% in 2017, 0.29% in 2018 and 0.6% in 2019. The physicians in the hospital referred 207 people to the palliative care team in 2019. Only 1.46% of inpatient adults with cancer in the wards were referred to the palliative care team in 2019. Only 41.54% of these referrals received palliative service. The reasons for not receiving it were that the patient died or went home or that staff could not visit the patient. This statistic shows how difficult the access to palliative care services is and how low the level of access is. Nevertheless, despite a slow increase, this data shows slight progress of the palliative team.

5.8.4 The mode of operation

5.8.4.1 The role of the staff

All staff have an on-call day when they have responsibility for responding to requests for palliative services. They will visit patients, assess their needs, give an intervention and then evaluate their intervention. The palliative team members communicate via an online group, where they share and discuss patients' cases. The physician who has referred the patient does not have access to this group. However, the team will record their work in the patient's medical records so that the physician can assess the treatments.

5.8.4.2 Palliative care screening tool

The physician in the clinic and ward screens people with a chronic illness using a screening tool to examine whether they need palliative services. If the score is 4 or more, the physician will send the patient to the palliative team. If the score is 0-3, they will observe the patient using the Edmonton Symptom Assessment Scale (ESAS). When the ESAS score is >70, they will send the patient to the palliative team. The palliative team will treat and follow up the patient. If the patient is at the end-of-life stage, the palliative team will provide end-of-life care or offer home care. Thus, the physician is the key to identifying patients who need palliative care.

5.8.4.3 Palliative care referral

Most referrals came from internists (74 cases) and paediatrics (15 cases). Those patients had medical diagnoses such as cancer, HIV-AIDS, tuberculous, diabetes mellitus and burn injuries. Physicians who are exposed to the palliative team are more likely to refer patients to the palliative team than those who are not. Thus, raising awareness among all staff would be vital for promoting this service.

5.8.4.4 Intervention

Patients commonly go to hospitals at the last stage of cancer. Therefore, they need palliative care to reduce signs and symptoms, improve their quality of life and help them to die with peace and dignity. An intervention depends on the personnel who deliver it. If the nurses were treating the patient, they made a nursing care plan. It started with an assessment, nursing diagnoses, planning, implementation and evaluation.

The pattern of physicians' interventions gives the impression that they consider medicine to be for symptom management. A summary of interventions in 2019 that included the patient's gender, age, diagnosis, signs and symptoms showed that interventions were delivered such as facilitating the patient to carry out their last wishes, physiotherapy to reduce pain and breathlessness, medicine to control pain and symptoms, spiritual guidance, family education and wound care management. There is no bereavement report or patient/family evaluation of the work because contact between staff and patients only occurs in the hospital.

5.8.5 The range of services provided by the palliative team

The palliative team opened the palliative outpatient clinic but it is limited to stoma/wound care only. Their ambition is to open an outpatient clinic for anyone who needs palliative care and to have staff on stand-by in the clinic. Although the palliative team already has one room in a new building, they have not opened the clinic yet because they are still preparing equipment and staff.

5.8.5.1 General clinic

The hospital provides two types of outpatient clinics: general and specialist. The service is covered by the national health insurance. The outpatient clinic serves thousands of people every day. The general clinic consists of more than 100 sub-clinics. Patients with cancer are scattered across three sub-clinics depending on their types of cancer. The sub-clinics are Obstetrics-Gynaecology, Ear, Nose and

Throat, Lung and Oncology. During the first visit, patients will be seen by a general physician except if they have a referral to see the specialist/subspecialist. The general physician will refer the patient to a specialist physician if they need one. The national health insurance will cover the fee. However, the patient will wait for several days or weeks to see the specialist because of the long waiting lists.

Patients can visit clinics in three ways: without a referral, via a referral by their General Practitioner or referral by a district hospital. All of them should register at the admission centre before meeting the physician in the clinic. The physician treats them, with four possible outcomes: first, they do not need further treatment and can go home with a medicine supply; second, the physician sends them to the Acute and Emergency unit or refers them to another hospital if they need emergency treatment; third, patients need hospitalisation; fourth, patients need further assessments, diagnostic tests or other tests.

Patients with cancer commonly face the fourth possibility. They receive a schedule for several diagnostic tests before the specialist physician decides on cancer treatment for them. Those who need surgery can wait months, years or longer due to limited capacity in surgical units. There are only 24 beds in the surgical unit. During this time, patients do not have access to palliative care. As a result, they just wait in the shelter/home without any healthcare provider supervision. In the future, screening patients in shelters can be the first step to offering palliative services. The team could provide full-time staff to serve patients and deliver home/shelter care in shelters.

5.8.5.2 Specialist clinic

The specialist clinic's purpose is to serve people who want a faster service with modern diagnostic or assessment tools and services from specialist or subspecialist physicians. The specialist clinic consists of 10-15 sub-clinics. The clinic provides excellent medical examinations and pharmaceutical services. Patients can register, choose a specialist physician and receive a treatment schedule quickly. However, this service is only for those who can pay the fee. Patients in the general clinic cannot visit a specialist physician directly unless they are willing to pay. Some patients visit a specialist to cut the waiting time, because only specialists can decide on cancer treatment. Wealthy people are those most likely to access the specialist clinic. In the future, the team should request health insurance to cover the palliative care service so that all patients can access the service.

5.8.6 Actions to improve the service

Since it first started, the palliative team has provided services using a team approach. They support people at advanced stages of illness by providing holistic support for bio-psycho-socio-spiritual needs. It is expected that their service will spread to the first level of primary care in all district hospitals. Several actions that have been formally proposed are explained in the following list.

1. Increasing staff's knowledge, skills and competence through formal and informal education.

In the first three years, all staff already had knowledge, skills and competency in palliative care. Every year, the team members are allowed to have palliative care training or attend seminars inside and outside the country. In 2018, two specialist physicians had training run by trainers from the Ministry of Health in Jakarta, and in turn, they will train others in their institutions. Two other physician specialists and five nurses were undergoing palliative care training. Four nurses attended a symposium for palliative training in Surabaya and two physicians attended an international workshop on palliative care in Jakarta. All of them are now attending three years of palliative training in the hospital. In the middle of 2019 one nurse finished her master’s specialist in palliative care. The team held palliative care symposia or conferences and attended several events as speakers or participants: a survivor symposium on the Republic Indonesian television channel, a symposium in Cirebon and in the Ear, Nose, Throat physician specialist symposium. They also provided palliative training for family caregivers in ten hospitals in West Java Province in November 2018.

2. Provide infrastructure, facilities and equipment for the outpatient clinic, inpatient wards and home care.

Palliative services have implemented palliative filtering to screen patients for palliative care needs in each inpatient ward and outpatient clinic. In 2019, physicians referred 207 people in inpatient wards to the team. Also, in April 2016, they opened an outpatient clinic for stoma and wound care.

The team has been creating an organisational structure for the palliative outpatient clinic, job descriptions, identifying the types of services to be provided, preparing a proposal for the installation of a palliative outpatient clinic in the Oncology Centre building, preparing a proposal for a palliative care service policy (filtering criteria for patients eligible for the palliative clinic), creating a standard operating procedure in the palliative clinic, and applying tariff patterns to palliative service in inpatient wards, outpatient clinics and home care. In 2019, the hospital approved the need for an outpatient clinic by providing one empty room for a clinic in a new building. However, it is still without equipment. The clinic was still closed when the researcher did data collection in February 2020.

3. Completing palliative management guidelines, operational standards procedures and improving patient access to palliative team services.
The team has created a palliative patient management guide, operational standards for procedures for providing palliative services, a proper flow of services for patients, palliative patient management guidelines and a home-care clinical pathway.

4. Improving the service for outpatients and inpatients.
The national health insurance does not cover palliative care fees because it is a new service that requires new tariff patterns. The palliative team proposed tariffs based on hospitalisation costs. They arranged financial aid for poor people in the clinic, and the fee for specialist physicians in the general clinics is the same as the general physician fee. This financial aid aims to help patients access specialist physicians. The home-care tariff is the same as the specialist fee without a transport fee. This might be linked to the fact that the palliative staff prefer to visit patients in and around Bandung City rather than patients outside Bandung.

The team conducted community events and social activities with palliative care patients, cancer survivors, and those with other chronic illnesses once a year. They raised public awareness of palliative care via social media and mainstream media by participating in talk shows on TV and radio, talked to people on car-free days and promoted awareness through a series of public events, such as the hospital’s birthday celebrations, training for staff on palliative care day in October and a fun run on world palliative care day every October. They also disseminated knowledge via webinars, social media and universities.

5. Collaborating with provincial government, local government, health services, community and non-government organisations.

Their most significant achievement was they all trained together with members of Indonesia Cancer Society and Singapore International Foundation. The latter provided trainers, the former funded the costs and the hospital provided a location and staff. This training ensures member have the same knowledge and skills in palliative care. This collaboration will also facilitate spreading the palliative care service into the broader community. They had a meeting with the district hospital to discuss the arrangement of community access to palliative care.

6. Providing a monitoring and evaluation service for the palliative care service.

The palliative care services evaluated their service in 2017 using strengthen-weakness-opportunity-threatened (SWOT) analysis. Based on the result, the team used diversification strategies to improve their work. They forwarded proposals in 2017 to improve the service.

Nonetheless, some of their requests were not granted until 2018 because the hospital did not have enough funds. For instance, direct services to outpatients and home care had not been granted at the time of writing to clarify. The staff did their jobs using their own equipment. They even bought it for patients because insurance did not cover health equipment. The team reported their activities to the hospital director of human resources and education.

5.8.7 Provision for nurse-led intervention

Initially, three out of 15 members of the primary palliative care team were nurses. Sadly, one of the three nurses has sadly died in 2021 because of cancer one year after I interviewed her. She was a master specialist nurse in oncology who worked as chair of the Nursing Credentials Committee. She had trained in palliative care both in Indonesia and overseas. She was the leader of the palliative nurses and had actively worked to improve palliative care in that hospital. The other two nurses have bachelor’s degrees; one works in quality control and one in the general intensive care unit. To improve competence, the palliative team proposes having a human resources development programme for all members, including nurses. Of 18 nurses one has a master’s in palliative care; she is the only one to have a formal qualification in palliative care. Her presence is expected to bring a palliative care nurse approach to the team.

The wound care team was formed earlier than the palliative care team. Currently, only the wound care team can meet outpatients who need palliative care. They combine their knowledge and skills in palliative care with their wound care skills. Even though they have never measured patients’ satisfaction level with their work, almost all nurses said patients were satisfied with their services. Talking sessions during wound care might effectively release patients’ stress, help them to accept their illness, heal their body and emotions, keep their spirits up and teach them how to deal with a stoma bag or do their activities. Data from the interviews indicated that other members were satisfied with nurses’ work in wound care. This step is a significant opportunity to apply nurse-led intervention in palliative care.

Nurse-led intervention is possible through nurses’ presence. They can be the pioneers in providing the intervention. All the nurses in the team could start a nurse-led palliative care approach, a nurse-led intervention guide and nurse-led care planning in the hospital. The palliative team could set a goal to increase referral rates to 10% and rates of palliative care services to 65%. This target seems reasonable if the team provides staff who can focus on the palliative service. If a nurse visits one patient daily, they can visit 365 patients in one year.

The outpatient clinic represents the most significant need because thousands of people with chronic illnesses go to the hospital daily with severe symptoms. The team could open an outpatient clinic for consultation and intervention to reduce patients’ signs and symptoms. Staff with an on-call schedule could work full-time in the outpatient clinic. The hospital can afford to fund the service in an outpatient clinic because health insurance covers outpatients’ clinic fees, except for stoma and wound care.

5.9 Discussion

The structure of the service. The team has served a limited number of people in the three years since they started the service because staff also have primary responsibilities in their department. Previous studies found that palliative care staff need to close the gaps, including in policymakers' decisions (Centeno et al., 2016). The inadequate ratio of staff to patients causes an ethical-moral problem for the team and increases the distress of the staff and patients (Wiersma et al., 2019). However, teams in other countries successfully started their service with several limitations and insufficient resources (Akintude et al., 2018). Learning lessons from the sharp increase in palliative care in Europe in the 1960s, the first step was to form hospital-based, home-care and inpatient hospice programmes (Clark, Have and Janssens, 2000). The team already has an inpatient and outpatient palliative care service. This step is a good start to reaching more people. It is recommended that they should continue the service and reach more patients in district hospitals.

Physicians at Hasan Sadikin Hospital screen patients in the outpatient clinic and inpatient wards. Nevertheless, a previous study said the Emergency Room and Intensive Care Unit were ideal for screening palliative care needs and early consultation could reduce costs, symptom burdens and unnecessary suffering (Bowman et al., 2015, Zalenski et al., 2017). Screening patients at the first level might be better for providing earlier interventions. The hospital staff have initiated a collaboration with Puskesmas to screen patients. This collaboration is expected to reduce the significant patient queueing at Hasan Sadikin and give earlier treatment to patients to reduce their suffering.

The team used diversification strategies to improve their work based on Strengthen-Weakness-Opportunity-Threatened (SWOT) analysis. Evaluating the programme could be essential for considering details of services and having a better approach in future. Evaluation also strengthens relationships between staff and patients because their interaction creates security and trust and enhances teamwork (Klarare et al., 2019). The staff still needed to find the most affordable way to reach people. They had already reduced the tariff, raised donations to buy equipment for patients and visited patients at home voluntarily. However, these actions cannot increase the number of people who access the services.

Patient access to the palliative care team. Only seriously ill people could access the outpatient palliative care service. Inpatient service access was deficient in relation to people needing palliative care services: <0.6% between 2016 and 2019. Paying fees for palliative care was a significant barrier since almost 80 million people in Indonesia receive health insurance benefits from the government (BPJS, 2019b). Previous study mentions the benefit of telehealth palliative care as a way of delivering intervention and reducing costs across Scotland (Johnston et al., 2012a). This intervention is feasible since internet usage in Indonesia was relatively high. Smartphone users reached 167 million people in 2021, or 89% of the total population of Indonesia, driven by cheap internet tariffs (Hanum, 2021). Media platforms (WhatsApp video calls, Zoom, Teams, Google Meets, Messenger, etc.) could be used when assessing, giving interventions and evaluating and consulting patients and family caregivers to reach more patients. Telehealth would decrease costs, save energy and time, and reduce burdens for people in remote areas or with deteriorating conditions. Telehealth programmes could serve these people rather than making them wait in the clinic (Guzman et al., 2020). Discussion between stakeholders, raising awareness of patients and families and access to palliative care would enable people to access palliative care programmes through a national policy (Scaccabarozzi et al., 2017).

The mode of operation. All the staff had an on-call day to answer palliative service requests. However, the evidence shows that nurses do most interventions in hospitals. This finding was similar to that for Macmillan Specialist Care in Europe, where nurses spent more hours giving intervention at home in 2014-2016 (Johnston et al., 2018). Since the team has limited staff, home care might be the better solution for delivering care through training family caregivers. There is family culture in Indonesia, where the family members became caregivers for their family. The staff have collaborated with the government, the community and NGOs. This collaboration was expected to be a milestone regarding spreading the palliative service with Puskesmas, which was available in all villages in Indonesia. In addition, there was one cadre for every ten households, with staff provision.

The government could use this programme to spread the palliative care service by training volunteers to screen and deliver intervention with Puskesmas supervision (Kristanti, Setiyarini and Effendy, 2017a).

MacMillan's specialist palliative care at home service in the United Kingdom is an example of successful palliative care run by multidisciplinary teams at home, in the community and in care homes. They served 85% of adults with cancer and 70% died at home (DeRoo et al., 2013). MacMillan Evaluation in 2017 noted that most of the patients (94%) were referred to the MacMillan specialist care at home service (Johnston et al., 2018). *Puskesmas* (primary healthcare) could modify Macmillan and Kerala models, which are reasonable service models, by adopting and adapting small parts of them. There is provision and an opportunity to use this model because there are volunteers in every small neighbourhood in Indonesia.

The range of services provided by the palliative team. The hospital provided inpatient ward and outpatient palliative care services. This finding aligned with the World Health Organisation''s guidance to include palliative care services in the health system (WHO, 2020a). Adults with cancer commonly receive a schedule for several diagnostic tests before physicians decide on the cancer treatment. During this time, the patient does not have access to palliative care or healthcare supervision. This causes some anxiety and uncertainty for patients because they did not know whom to contact while they are waiting. Every institution can provide services depending on its resources. It could offer comprehensive treatments with several approaches to minimise costs and facilitate the program's sustainability (Dryden-Peterson et al., 2016).

Provision for nurse-led intervention. Nurse-led intervention is possible through nurse's presence beside patients. They could be pioneers in providing interventions. Nurses could start a nurse-led intervention guide in the hospital by serving at least one inpatient daily. This target is achievable because every day, one nurse is standby, ready to do palliative tasks. If the nurse visited one patient every day, then in one year, they could visit 365 patients. The most significant need is an outpatient clinic to reduce patients' burdens and needs. Regarding fees, the team has initiated collaboration with NGOs and other institutions to raise donations.

5.10 Summary

This study aims to investigate the current structure, patient access and services provided by an existing palliative care service in the hospital. Data were collected from public documents available from the hospital to get an overview of its services. Data were compiled to provide a descriptive explanation of information. Inclusion criteria included documents about palliative care services.

The audit showed data that the palliative team at Hasan Sadikin were slow to serve the people who needed palliative care. They served adults with cancer in the inpatient wards and outpatient clinics. They worked to improve their knowledge and skills, provided standard operational procedures, provided guidelines and collaborated with other organisations to raise awareness of palliative care. They also evaluated their work to give a better input to improving their services.

Chapter 6 The survey; design and methods

This study was a quantitative study to gather the data about the patients and their family caregivers' needs and burdens after patients being diagnosed with cancer. The study design for all studies can be seen in **Appendix 2 Research methodology.**

6.1 Methods of survey

6.1.1 Design and Setting

This study was a quantitative study which used surveys. The research is carried out in Hasan Sadikin Hospital and shelters around Hasan Sadikin Hospital in Bandung, West Java Province, Indonesia. Hasan Sadikin Hospital is a public and teaching hospital that collaborates with health education institutions. It has the only palliative care team services in West Java Province. The researcher conducted stages 1-3 in this hospital and surrounding shelters. The city council did not have data on the number of shelters but the researcher identified approximately 30. 11 were removed from the lists because five were for children, two were for people with eye diseases, three were temporary shelters and one was for someone with HIV/AIDS. The researcher toured these 19 shelters and excluded six more shelters from the 19 lists because three shelters, managed by government agencies, required further correspondence and three other shelters were not housing any cancer patients. The researcher received permits for 13 of the shelters. All these shelters were managed by NGOs that raised money from ordinary people. Of these 13 shelters, eight shelters belonged to Rumah Teduh Sahabat Iin (=Iin friends' shelter) and the rest belonged to Kasih (love shelters), Sedekah Rombongan (religious donation), Rejeki Rombongan (religious donation), Daarul Tauhid (religious donation) and Indramayu (District Government donation). Rumah Teduh Sahabat Iin had 15 shelters in total; his other shelters were for children (one) and eye illnesses (two) and he had two in Bandung Municipality, one in another district and one outside West Java Province.

Each shelter had an average of 20 beds; 80% were occupied by adults with cancer and their family caregivers. They provided various services. All offered a standard single mattress without a bed for the patient only, rice (staple food), mineral water and a communal kitchen toilet and laundry. Three shelters provided a room for two people with only a single mattress. The patient could share the mattress with their caregiver, or the caregiver could sleep on the floor in the same room. Seven shelters provided a communal bedroom with several mattresses on the floor but no beds. Several shelters provided a curtained screen around each mattress to provide some privacy, but others did not. The Rumah Teduh shelter was the only shelter that was willing to buy prescription drugs and medical tools for its residents at no charge. Both Rumah Teduh and Sedekah Rombongan had an ambulance to transfer patients to or from a hospital and their house or shelter. Only one shelter, Sedekah Rombongan's, could be reached by car. Others could only be reached by wheelchair or on foot as they were in very narrow lanes less than 1-metre wide.

Patients decided to stay in a shelter for various reasons, for example because their house was far away, they were seriously ill, very weak, unable to walk, needed to attend daily radiotherapy or to save money. Most of them came from lower-income backgrounds. The shelters are surrounded by public houses. Bandung City is 167,30 km^2; 2,288,570 live there and the density per km^2 is 13,679 people, which is the densest population in Indonesia.

6.1.2 Correspondence

The researcher requested permission (Appendix 8) to conduct research at the hospital. The researcher conducted stage 3, the patients and family caregivers' surveys in the hospital outpatient clinics. The officers in clinics were contacted to explain the research purpose and provided the documents and permit from the hospital director. The researcher then made a note to the nurse matron in the following polyclinics: Obstetrics-Gynaecology, Ear, Nose and Throat, Lung and Oncology. These clinics were servicing adults with cancer. The matron then introduced the researcher to potential participants, who had gathered at the front of the clinic while waiting for their appointment. The researcher explained the research aim and provided a question-and-answer session for potential participants and started to recruit patients in hospital between 16 January and 9 February 2020. No identifiable data or medical-records data were collected except patients' medical diagnosis.

After finishing stages 2 and 3, the researcher conducted stage 4, interviews with the palliative care staff. Participant criteria was presented to Doctor Gatot, and he suggested eligible participants. All of them agreed to be a participant except for one nurse, who said she was too busy to clarify with her job. The researcher stopped recruiting because the minimum participant numbers had been reached. The participants were invited to be interviewed in a place they felt comfortable in. Eight staff chose to be interviewed in their room at the hospital and two staff chose the teaching room in the Universitas Padjadjaran in front of the hospital complex. All staff finished interviews without any difficulty except one participant, who received three calls during the session. She is a nutritionist leader, and is constantly on stand-by, so she could only be interviewed during her break time.

The process in shelters began after the researcher submitted applications for research permission to the West Java Provincial Government through the National Unity and Politics Agency. This recommendation letter was then taken to the Bandung City National Unity and Politics Agency, which issued a research permit for the shelters around Bandung. The researcher submitted the proposal and ethics approval from the University of Glasgow as required by this letter. This letter was the basis for applying for research permits at the shelters. The researcher then approached shelter officials to explain the purpose of the study. The officials agreed to let her contact the prospective participants by inviting them to meet her. The researcher explained the study's purpose in the same way to the potential participants and provided a question-and-answer session. Participants in the shelters were recruited from 26 November 2020-February 2021.

The purpose of quantitative data analysis is to provide summaries of tendencies, relations and associations between variables that represent groups or events. The scores from questionnaires were seen thoroughly by editing, coding and tabulating them. The results were then analysed quantitatively, using descriptive statistics to show the outcomes for patients' needs in palliative care. The data were displayed manually to show the level of participants' needs and burdens using specific software, *SPSS* (Ewertowski et al., 2018), to show descriptive statistics (means-median, frequency, percentage).

6.2 Population and sample

6.2.1 Population

This study aimed to survey the needs and burdens of patients with cancer and family caregivers in Indonesia. There were two groups of the population, adults with cancer and their family caregivers. The hospital serves around 700-800 patients every month. Patients with cancer in Indonesia mostly suffer from large tumours, with bloody wounds and severe pain, because they go to the hospital in the last stages, so they need family caregivers to care for them. This means that the number of caregivers is almost the same as that of patients.

6.2.2 Sample

The researcher collected data on the participants' demographics: gender, age (but not date of birth), marital status, ethnicity, employment status, education level, distance from the hospital; the medical data concerned the type of cancer, comorbidities, performance status and time since diagnosis. The researcher needed the same demographic data for family caregivers plus the duration of caregiving and the relationship to the patient. The primary data from the questionnaires was about patients’ and family caregivers' outcomes. The questionnaires measured participants’ palliative care needs, including physical and psychological symptoms and support needs, to identify patients needing help with psychological aspects, the health system and information, physical and daily living, patient care, support and sexuality needed one month after been diagnosed with cancer and to assess burden and need on the family caregiver.

The researcher used the *Krejcie & Morgan* table formula to calculate the sample for the surveys with a 95% confidence level, 0.5 standard deviations and a 5% confidence interval (Taherdoost, 2017). The sample population, as shown in the table, was 248-254. Hence, the researcher expected to recruit 250 participants for each group. The study had 227 patients and 220 caregivers.

6.2.3 Sampling technique

The researcher used purposive sampling with inclusion criteria for patients: 1) adult patients 18 years old and over 2) adults with cancer who were accessing palliative care services in the hospital. The exclusion criteria for patients were: 1) patients who were too weak to answer the questions or 2) patients with high cognitive dysfunction, a diagnosis of delirium, or experiencing mental disorders. Inclusion criteria for the family were:
1) adult family members 18 years old and over, 2) have a relationship with the patient (spouse/children/parents/siblings/other relatives), and 3) act as the main carer for the patient. There were no exclusion criteria for family members.

6.3 Participant eligibility criteria

Stage 3 involved conducting surveys about patients' and family caregivers' health, i.e. level of needs and burdens of patients and family caregivers who were accessing palliative care services at the hospital. Eligible participants were adult patients with cancer and their family caregivers who have a relationship with them, and they were invited to take part in this survey. The researcher went to the hospital and the shelters and asked people whether they wanted to participate in this research. If they were willing to do so, the researcher asked their name and home/work/email address for communication purposes, e.g. to send participant information sheets (Appendix 9) or questionnaires to interested parties or arrange interviews.

The researcher stated that all personal data collected from patients (i.e. name, home/work/email address, telephone number) would be processed and stored in password-protected electronic files in secure University of Glasgow storage separately from data in the questionnaires. Only the research team members would have access to personal data and would not share it with anyone outside the research team. The data would not influence the therapy process at the hospital.

The researcher then supplied the patients with the participant information sheet and the privacy notice (Appendix 9) and explained that they had 48 hours to decide whether they wished to participate. When a patient agreed to do so, the researcher asked them to sign two copies of the participant information sheet and consent form (Appendix 9). The researcher kept one copy and gave one copy to the participant.

6.4 Data collection process

6.4.1 Data collection tools

The researcher conducted the surveys and the patients filled out 1) Integrated Palliative Outcomes Scale (IPOS) to measure their reported outcome scale and the Supportive Care Needs Survey 34 (SCNS) to measure their met and unmet needs. The researcher distributed the SCNS partner and family caregivers' version and Zarit Burden Interview (ZBI) questionnaire (for family caregivers) (all questionnaires are in Appendix 10-11. The participants completed the questionnaires at the hospital, at home/in shelters and returned them to the researcher. If they had not returned the questionnaire a week later, the researcher contacted them to ask for it to be returned and gave them a second week in which to return the questionnaire. This study needed patients and family caregivers to complete the questionnaires – one family caregiver for every patient. However, patients and family caregivers were still eligible to participate if one refused to participate. At stage 3, patients and family caregivers were identified via a list of patients with cancer who had gone to the hospital or a shelter. Having completed stage 3, ten patients and ten family caregivers were subsequently invited to participate in stage 4 based on their characteristics.

6.4.2 Skills needed for data collection

The researcher has the skills to do data collection because of a statistics course taken on quantitative and qualitative data while studying for bachelor’s and master’s degrees. The researcher had 18 years of experience as a nurse and a supervisor of nursing students in hospital and is familiar with using many tools when assessing/surveying patients/family members and other groups in hospital. To refresh her skills, the researcher took statistics courses at the University of Glasgow offered by the Information and Technology team. 20 credits were gained related to research processes via courses at the university. The researcher also joined a postgraduate forum to discuss the dissertation thesis plan between them.

6.4.3 Researcher experience in data collection

The author of this PhD thesis, referred to here as ‘the researcher’, and the two other researchers, referred to as supervisor, involved in the study. All of them have a Clinical Practice for Research certificate or have attended a Good Clinical Practice training course at NHS Greater Glasgow and Clyde to reduce or eliminate risks. The researcher also took the General Data Protection Regulation (GDPR) course and information security course training through the University of Glasgow Moodle. In addition, all of them have experience working in the hospital and are familiar with using methods to collect quantitative and qualitative data from patients and families.

6.4.4 Data sources and sharing

Demographics were collected directly from patients and medical data were taken from medical records: the type of cancer and the treatment. Data will not be shared with a third party. The researcher used the patients’ medical data (the diagnosis, how long ago they were diagnosed, the type of cancer) to recruit the participants for stage 4. The patients were fully informed about this data before they agreed to participate.

6.4.5 Data collection flow

In the first, the researcher targeted 250 patients and 250 family caregivers who fulfilled the inclusion criteria. The questionnaires were distributed to 250 patients and 250 family caregivers; 227 (90.8%) patients and 220 (88%) families returned the questionnaires, making 447 participants. All participants completed two questionnaires to measure their burdens/outcomes and needs. The original answers were divided into 5 answers. The scores 1-=not applicable, 2=satisfy, 3=moderately and 4=moderate, 5=high need. The researcher calculated the score to find the most common burden and the most need met and unmet need. Then, the data were analysed using SPSS version 26.0 to describe the frequency of the burdens and needs. The higher the score, the higher the burden and the greater the need for supportive care. The supportive care need is grouped into several domains. The researcher used Standardising a Likert summated score to find the mean of each domain.

'Standardising a Likert summated score If m equals the number of questions in a scale and k is the value of the maximum response for each item, the standardised score is obtained by summing the individual items, subtracting m and then multiplying the resulting value by 100/(m×(k-1)). A standardised Likert summated score has possible values ranging from zero to 100. For example, there are 3 items in the sexuality needs domain of the SCNS and each item has a possible response of 1 to 5. For an individual who responded with answers of 3, 2 and 4, their Likert summated scale would be 9 (i.e., 3+2+4), their adjusted value would be 6 (i.e. 9 – 3) and their standardised score would be 50 (i.e. 6×100/ (3*(5-1)))' (Boyes, Girgis and Lecathelinais, 2009).

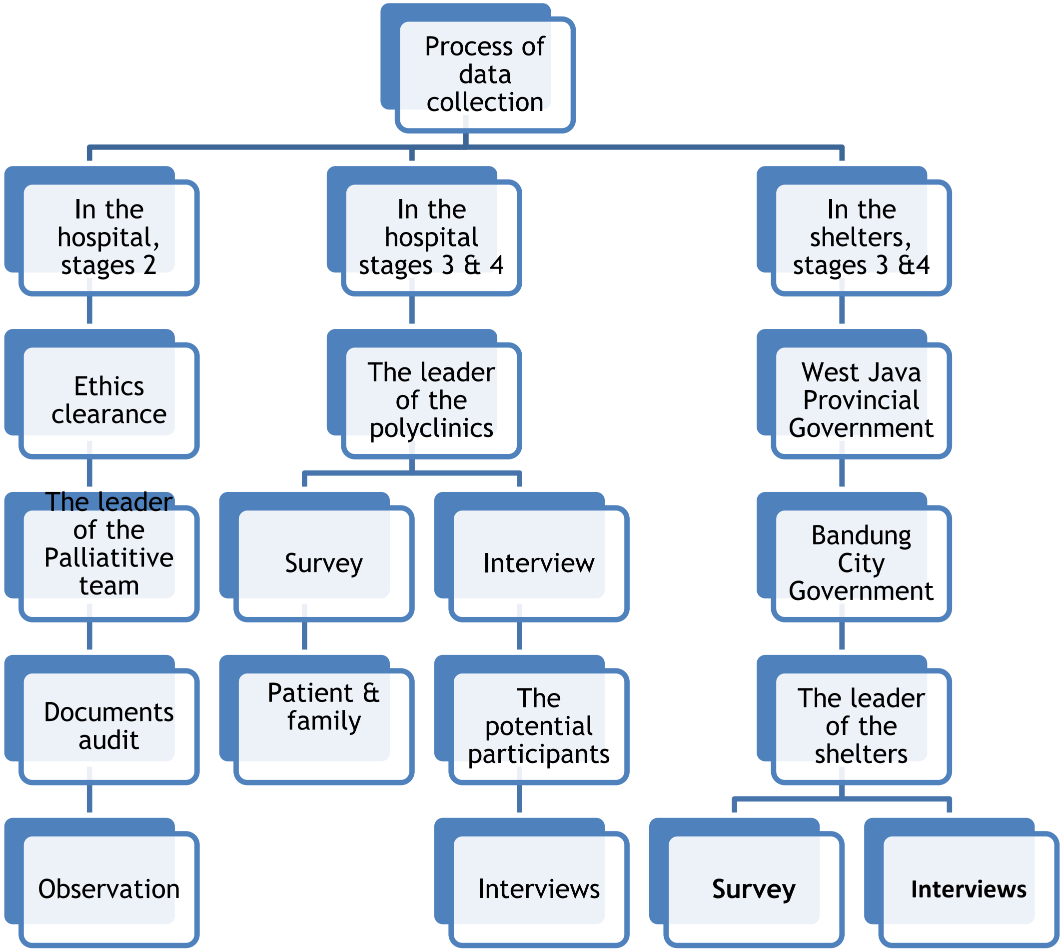


Figure 6-1 Data collection flow.

Participants who wanted to complete the questionnaire at home were supplied with an envelope and a stamp. To collect the questionnaires from those living in shelters, the researcher met a minimum of 10 participating patients and family caregivers every day, which meant that the survey was completed within 3 months in all the shelters. This process was used because the participants wanted to give their questionnaires back directly rather than by post. Some of them wanted to ask questions about items they had not understood. The researcher also found this an easier way to find prospective participants and to check the questionnaires had been fully completed.

6.4.6 Individuals affected and geographical area covered

The researcher took data from 227 patients with cancer, 220 family caregivers and 10 palliative care staff (for stage 4) who are involved in Hasan Sadikin Hospital and shelters, West Java Province, Indonesia.

6.4.7 Participants' responses

The researcher was able to recruit participants quickly, as every day around 150 patients with cancer attend the clinic and there are 10 new residents in 13 shelters. Some agreed to take part on the same day I approached them for several reasons. Some of them said they had nothing to do in the waiting room, so they were happy to read information and answer some questions. Others said that they wanted to help to improve quality of care, and some said they just wanted to pass the time reading and answering questions during their lengthy wait in the clinic. Every day, thousands of visitors gathered around the clinics. They could wait three to seven hours there, so they were happy to do something distracting, even just reading the questionnaire.

The researcher followed the same procedure each day at the outpatient clinic to find potential participants. Some patients who did not meet the criteria wanted to participate but were rejected by the researcher with an explanation. They had other chronic illnesses; had cancer symptoms but had not been diagnosed with cancer; or had a cancer diagnosis but were younger than 16. Rejected caregivers were those who did not have any family relationship with the patient, for example a paid carer, a neighbour or friend, and those who were younger than 18. They asked the researcher directly whether they could participate or not, or the participants suggested their families. In summary, the student rejected more than 400 participants because they met the exclusion criteria.

6.5 Research ethics

A complete account of all research activities was given ethics approval by the ethics committee of the School of Medicine, Veterinary and Life Sciences Ethics, University of Glasgow and Hasan Sadikin Hospital, Indonesia. Because data were collected outside the United Kingdom, the researcher applied to the Data Protection Impact Assessment (DPIA) at the university. The aim of a DPIA is to build and demonstrate compliance and trust regarding the protection of participants' data. The researcher submitted the DPIA recommendation, proposal and application form to the ethics committee. After receiving the approval, the researcher applied for ethics clearance to the ethics board of Hasan Sadikin Hospital, which took around two months to receive.

6.5.1 Ethics approval

The researcher received ethics approval from the School of Medicine, Veterinary and Life Sciences Research Ethics Committee, University of Glasgow, project number 200180198, and ethics clearance (appendix 7) from Hasan Sadikin Ethical Board Committee, number LB.02.01/X.6.5/344/2019. Permission was requested from Hasan Sadikin Hospital to conduct the research at the hospital and a recommendation from the Indonesian Ministry of Research and High Education.

6.5.2 Ethical issues

6.5.2.1 Respect for participants

Respect for human dignity. The researcher considered the rights of the subjects and obtained information about the research by preparing a consent form. Subjects had freedom to participate or not (autonomy). The participants received information about the benefits of and barriers to joining this research.

Confidentiality. Subjects' privacy and confidentiality were respected by listing codes only on the questionnaire sheet; there is no patient identity (name, address) on the datasheet (anonymity) and data is not released to any third party. Participants revealed demographic data such as gender, age (but not date of birth, marital status, ethnicity, employment status, education level, distance from their home to the hospital), and medical data – (the type of cancer, comorbidities, and time since diagnosed).

Justice for inclusiveness: the research was conducted honestly, carefully and professionally and paid attention to subjects' psychological and religious sensitivities. The researcher did not force patients to answer the questions if they felt uncomfortable in doing so.

Risk to participants. It was anticipated that patients would feel sad or uncomfortable when thinking about their symptoms, pain, expectations of palliative care and diagnosis or prediction about their life span/limited end of life period.

Non-maleficence. There was no potential harm in this research because there were no interventions; however, some patients may have felt unhappy/unsatisfied when reporting their outcomes, but that these effects on the subject (non-maleficence) could be minimised by allowing them to complete the questionnaires at home then return it using the stamped addressed envelope provided.

Beneficence. There was no direct impact on any participant in this study. However, the results, feedback on bespoke palliative care services, will benefit them in the future. The benefits for providers are useful feedback on care plans and multidisciplinary evaluations of palliative care, help resolving patients' needs and help making intervention plans related to patient signs and symptoms to better meet patients' needs. The benefits for patients are that the assessment covers all aspects of patient needs, especially those concerning the health system and information and patient care and support, and will provide a clear description of what patient needs in palliative care service are and how patients measure their quality of life. Patients and family caregivers can reflect upon and express their needs, burdens and expectations. They can also provide information regarding their unmet needs. The researcher as a nurse and lecturer also benefits from this study as it will help her and other providers to make intervention plans specifically designed to meet patient needs, as it will provide a clear outline of patients' palliative care needs.

6.5.2.2 Autonomy

The process of gaining informed consent. Participants received information about the project and were asked to provide written informed consent. Their participation was entirely voluntary and their decision will not affect their right to the best medical care/service from the hospital. Participants will have no access to the data; however, they can see the results by accessing articles published in scientific journals.

Support for participant rights. The University of Glasgow, as data controller, has a right to ensure security of identifiable data. If the study is evaluated or audited by regulatory authorities, the researcher and the investigator will protect participants' identity, original signed consent form, recorded and verbatim data and keep their data anonymous.

Prevent function creep, data quality and minimisation. To prevent potential function creep in this study, the researcher conducted pseudonymisation by writing a participant's initial name in the datasheet. The researcher also performed data minimisation by collecting as little of the participants' private data as possible by avoiding their date of birth, address, bank account, or other private identifying details. In Indonesia, it is common to ask for date of birth, address, gender, religion and ethnicity, so there are no barriers to asking about private data. Private data in Indonesia is the family card identity number and identity card. All participants clearly understood that they could withdraw at any time if they thought their data should not be given to us. They believed the researcher would keep their information as prudent as described in the privacy notes. Access restrictions were put in place by only allowing the researcher to access the stored data during data collection and analysis.

Justice. The researcher did not conduct any interventions for participants, so there was no justice issue in this study. However, all the eligible participants were given the same opportunity to be involved in this study.

6.6 The process of gaining informed consent

6.6.1 Information and consent process

Eligible participants were invited to take part in the study via information sheets. The researcher gave them the Participant Information Sheet and Privacy Notice. They had the opportunity to ask further questions and 24-48 hours to decide whether they wanted to take part or not before confirming and signing a consent form. To maximise their ease of understanding, the researcher asked them to write their initials and date in the tick box and read the consent form aloud before signing. They signed two copies of the consent form, one for them and one for the researcher.

6.6.2 Anticipated outcomes

It was anticipated that patients would feel sad or uncomfortable when they thought about their symptoms, pain, expectations about palliative care and diagnosis or prediction about their life span/limited end of life period. The researcher understood that this type of conversation may cause mild emotional distress. It was made clear that the interview would be stopped until the participant was feeling better if this happened. The participant would be asked whether they wished to continue the interview or to end it.

The researcher did not anticipate that participating in the study would cause any harm to participants. Furthermore, the researcher was mindful of a low risk of stress caused by discussing issues related to palliative care services or personal circumstances that some participants may experience. However, the researcher and her supervisors are experienced nursing professionals and could mitigate this risk should it materialise. At every interview, the researcher had a list of organisations with telephone numbers and email addresses people could use should they want extra support.

At the end of each interview session, 10 minutes were allocated to debriefing so that participants could ask questions, raise concerns, or reflect upon the session. Confidentiality was the principal ground rule during interviews and was emphasised alongside voluntary participation at all key communication stages between the researcher and potential participants.

6.6.3 Dealing with refusals and withdrawals

When a potential participant refused to participate (or dropped out after consenting), the researcher thanked him/her and assured him/her that their decision would not affect them in any way. If they wished to offer a reason for declining participation, the researcher recorded this and used it as part of the analysis. Research participants were free to withdraw at any point if they wished without a requirement to justify their decision. If the withdrawing participant wished to offer a reason for withdrawing, the researcher would record this and use it as part of the analysis. No participant dropped out of the study.

6.6.4 Recruitment and participation procedures

Approaching potential participants. Two different recruitment approaches were used to enhance the recruitment rates of potential participants at the hospital and shelters: posters and meeting potential participants. The researcher displayed posters about the study in the hospital and shelters so that potential participants could contact her for further information. At the hospital, the palliative team leader, Doctor Gatot, introduced the researcher to the staff. Simultaneously, the nurse matron in the polyclinics introduced the researcher to the patients with cancer and family caregivers. The researcher also approached the shelters' owners to request meetings with adults with cancer and their families staying in the shelters. The potential participants who met the criteria were invited to participate.

6.6.5 Researcher’s relationship with the participants

There was no relationship between researcher and participant. Participants had the right to participate or not participate in this study. The participants were informed that the study results would be disseminated in scientific journals or other publications without disclosing their personal information. The patients were adults with cancer, many of them suffering from their symptoms and side-effects of therapies, representing a vulnerable group. Family caregivers were members of the patient's family who were caring for the patient during their illness. The staff was members of the palliative care team. There were no initial concerns over the type of processing used or security flaws. The potential participants expected the researcher to use their data only for the purpose of this project and not to share it with another party.

Even though the researcher did not have a relationship with participants before data collection, most of them contacted her afterwards to ask for a lot of information about their care, including money issues. Every time the researcher was present, a group of people wanted to hear some solutions for their problems. Some relevant information was provided, including a donations link. This made a bond but did not affect the results. It did mean that the researcher knew more about their needs and burdens, though. Heartbreakingly, Three of the participants died during the data collection period, that made the author felt upset. Also, one lady with breast cancer in end-of-life care asked the researcher to take care of her daughter, aged 17 with a disability. The girl was unaware of the child abuse she had suffered: an older man had raped her when she was ten. The researcher said politely that she would find an orphanage for her daughter when her time came.

6.7 Questionnaires, validity and reliability test

The researcher distributed four questionnaires; two to each group’s patients and family caregivers, which were intended to measure participants’ outcomes and needs. The questionnaires were mainly used to measure needs and burdens. All questionnaires use rating scales.

6.7.1 The Integrated palliative care Outcome Scale (IPOS)

Patient-reported outcomes (PROs) are direct indicators from the patient without the interpretation of the clinician (Almeida, Martins and Lima, 2021). One of the tools of PROs is the Integrated Palliative care Outcomes Scale (IPOS). The previous study found that patients who completed PROs were more motivated to participate in their care (Kane et al., 2018). A routine PROs assessment should be done every day to predict the probability of dying in the ward (Coym et al., 2020).

First developed in 1999 by Hearn and Higginson, the Palliative Outcomes Scale (POS) evaluates outcomes for patients with advanced cancer (Hearn and Higginson, 1999). The newer version, IPOS, aims to measure the effect of patients' physical and psychological needs to help healthcare provide advisable intervention and measure significant changes in patients. The IPOS showed good construct validity and reliability (*Spearman rho* =0.43-0.80) with internal consistency *Cronbach's alpha* =0.65 (Bausewein et al., 2011). IPOS can measure symptoms in more detail to assess physical symptoms, psychological, emotional and spiritual needs, provision of information and practical support (Collins et al., 2015). This tool is a quick clinical measure for assessing palliative care needs, including psychological and psychological symptoms, spiritual considerations and practical and emotional concerns of patients (Sandham et al., 2019).

The questions are scored using a Likert scale, from not at all (0) to overwhelmingly (4). The first ten questions ask about physical signs and symptoms caused by cancer or side-effects of treatment like pain, breathlessness, sleepiness, vomiting, nausea, a sore mouth, dryness, immobility, loss of appetite and constipation. Patients choose a score of 0-4 depending on their condition. The total score shows their actual condition. The next nine questions ask about and assess the following dimensions: physical, emotional, psychological, spiritual, provision of information and support, and family; an additional question asks who helped the patient fill out the questionnaire (Bausewein et al., 2011). Five response options are provided for each of these dimensions. Only one answer is allowed for each question. The overall profile score is useful for understanding their overall experience and needs and strengths at a specific time. These patient-reported measures showed an excellent ability to detect clinical symptoms, because they can report significant changes in patient needs (Maguire et al., 2013).

The IPOS score describes the signs and symptoms of a patient with palliative care, rated on a scale: 0=not at all, 1=slightly, 2=moderately, 3=severely, 4=overwhelmingly. An item score of zero or one requires less clinical attention than an item score of three or more. These scores indicate that patients do not have a problem with their symptoms: the higher the score, the more the participant needs a clinical response to relieve the symptoms. The results can be used to calculate individual item scores and an overall profile score. The first ten items aim to measure individual scores. The total score can range from zero to 40. The second ten items are the overall profile score, which are useful for understanding the patient's overall experience and status and their needs and strengths at a specific point in time. Scores can change every day depending on how patients feel.

There are several questionnaires that can be used to measure the patient-reported outcomes such as palliative care outcomes, holistic need assessment and functional assessment of cancer therapy. The researcher chose this tool because it was initially answered by the patient, so it benefits both patients and providers and also helps providers plan interventions related to patients’ symptoms and meet patients’ needs. As there is not an Indonesian version, the researcher translated it and did validity-reliability tests before using this tool.

6.7.1.1 IPOS validity test

The IPOS questionnaire had never been used in Indonesia. Hence, three researchers who were speakers of Indonesian and English, conducted a back translation. The first person translated the original instrument from English to Indonesian. The second person translated it back into English These results were then translated into Indonesian by the third person. The results were corrected by the researchers and no change in meaning was found in the questionnaire. The questionnaire was then tested on 23 participants and obtained valid and reliable results, with a Cronbach's alpha value of 0.836. (Appendix 12). Validity test comparing the *r* count with the *r* table. If the *r* count is greater than the *r* table, then the item is valid, and vice versa. The *r* count value can be found using *SPSS* and the *r* tables are obtained from a *product moment* table. An *r* count value > 0.3 is considered valid. The significant level of the validity test is tested via survey for 23 samples. The significant level can be found by using the following formula:

df = population -2 = 23-2 = 21. The *r* table for 21 = 0.433. This means items are valid if *r* count is > 0.433. The Item-Total Statistics table provides information about the validity test. To determine what is a valid question, look at the correlation of a value in the 'Corrected Item-Total Correlation' column (Pagano, 1994). Criteria for a valid question if value of correlation > correlation table on the Pearson correlation table (Pagano, 1994). The value of the *r* table is 0.433. So, questions Q8 and Q9 have a correlation value of < 0.433, indicating that those questions are invalid. Q8 asks, 'Have you had as much information as you wanted?' and Q9 asks, 'Have any practical problems resulting from your illness been addressed?' Q10 only asks who helped the patient fill in the questionnaire, so we cannot say it is not valid. Therefore, we had three invalid questions (Q8, Q9 and Q10), but these items were considered important, so they were not removed from the questionnaires. An instrument's reliability shows the level of consistency. Thus, it can be said that this questionnaire is valid.

6.7.1.2 IPOS Reliability test

The test was performed by comparing *Cronbach's alpha* with 0.6. If Cronbach's alpha > 0.6, then it is reliable. There was no statistically fixed value to determine the reliability criteria of the measuring instrument. However, experts argue that the question is valid if *Cronbach's alpha* > 0.7 (Tsang, Royse and Terkawi, 2017). The results show a value of 0.838 > 07, indicating that all questions are reliable. In conclusion, the IPOS questionnaire is reliable, with *Cronbach's alpha* at 0.838..

6.7.2 The Supported Care Needs 34 (SCNS)

The first tool, developed in the early 1990s, consisted of long-item (52) and short-form surveys (32) for assessing patient needs regarding psychological support, health-related information, physical and daily living, care and support and interpersonal communication (Li and Girgis, 2006). The newest tool has two versions, 59 and 34, to identify patients needing help with psychological support, the health system and information, physical and daily living, care and support and sexuality one month after being diagnosed with cancer (Sanders et al., 2010). Previous study stated that the 34-item version is in almost perfect agreement with the high level of internal consistency and with the *Cronbach's alpha* coefficient at 0.86-0.96 for 5 factors (Boyes, Girgis and Lecathelinais, 2009). This measurement will identify the unmet needs. The items measured responses on a Likert-scale from no need to high need, with scores ranging from 0-225.

There are five possible answers to choose, from 1 to 5, divided into no need and moderate need. Scores 1-2 are for no need; score 3-5 are for some need. A score of more than 2 shows there is a need for that item. The point for every score can be seen in the table below.

Table 6-1 The score value

Score 1= Not applicable	This was not a problem for me as a result of supporting someone with cancer.
2= no need	Satisfied- I did need help with this, but my need for help was satisfied at the time.
3= low need	I did need help with this, but my need for help was satisfied at the time.
4= moderate need	This item caused me concern or difficulty. I had some need for additional help.
5= high need	This item caused me concern or difficulty. I had a strong need for additional help.

The items are divided into four: physical needs, psychological needs, sexual needs and patient care. SCNS scores in quotation marks describe the domains in which there are most needs by the participant. Investigators originally developed the SCNS-SF34 in Australia to identify unmet needs cancer patients have in five domains: physical and daily living (items 1-5), psychosocial (items 14-16, 17), patient care and support (items 18-22), health system and information (items 23-30, 32-34) and sexual (items 15, 16, 31), with *Cronbach's alpha* coefficients at 9.87 for all domains.

This tool is useful for assessing patients' needs in Indonesia because it covers all aspects that patients need, especially regarding the health system and information and patient care and support, giving a clear description of the patients' needs in palliative care service. In addition, it does not deal with subjects that are avoided or taboo for people in Indonesia'. It is also advisable for all patients with cancer and relatively easy to answer for people with a low education level. SCNS 34 for patients (Appendix 10), was first translated and used in Indonesia by Afiyanti (Afiyanti, Milanti and Putri, 2018) with a validity test score of 0.302-0.792 and a Cronbach's alpha score of 0.933. The researcher used this Indonesian translation with permission from Afiyanti, believing that the Indonesian version of SCNS 34 for patients (Appendix 10) was good enough to measure the Indonesian patients' needs.

6.7.3 Zarit Burden Interview (ZBI)

Initially developed in 1980 by Zarit, Reever and Bach-Peterson to assess family caregivers' burden as a self-reported burden, has been commonly used and validated in many countries (O'Rourke and Tuokko, 2003, Bachner and O'Rourke, 2007). The tool consists of 22 questions; each item is rated on 5-point Likert-type scales from never to nearly always. This questionnaire measures family caregivers' burden with a rating scale of zero to 5: 0=never, 1=rarely, 2=sometimes, 3=quite frequently and 4=nearly always. Participants can circle the score which best describes how they feel. The total score is then grouped into four levels: little or no burden for a total score of 0-20, medium burden for 21-40, high burden for a score 41-60, severe burden for a score of 61-88. A score of > 40 means there is a high risk of depression.

The instrument demonstrated good validity and reliability when measuring caregivers' burden regarding dementia in Singapore (Seng et al., 2010). Psychometric testing using the short-form ZBI for family caregivers caring for someone with schizophrenia in China found that *Ballesteros ZBI-12* and *Gort ZBI 7* gave the best performance (Yu et al., 2018).

The researcher used this tool because it is sensitive enough to measure specific aspects of family caregivers' burden and had already been used widely in Indonesia. The ZBI Indonesian version by Purdani was used to measure the family burden caused by caring for patients post-stroke (Purdani, Agusman and Rachma, 2016). Purdani used translation professionals to translate the English version into the Indonesian language, then experts tested the content and stated that the questionnaire was valid and reliable with a content test value of 3.681. The researcher looked at this version and made several corrections before using it.

The Indonesian version of the ZBI was modified, for example, ‘patient with post-stroke’ was changed to ‘patient with cancer’.

6.7.4 The Supportive Care Needs Survey 45 for partners and caregivers (SCNS)

'The SCNS is a promoting tool to measure multidimensional unmet needs of cancer caregivers across the illness trajectory and to discern among group experiencing a different level of un-meet need' (Girgis, Lambert and Lecathelinais, 2011). The SCNS was developed to identify unmet needs of family caregivers. Just like the SCNS for patients, this survey has five answer options, from ‘Not Applicable’ to ‘High Need’. The scores range from 0 to 225, the same with the SCNS for patients. The items are divided into four domains: physical needs, psychological needs, sexual needs and patient care. SCNS scores in quotation marks describe the domains most needed by patients.

This questionnaire has been translated into several languages. The one in Chinese showed a good internal consistency, with Cronbach's alpha coefficients ranging from 0.79 to 0.89 for the four subscales and 0.94 for the total scale (Liu et al., 2020). The Dutch version showed internal consistency for the SCNS-P and C45-D and all subscales were highly consistent, with Cronbach's alpha coefficients ranging from 0.82 (*Practical needs*) to 0.97 (*Health care and Illness related needs*). Cronbach’s alpha for the SCNS-P and C45-D is 0.98. The domain ‘Work and Social Needs’ showed a high correlation (0.523) with a burden caused by informal care (Rietveld et al., 2019).

This tool is advisable for assessing caregivers’ needs in Indonesia because it covers all aspects of their needs, especially those regarding information and practical needs, healthcare and service needs, work and social needs and psychological and emotional needs. The researcher translated this tool and did a validity-reliability test before using it because it had never been used in Indonesia.

The researcher translated the questionnaire into Indonesian versions and then tested them for validity and reliability. This test aimed to determine whether the questionnaire can be relied on to retrieve data. An instrument is valid if it can measure what it aims to measure. A validity and reliability test should be done before using a questionnaire that has never been used before. If the instrument is invalid and unreliable, the research results are also invalid and unreliable. Validity in research means there is similarity between the data collected and the actual results of the study object. For instance, if the object of study is a certain level of anxiety, then the data collected must be about that level of anxiety. The reliability test helps determine whether an instrument can be used more than once and produce consistent data.

6.7.4.1 SCNS 45 partners and caregivers' validity test

The researcher changed it into an Indonesian version via the following steps. Certified institutions did the translation of the original language into Indonesian. The content was tested by three nursing experts in Indonesia. They reviewed it to determine whether all questions included content regarding the concepts to be examined. The assessment results obtained average values of 3.75, 3.73, 3.506 = 1104/3 = 3.68 where the value of 3 = relevant. This questionnaire was tested on 25 participants. It was found that questions numbered 2, 8, 9, 10, 15, 20, 39 and 44 have a correlation value < 0.396, which indicates that these questions are invalid (Pagano, 1994). Because these items were considered important, they were not removed from the questionnaire. The researcher decided to do this because the '*Cronbach's Alpha* if Deleted Items' column also remained above 0.7 (Pagano, 1994). Thus, the researcher can say that this questionnaire is valid, with values of 4.14-7.78.

6.7.4.2 SCNS 45 partners and caregivers' reliability test

The results found that the value of Cronbach's alpha = 0.944> 0.6. Thus, all questions are reliable. Moreover, the reliability is perfect. In summary, SCNS questionnaires are reliable, with Cronbach's alpha at 0.944.

6.7.5 Pilot study

The researcher did a pilot study for the translated IPOS and SCNS P&CG to the adults with cancer in another hospital. The validity and reliability tests from those pilot studies above showed that the questionnaires are valid and reliable.

6.8 Data analysis

The researcher used *SPSS* in analysing the quantitative data. The purpose of quantitative data analysis is to provide summaries of tendencies, relations and associations between variables that represent groups or events. The scores from questionnaires in stage 2 were seen thoroughly by editing, coding and tabulating them. The results were then analysed quantitatively, using descriptive statistics to show the outcomes for patients' needs in palliative care. The data were displayed manually to show the level of participants' needs and burdens using specific software*, SPSS* (Ewertowski et al., 2018), to show descriptive statistics (means-median, frequency, percentage).

The quantitative data were analysed using *SPSS* version 26.0. The researcher calculated the mean, median, standard deviation, min-max score and percentage to describe the level of reported outcomes, burdens and needs.

After receiving the questionnaires, the researcher checked all the items. When an empty answer was found, the researcher visited the sample and asked why they did not answer. If the patients agreed to finish the answer, then the researchers gave back the questionnaire to be filled in. This activity can be done because the researcher visited the shelters every day so they were able to meet the respondent frequently. The same procedure is done for the sample in the outpatient clinics so that all the questionnaires are filled completely. The flow of the data analysis can be seen in Figure 5-2.

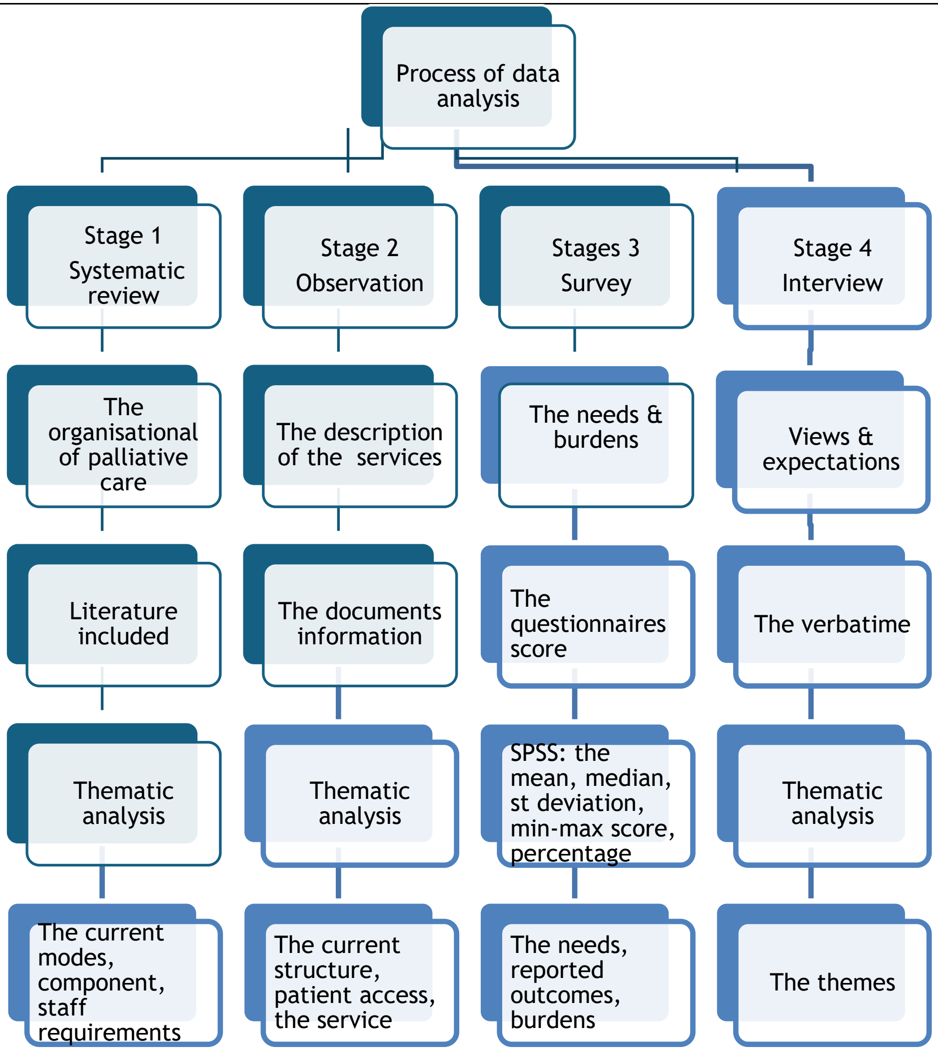


Figure 6-2 The data analysis flow

6.9 People and Public Involvement (PPI)/public engagement in science

6.9.1 The recruitment

People and Public Involvement is an active partnership between patients, the public and researchers (NHS, 2014). The public can benefit from research by actively participating in the research process (Weldring and Smith, 2013). Public involvement aims to transform health outcomes through research, then the research information is provided to the public by organisations, communication, consultation or participation (Boudioni, McLaren and Lister, 2017). By joining a group, the patient can participate and benefit from the research process (Butler, 2017).

The researcher had a patient and public involvement group attached to her palliative care research group led by Professor Johnston in the School of Medicine Dentistry and Nursing. Steps for recruiting to the PPI started with posts on social media, including Twitter, and emails (Appendix 13). Flyers were circulated through friends and left in libraries and public places like shopping centres, bus depots, The researcher developed the following criteria for prospective members: adults with experience of cancer, adults who want to influence research in palliative care for adults with cancer in a resource-challenged country, adults with experience of palliative care in hospital, adults wanting to be an advisor to a project on developing palliative care in Indonesia. Roles could be helping to create a recruitment strategy, assisting with developing themes from data, reviewing writing styles, helping with a lay summary or helping develop patient information leaflets for the new services. All contributions would help to make the thesis better and the research more meaningful. The benefit of involving the PPI in this study was already published, which helped improve the research quality and received the point of view of the PPI (McParland et al., 2023).

6.9.2 The role of patients, caregivers and public involvement in this project

The researcher recruited three members for this PhD study. They agreed to be involved with helping to create a recruitment strategy, assisting with developing themes from data, reviewing writing styles, helping with writing a lay summary and helping develop patient information leaflets for the new services. They were someone whose career had been spent with adults with cancer, a nurse for adults with cancer and a patient with cancer. The researcher recruited them through university People and Public Involvement (PPI) meetings in a hotel, advertisements on social media and personal approaches via email. Professor Johnston held a mini-seminar in one hotel in Glasgow and invited people who met the PPI criteria. All the PhD students presented their thesis proposals, then asked the audience whether they willing to be a PPI member. The researcher gained one PPI member, Orlando Aguilan, through this seminar. He is a nurse and works in a care home in Glasgow. He has been taking care of elderly people and adults with cancer for a long time, including his mother, who died one year before our first meeting. Orlando has the same background as the researcher; he comes from a neighbouring country, the Philippines. The situation regarding palliative care in his country is almost the same as in Indonesia. Orlando gave his insights as both a family member and a professional caregiver. We met twice in a café in Glasgow and kept updated through email. Orlando highlighted the urgency of breaking bad news about the condition of Indonesian patients with cancer, because there is a culture of not talking about death when people are still alive. As a nurse, Orlando was impressed that a nurse could initiate talking about it to a patient first, then to family. The readiness of both will smooth the discussion about palliative care. If both parties know what to do, patients can enjoy their life with chronic disease happily and reduce the cost burden for family caregivers.

The researcher recruited two other people from social media. Both are Indonesian and work as nurses. One nurse has experience taking care of her late mother, who had cancer. The other was diagnosed with breast cancer, had surgery and was still taking oral chemotherapy oral when she agreed to be a PPI member. The research questions were developed via informal meetings, email and Zoom meetings. All members agreed that the themes constructed from these meetings represent their experience. The PPI members reflected on their experiences of when they were often considered not to be a part of the patient care. One of them reflected on the incredible reactions of patients when palliative care addressed their wishes and their will in the end of their life.

The caregivers commented on specific questions that would allow respondents to give the best answers and what are the best questions for sensitive issues. They also shared their thoughts in data analyses and discussion sessions. One member noted the importance of presenting data as research questions and describing the background of the research setting to make more sense of the research and find the themes. Another member emphasised the significant difference in care cultures' treatments in low- and middle-income and high-income countries. He also emphasised the importance of nurses-patient-family activities relating to palliative care to promote cancer and palliative care self-awareness. One member reflected on her experiment during cancer treatment. She said that almost everything the participants said in this research is the same as in her previous experience. She was impressed by the role of the information, the support system provided by the family and the staff and the painkillers for patients with cancer. Another member reflected on her experience of taking care of her late mother, who had cancer. As a nurse, she knew what her mother needed and could address her needs. However, the hospital system at the time did not have a proper service for ordinary people. So she thought that palliative care should be applied to all people.

The evidence-based practice for this project received five points of view: from patients, families, healthcare providers, systematic reviews and the researcher herself. All the findings have a data set saying what themes relate to bespoke palliative care and the development of a nurse-led intervention in Indonesia. The results were shown to the PPI members and they agreed with the results. The researcher will disseminate the findings to the public through publications and is in touch with the PPI members, except Orlando. Contact ended in 2021. At the time, Orlando said he was very busy during the pandemic, many of his patients died from Covid-19.

6.10 Chapter summary

This chapter described the methods and design of a survey that investigated the level of the needs and the reported outcomes of the patients and the burdens and needs of the family caregivers in West Java Province, Indonesia. This was a quantitative, cross-sectional survey, which was developed with direct patients and public involvement. The sample comprised people with cancer and their family caregivers, who were recruited using purposive sampling. The *Krejcie & Morgan* table formula was used to calculate the required size sample. Data were collected using four valid and reliable self-reported questionnaires, namely the SCNS for patient and family, IPOS and ZBI. The survey received ethical approval from the University of Glasgow MVLS Ethics committee (ref no. 200180198) and from Hasan Sadikin Hospital LB.02.01/X.6.5/344/2019. Data were treated as confidential and pseudonymised for analysis purposes. The data were descriptively analysed using SPSS software and interpreted as shown in Chapter 7. This result explained the level of the needs and the reported outcomes of the patients and the burdens and needs of the family caregivers. The key ethical principles are applied during the research including confidentiality, justice, autonomy, balancing harm and benefit to ensure this research did not cause any harm to the informants. The researcher received input from people and public involvement.

Chapter 7 Survey results; the need and burden of adults with cancer and their family caregivers

The third stage uses survey findings to describe patients’ and family caregivers' reported outcomes, needs and burdens regarding supportive care needs. This study aims to investigate patient-reported outcomes, level of supportive care needed, and burdens of people and families who access the hospital. The research question is: what is the level of need and burden of adults with cancer and their family caregivers who go to Hasan Sadikin hospital?

7.1 Findings from the patient sample

This section provides information about the recruitment process. The researcher recruited participants in two different settings, the hospital and shelters around the hospital, and 250 patients and 250 caregivers consented to take part. From October 2019 to February 2021, the researcher approached 227 patients and 220 family caregivers recruited in 90 days. Four hundred people (170 patients and 230 caregivers) were excluded because they did not meet the study criteria. In addition, 23 (9.2 %) patients and 30 (12 %) caregivers declined participation. They were given a questionnaire pack to complete and return to the researcher. Most participants in shelters and the outpatient clinic returned their questionnaires within one week. Even though the researcher provided a stamped addressed envelope, the participants in the clinic said they were happy to fill the questionnaire in as soon as possible because they had enough time to do so while waiting for the physician. The people in the outpatient clinic commonly waited more than two hours to see the physician. The overall response to the survey was excellent: the researcher reached a sample size of 91% for adults with cancer and 88% for family caregivers. Reasons for not returning a questionnaire varied; they are outlined in Table 7-1 below.

Table 7-1 The process of the recruitment of the participants and the results

Process	Patient	Family caregivers
Target sample size	250	250
Questionnaires distributed	250	250
Questionnaires returned	227	220
Response rate (%)	91%	88%
Reason for not returning the questionnaires:		
• Not able to	3	7
• Had died	11	0
• Went home temporarily	3	15
• Did not understand how to complete it.	3	3
• No reason	3	5

7.1.1 Description of the participants

In total, 227 patients participated (response rate 91%). The typical patient was middle-aged. Most participants (Table 6-2) were Sundanese (84%) married (81.5) women aged 36-55 (63.9%). Around 63.9% of participants had been diagnosed with cancer aged 36-55. This number shows that a younger group was diagnosed with cancer rather than an older group. Just over half of the patients were occupied at home as housewives (51.5%) and had only primary education (57.5%). The mean distance from patients' hometown to hospital was 149.3 km (*SD*=271.7) and the mean time since diagnosis was 1.69 years (*SD* 2.7). Just over one-third of participants (35.7%) were diagnosed six to twelve months prior to participating in this study. The striking point is that most participants did not have comorbidity (85%), others had 1-3 comorbid illnesses. Close to 61% reported high levels of pain.

A wide range of cancer diagnoses was reported (Figure 6-1). The highest proportion of patients, 36 people (16%), had been diagnosed with breast cancer, out of 23 cancer types. Compared to the top six typical cancer types in Indonesia (lung, breast, colorectal, cervix, liver and mouth cancer), this finding shows the absence of lung cancer in the top 10 cancers. Moreover, eye cancer (4%), lymph cancer (5%) and osteosarcoma (5%), which are not in the top ten cancer types in Indonesia. The chart shows the cancer types of the participants.

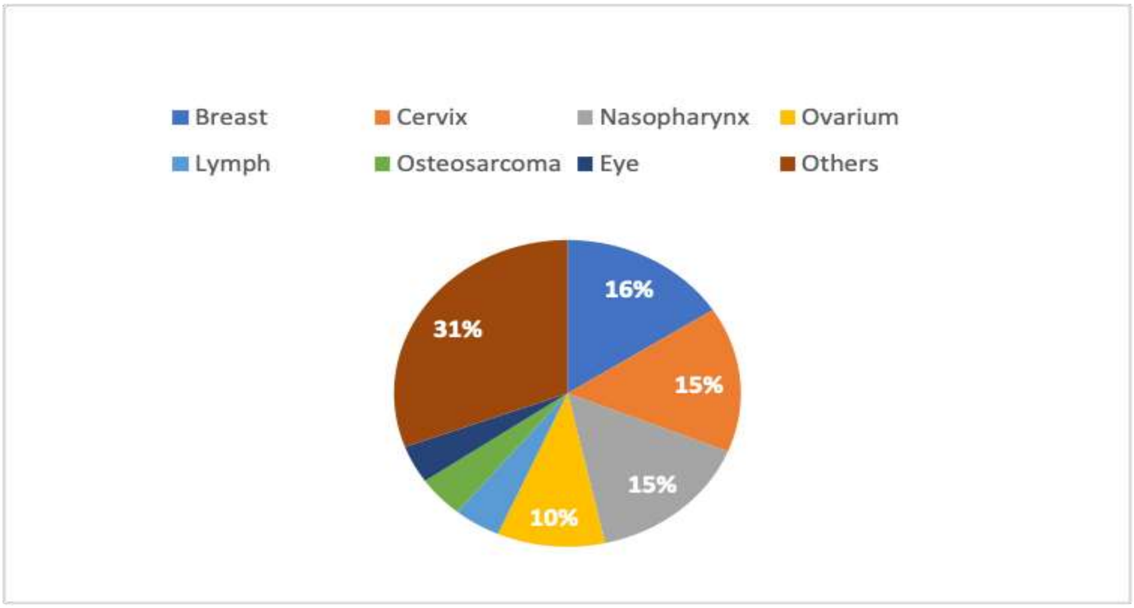


Figure 7-1 The cancer types

The summary of participants’ demographic data is presented in Table 7-2.

Table 7-2 Demographic data of the patient participants (n=227)

Variable/ Category	Patients
	Mean (*SD*); Range
Age	45.3 (12); 16-75
Distance home to hospital (km)	149.3 (271.67); 2-3000
Duration since been diagnosed as cancer	1.69 (2.7); 0-20 years
	***n* / %**
Gender Female	 160 (70.5)
Age in years <36 36-55 >55	 40 (17.6) 145 (63.9) 42 (18.5)
Marital status Married Single Widow	 185 (81.5) 14 (6.2) 28 (12.3)
Ethnicity Sundanese Javanese Others	 192 (84.6) 30 (13.2) 5 (2.2)
Education level No school Primary Junior High Bachelor	 3 (1.3) 131 (57.8) 42 (18.5) 47 (20.7) 4 (1.7)
Duration since been diagnosed as cancer 0-6 months >6-11 months 1-2 years >2 years	 81 (35.7) 68 (30.0) 34 (15.0) 44 (19.4)
Pain level (face scale) Light Moderate Severe	 22 (9.7) 67 (29.5) 138 (60.8)
Distance (home-hospital in km) 1-200 >200	 196 (86.4) 31 (13.7)
SD=standard deviation: Standard deviation measures the dispersion of a data set relative to its mean. *Km=kilometres*	

7.1.2 Patient’s symptoms and concerns

Table 7-3 outlines the top 5 most distressing physical symptoms and emotional concerns reported by patients, measured using the IPOS scale. The table shows that almost all participants had a high score. The higher the score, the higher the burdens and the needs for supportive care. Further analysis showed that the total IPOS mean score was 30.2 (*SD* 13.0, range 3-62, possible maximum 68). The physical outcomes mean score was 16.0 (*SD* 9.4, range 0-40, possible maximum 40) and the score for psychological outcomes was 14.1 (*SD* 4.5, range 2-27, possible maximum 24).

The most prominent physical symptoms experienced included pain (50%), weakness (27.8%), a sore mouth (18.5), poor mobility (17.6%) and drowsiness (16.3%). Similarly, the top emotional concerns reported were the anxiety of family or friends (45.4%), practical problems resulting from the illness (38.3%) and feeling at peace (23.3%). Notably, most patients reported as not feeling depressed (27.8%), able to share their feelings (22.5%) and did not have as much information as they wanted (15%). Around 77.5% of participants completed this questionnaire with family help. Outside the 10 suggested outcomes, 73.6% of participants who took part did not have other symptoms and only 18.1% reported as having one other symptom. Complete IPOS scores are in Appendix 14.

Table 7-3 Patients' symptoms and concerns of Pros according to the IPOS (n=227)

No		Item	Not at all		Slightly		Moderately		Severely		Over-whelmingly	
			f	%	*f*	%	*f*	%	*f*	%	*f*	%
1	A	Pain	31	13.7	32	14.1	35	15.4	81	35.7	**114**	**50.2**
2		Shortness of breath	**112**	**49.3**	22	9.	39	17.2	22	9.7	32	14.1
3		Weakness	**49**	**21.6**	34	15	45	19.8	36	15.9	63	**27.8**
4		Nausea	**93**	**41**	38	16.7	47	20.7	20	8.8	29	12.8
5		Vomiting	**120**	**52.9**	34	15	34	15	13	5.7	26	11.5
6		Poor appetite	**67**	**29.5**	2	11.9	54	23.8	40	1.6	39	1.2
7		Constipation	**129**	**56.8**	23	10.1	29	12.8	17	7.5	29	12.8
8		Sore mouth	5	33	40	17.6	41	18.1	29	12.8	**42**	**18.5**
9		Drowsiness	**83**	**36.6**	24	10.6	46	20.3	37	16.3	37	**16.3**
10		Poor mobility	**93**	**41**	34	15	39	17.2	21	9.3	40	**17.6**
12	Q	Feeling anxious about your illness or treatment.	20	8.8	10	4.4	61	26.9	47	20.7	**89**	**39.2**
13		Have any of your family or friends been anxious or worried about you?	8	3.5	9	4	30	13.2	77	33.9	**103**	**45.4**
14		Have you been feeling depressed.	**63**	**27.8**	29	12.8	52	22.9	34	15	49	21.6
15		Have you felt at peace?	30	13.2	30	13.2	**70**	**30.8**	44	19.4	53	23.3
16		Have you been able to share how you are feeling with your family or friends as much as you wanted?	**51**	**22.5**	27	11.9	**52**	**22.9**	48	21.1	49	21.6
17		Have you had as much information as you wanted?	34	15	31	13.7	**102**	**44.9**	25	11	35	15.4
18		Have any practical problems resulting from your illness been addressed?	17	7.5	16	7	31	13.7	6	33.5	**87**	**38.3**
11		Number of other symptoms.	None		One		Two		Three		Four	
			f	%	f	%	f	%	f	%	f	%

			167	**73.6**	41	18.1	14	6.2	5	2.2	0	0
19		How did you complete this questionnaire?	Myself		Family		Staff		Mixed			
			f	%	f	%	f	%	f	%		
			1	0.4	**164**	**72.2**	6	2.7	56	25.4		
		* Total number of participants answering. A* A list of physical symptoms, which participants may or may not have experienced. Q* A List of psychological/emotional symptoms. The **bold** items are the most reported outcomes										

7.1.3 Patient's supportive care needs

This section sets out patients' needs for supportive care, measured using the Supportive Care Needs Survey for the patient (SCNS-34 Patient). The mean total score was 133.6 (*SD* 24.8, range 3-62, possible maximum 170). Table 7-4 outlines the top 5 highly supportive needs. The top highly need was discussing treatment with staff (74%), having explanations of tests (70.9%), being adequately informed about the benefits and side-effects of treatments before you choose to have them (70.9%) being informed the side effect of the treatment (70.9%), and have more cancer specialist (70%). Unexpectedly, the majority of respondents marked the sexual domain as not applicable with the level of support needed for the changes in sexual feelings (42.3%), sexual relationships (40.1%) and information about sexual relationships (37.4%). Only 23.3% of them highly need support for item changes in sexual feeling, 24.7% for sexual relationships and 30% for information about sexual relationships. The details can be seen in Table 7-4.

Table 7-4 Supportive care needs score of patients from the SCNS for the patient (n=227)

No	Item	Not applicable		Satisfied		Low need		Moderate need		Highly need	
		f	%	f	%	f	%	f	%	f	%
1	Pain	24	10.6	19	8.4	26	11.5	44	19.5	114	50.2
2	Lack of energy	34	15	16	7	42	18.5	46	20.3	89	39.2
3	Feeling unwell a lot of the time	36	15.9	14	6.2	36	15.9	50	22	91	40.1
4	Work around the home	27	11.9	22	9.7	46	20.3	50	22	82	36.1
5	Not being able to do the things you used to do.	38	16.7	16	7	38	16	46	20.3	89	39.2
6	Anxiety	29	12.8	22	9.7	38	6.7	61	26.9	77	33.9
7	Feeling down or depressed	38	16.7	14	6.2	45	19.8	55	24.2	75	33
8	Feelings of sadness	38	16.7	15	6.6	35	15.4	52	22.9	87	38.3
9	Fears about the cancer spreading	26	11.5	13	5.7	19	8.4	44	19.4	125	55.1
10	Worry that the results of treatment are beyond your control.	19	8.4	11	4.8	26	11.5	51	22.5	120	52.9
11	Uncertainty about the future	28	12.3	13	5.7	28	12.3	53	23.3	105	46.3
12	Learning to feel in control of your situation	17	7.5	29	12.8	43	18.9	62	27.3	76	33.5
13	Keeping a positive outlook	23	10.1	21	9.3	43	18.9	51	22.5	89	39.2
14	Feelings about death and dying	38	16.7	13	5.7	26	11.5	36	15.9	114	50.2
15	Changes in sexual feelings	96	**42.3**	16	7	30	13.2	32	14.1	53	23.3
16	Changes in your sexual relationships	91	**40.1**	19	8.4	30	13.6	31	13.7	56	24.7
17	Concerns about the worries of those close to you	16	7	19	8.4	35	15.4	40	17.6	117	51.5
18	More choice about which cancer specialists you see	1	7.5	9	4	21	9.3	21	9.3	159	**70**
19	More choice about which hospital you attend	22	9	12	5.3	23	10.1	22	9.7	148	65.2
20	Reassurance by medical staff that the way you feel is normal.	14	6.2	8	3.5	26	11.5	31	13.7	148	65.2
21	Hospital staff attending promptly to your physical needs.	12	5.3	13	5	18	7.9	33	14.5	151	66.5
22	Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs.	12	5.3	16	7	19	8.4	34	15	146	64.3
23	Being given written information about the important aspects of your care.	11	4.8	18	7.9	17	7.5	33	14.5	148	65.2
24	Being given information about aspects of managing your illness and side-effects at home	14	4.4	10	6.2	20	8.8	31	13.7	152	**67**
25	Being given explanations of those tests for which you would like explanations	7	3.1	12	5.3	16	7	31	13.7	161	**70.9**
26	Being adequately informed about the benefits and side-	9	4	13	5	15	6.6	29	12.8	161	**70.9**

	effects of treatments before you choose to have them										
27	Being informed about your test results as soon as feasible.	6	2.6	16	7	15	6.6	37	16.3	153	**67.4**
28	Being informed about cancer which is under control or diminishing (that is, remission).	7	3.1	16	7	17	7.5	34	15	153	**67.4**
29	Being informed about things you can do to help yourself to get well.	6	2.6	16	7	15	6.6	37	16.3	153	67.4
30	Having access to professional counselling (eg, psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it	22	9.7	14	6.2	16	7	36	15.9	139	61.2
31	Being given information about sexual relationships	85	**37.4**	20	8.8	33	14.5	21	9.3	68	**30**
32	Being treated like a person not just another case	8	3.5	14	6.2	17	7.6	34	15	154	67.8
33	Being treated in a hospital or clinic that is as physically pleasant as possible.	8	3.5	13	5.7	15	6.6	31	13.7	160	70.5
34	Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up.	8	3.5	12	5.3	13	5.7	26	11.5	168	**74**
	*Number of participants answering this item. The first five items are the most met need. The following five items receive the highest score for unmet need.										

The total scores were grouped into five domains (Table 7-5): patient care and support, physical and daily living, psychosocial needs, sexual needs, and health system and information. Then the researcher calculated the summated rating scale distributions to find participants' responses for each item. A 'summated rating scale' is a type of assessment instrument comprising a series of statements measuring the same construct or variable to which respondents indicate their degree of agreement or disagreement. The number of response options for each item varies, often from 1 to 5 points (e.g. from strongly agree to disagree strongly). Response values for individual items may be added up to obtain a total or average score that reflects a person's general attitude toward the construct of interest.

Table 7-5 Summary of the Likert summated scale summary

DOMAIN	Number of items	Min-max the questionnaire	Min-max participant's score	Mean/ *SD*	Median/IQR
Patient care & support	5	5-25	0-50	40.7 (13.1)	50 (15)
Physical and daily living	5	5-25	0-50	33.7 (14.4)	35 (25)
Psychosocial needs	10	10-50	3-50	34.7 (50)	37.5 (16)
Sexual	3	5-15	0-50	22 (17.7)	20.8 (33)
Health system & information	11	11-55	0-50	41.9 (10.5)	45.4 (11)

SD = standard déviation ; IQR = interquartile range

7.2 Findings from the family caregiver sample

7.2.1 Description of the participants

In total, 220 family caregivers completed questionnaires, giving a response rate of 88%. The majority were Sundanese people (86.8%) and male (50.9%). The mean age was 40.16, *SD* 13.6, with a range of 18-72 years old. Almost half of participants were 36-55 years old (49.3%); the next biggest group was less than 36 years old (36.8%); and 86.1% of family caregivers were under 55 years old. The mean distance from home to hospital was 164.7 km, *SD* 1.12 (1-3000km), and 101 participants (45.9%) lived 51-100 km from the hospital. Of these, 175 people are married (79.5%) and working as housewives (35.6%). Almost half the participants had just finished primary school (45%). The mean duration as a caregiver was 1.17 years (*SD* 1.69), mostly less than a year (75%). The caregivers' most common relationship to the patient was as their spouse (36.4%), mostly as a husband. Seventy-five per had been in their role as a caregiver for less than one year (Figure 7-3). Details of the demographic data are summarised in Table 7-6.

Table 7-6 Demographic data of the participants' family caregivers (n=220).

Variable/Category	**Family caregivers**
	M (*SD*); Range
Age	40.16 (13.6) 16-72
Distance home from the hospital (km)	164.7 km (1-3000 km)
Duration as a family caregiver	1.17 years
	n/%
Gender	
Male	112 (50,9)
Age in years	
<36	81 (36.7)
36-55	109 (49.3)
>55	30 (13.6)
Ethnicity	
Sundanese	191 (86.8)
Javanese	22 (10)
Others	7 (3.2)
Work status	
Housewives	78 (35.5)
Worker general	39 (17.6)
Entrepreneur	35 (16)
Jobless	28 (12.7)
Others	40 (18.2)
Education level	
No school	1 (0.5)
Primary	99 (45)
Junior	46 (20,9)
High	61 (27.7)
Bachelor	13 (5.9)
Duration as a family caregiver	
<1 year	165 (75)
1-2 years	28 (12.7)
>2 years	27 (12.3)
SD=standard deviation Standard deviation measures the dispersion of a data set relative to its mean. *Km=kilometre*	

7.2.2 The family caregivers' supportive care needs

This section sets out the family caregivers' supportive care needs, including the most met and unmet needs. Most participants reported needing supportive care in all domains except the sexual domain. The top highly need was finding out about life and travel insurance for a person with cancer, chosen by 70.5% of participants. The next three were financial support (69.1%), obtaining the best medical care (61.4%), needing to discuss their concerns with the physicians (60.9%), followed by obtaining adequate pain control (60.9%). The top non-applicable needs were addressing problems with patients' sex life (42.3%), dealing with others not acknowledging the impact of caring for a person with cancer (27%), getting emotional support (21.4%), working your feeling about death/dying (19.1%) and getting emotional support for your loved one (17.7%). The most striking point is that the sexual domain was chosen as a non-applicable need by an average of 42.3% of the participants. This trend was similar to the patients' group answers, where no need was the chosen answer to the question about sexual needs. Further analysis showed that the mean was 170.6, *SD* 29.8, with a minimum-maximum of 57-225. The results obtained from the summary statistics are presented in Table 7-7.

Table 7-7 Supportive care score of family/partner from the SCNS family caregivers and partners questionnaire (n=220).

No	Item	Not applicable		Satisfied		Low need		Moderate need		Highly need	
		f	%	*f*	%	*f*	%	*f*	%	*f*	%
1	Accessing information relevant to your needs as a career/partner.	13	5.9	19	8.6	34	15.5	42	19.1	112	50.9
2	Accessing information about the person with cancer's prognosis, or likely outcome	9	0.1	20	9.1	27	12.3	39	17	125	56.8
3	Accessing information about support services for careers/partners of adults with cancer.	11	5	16	7.3	25	11.4	54	24.5	114	51.8
4	Accessing information about alternative therapies?	23	10.5	17	7.7	44	20	57	25.9	79	35.9
5	Accessing information on what the person with cancer's physical needs are likely to be.	15	6.8	18	8.2	22	10	52	23.6	113	51.4
6	Accessing information about the benefits and side-effects of treatments?	6	2.7	27	12.3	19	8.6	48	21.8	120	54.6
7	Obtaining the best medical care for the person with cancer?	7	3.2	20	9.1	21	9.5	37	16.8	135	**61.4**
8	Accessing local health care services when needed?	12	5.5	20	9.1	28	12.7	47	21.4	113	51.4
9	Being involved in the person with cancer's care, together with the medical team?	1	7.7	28	12.7	23	10.5	53	24.1	99	45
10	Having opportunities to discuss your concerns with the doctors?	6	2.7	22	10	16	7.3	42	19.1	134	**60.9**
11	Feeling confident that all the doctors are talking to each other to coordinate the person with cancer's care?	10	4.5	28	12	23	10.5	52	23.6	107	48.6
12	Ensuring there is an ongoing case manager to coordinate services for the person with cancer?	11	5	26	11.8	29	13.2	53	24.1	101	45.9
13	Making sure complaints regarding the person with cancer's care are properly addressed?	7	3.2	31	14.1	1	7.7	36	16.4	128	**58.2**

14	Reducing stress in the person with cancer's life?	19	8.6	16	7.3	25	11.4	25	15.9	125	**56.8**
15	Looking after your own health, including eating and sleeping properly?	12	5.5	22	10	32	14.5	38	17.3	116	52.7
16	Obtaining adequate pain control for the person with cancer?	9	4.1	21	9.5	27	12.3	29	13.2	134	**60.9**
17	Addressing fears about the person with cancer's physical or mental deterioration?	21	9.5	12	5.5	31	14.1	42	19.1	114	51.8
18	Accessing information about the potential fertility problems in the person with cancer?	39	17.7	22	10	31	14.1	34	15.5	94	42
19	Caring for the person with cancer on a practical level, such as with bathing, changing dressings, or giving medications?	20	9.1	37	16.8	31	14.1	42	19.1	90	40.9
20	Finding more accessible hospital parking?	65	**29.5**	29	13.2	35	15.9	23	10.5	68	30.9
21	Adapting to changes to the person with cancer's working life, or usual activities?	18	8.2	23	10.5	43	19.5	63	28.6	73	33.2
22	The impact that caring for the person with cancer has had on your working life, or usual activities?	28	12.7	20	9.1	44	20	51	23.2	77	35
23	Finding out about financial support and government benefits for you and/or the person with cancer?	13	5.9	14	6.4	14	6.4	27	12.3	152	**69.1**
24	Obtaining life and/or travel insurance for the person with cancer?	17	7.7	12	5.5	12	5.5	24	10.9	155	**70.5**
25	Accessing legal services?	40	18.2	19	8.6	26	11.8	32	14.5	103	46.8
26	Communicating with the person you are caring for?	4	1.8	40	18.2	30	13.6	34	15.5	112	50.9
27	Communicating with the family?	3	1.4	42	19.1	28	12.7	38	1.3	109	49.5
28	Getting more support from your family?	4	1.8	35	15.9	18	8.2	38	17.3	125	**56.8**
29	Talking to other people who have cared for someone with cancer?	9	4.1	24	10.9	34	15.5	52	23.6	101	45.9
30	Handling the topic of cancer in social	20	9.1	20	9.1	37	16.8	6	30.5	76	34.5

	situations or at work it?										
31	Managing concerns about the cancer coming back?	22	10	23	10.5	38	17.3	43	19.5	94	42.7
32	The impact that cancer has had on your relationship with the person with cancer?	42	19.1	17	7.7	33	15	47	21.4	81	36.8
33	Understanding the experience of the person with cancer?	18	8.2	32	14.5	41	18.6	45	20.5	84	38.2
34	Balancing the needs of the person with cancer and your own needs?	12	5.5	24	10.9	34	15.5	49	22.3	101	45.9
35	Adjusting to changes in the person with cancer's body?	34	15.5	27	12.3	46	20.9	44	20	69	31.4
36	Addressing problems with your sex life?	93	**42.3**	27	12.3	32	14.5	21	9.5	54	21.4
37	Getting emotional support for yourself?	47	21.4	25	11.4	40	18.2	49	22.3	59	26.8
38	Getting emotional support for your loved ones?	39	**17.7**	28	12.7	36	16.4	50	22.7	67	30.5
39	Working through your feelings about death and dying?	42	**19.1**	21	9.5	23	10.5	38	17.3	96	43.6
40	Dealing with others not acknowledging the impact on your life of caring for a person with cancer?	61	**27**	40	18.2	33	15	29	13.2	57	25.9
41	Coping with the person with cancer's recovery not turning out the way you expected?	24	10.9	18	8.2	34	15.5	48	21.8	96	43.6
42	Making decisions about your life in the context of uncertainty?	35	15.9	28	12.7	41	18.6	42	19.1	74	33.6
43	Exploring your spiritual beliefs?	31	14.1	20	9.1	28	12.7	33	15	108	49.1
44	Finding meaning in the person with cancer's illness.	18	8.2	35	15.9	36	16.4	48	21.8	83	37.7
45	Having opportunities to participate in decision making about the person with cancer's treatment?	9	4.1	18	8.2	25	11.4	53	24.1	114	**51.8**

The total scores were grouped into four domains (Table 7-8): information and communication practical needs, healthcare and service needs, work and social needs, psychological and emotional needs. Then the researcher calculated the summated rating scale distributions, shown in Table 7-8, to find the response values for individual item scores that reflect a person's general attitude toward the construct of interest.

Table 7-8 Summary of a summated Likert scale

DOMAIN	**Number of items**	**Min-max**		**Mean/*SD***	**Median/ IQR**
		questionnaire	**participant**		
Healthcare & service needs	18	18-90	8-76	37.7 (9.3)	38.9 (13)
Psychological & emotional	14	14-70	1-50	29.6 (9.1)	30.3 (13)
Work & social security needs	8	8-40	0-50	33.43 (10.7)	34.3 (17)
Information & communication /practical needs	5	5-25	0-50	33.1 (11.4)	35 (18)

SD = standard deviation; IQR = interquartile range

7.2.3 The family caregiver's perceived burden

This section sets out the perceived burden of family caregivers for adults with cancer. As shown in Table 7-9, the biggest burdens (nearly always experiencing this condition) were that they felt strained around relatives (53.6%) and felt that they should do more to take better care of their family (43.7%), with feeling suffered because of involvement with relatives (40%). Next, was when they did not feel that the patient was asking for more help (43.3%) and feeling they should be doing more for the relative (41.8%).

Conversely, the participants reported these conditions as 'never feeling affected by their relationship (80.5%), never feeling afraid about their family future (67.7%), never feeling that the relative expected the participant to take care of them (66.4%), never feeling uncomfortable about having friends over because of the relative (66.4%) and never feeling that the relative is dependent on them (65.9%). Further statistical tests found that the ZBI mean score was 39.9, *SD* 19.2, with a minimum-maximum score of 3-88 (Appendix 14). In addition, summary statistics for the biggest burdens and the smallest burdens are shown in Table 7-9.

Table 7-9 The family caregivers' scores for burdens from the ZBI (n=220)

No	Item	Never		Rarely		Sometime		Quite Frequently		Nearly Always	
		f	%	*f*	%	*f*	%	*f*	%	*f*	%
1	Patient required more help.	14	6.4	18	8.2	48	21.8	45	20.5	95	**43.2**
2	Feel that because of the time you spend with your relative that you don't have enough time for yourself?	51	23.2	22	10	65	29.5	34	15.5	48	21.8
3	Feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	69	31.4	24	10.9	64	29.1	26	11.8	37	16.8
4	Feel embarrassed over your relative's behaviour?	51	23.2	22	10	34	15.5	45	20.5	48	21.8
5	Feel angry when you are around your relative	69	31.4	24	10.9	64	29.1	26	11.8	37	16.8
6	Feel that your relative currently affects our relationships with other family members or friends in a negative way?	177	**80.5**	11	5	64	29.1	2	0.9	1	0.5
7	Afraid what the future holds for your relative?	149	**67.7**	31	14.1	31	14.1	2	0.9	7	3.2
8	Feel your relative is dependent on you?	145	**65.9**	17	7.7	31	14.1	10	4.5	23	10.5
9	Feel strained when you are around your relative?	32	14.5	7	3.2	48	21.8	15	6.8	118	**53.6**
10	Feel your health has suffered because of your involvement with your relative?	58	26.4	13	5.9	36	16.4	25	11.4	88	**40**
11	Feel that you don't have as much privacy as you would like because of your relative?	2	32.7	24	10.9	55	25	18	8.2	51	23.2
12	Feel that your social life has suffered because you are caring for your relative?	85	38.6	21	9.5	35	15.9	24	10.9	55	25
13	Feel uncomfortable about having friends over because of your relative?	91	41.4	28	12.7	41	18.6	16	7.3	44	20
14	Feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	146	**66.4**	21	9.5	41	18.6	28	12.7	2	0.9
15	Feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	53	24.1	34	15.5	27	12.3	90	40.9	1	0.5
16	Feel that you will be unable to take care of your relative much longer?	93	42.3	14	6.4	26	11.8	12	5.5	1	0.5
17	Feel you have lost control of your life since your relative's illness?	91	41.4	29	13.2	26	11.8	43	19.5	44	20
18	Wish you could leave the care of your relative to someone else?	101	45.9	13	5.9	48	28.1	21	9.5	36	16.4
19	Feel uncertain about what to do about your relative?	69	28.3	25	10.2	51	20.9	25	10.2	50	20.5
20	Feel you should be doing more for your relative?	18	8.2	15	6.8	41	18.6	51	23.2	95	**43.2**
21	Feel you could do a better job in caring for your relative?	17	7.7	11	5	45	20.5	55	25	92	**41.8**
22	How burdened do you feel in caring for caring for their relative?	81	36.8	19	8.6	52	23.6	17	7.7	51	23.3

	* Total number of participants answering. Bold: The first five items are the most common reported burdens; the second five items are the outcomes for the least common burdens.

The total score was grouped into four levels to see the level of burdens and to see whether they are at risk of depression. Participants might have depression because of their burdens. It was found that more than 80% of participants had burdens; most were medium-level burdens (73 participants: 33.2%). Figure 7-2 compares the proportion of participants at every level of burden.

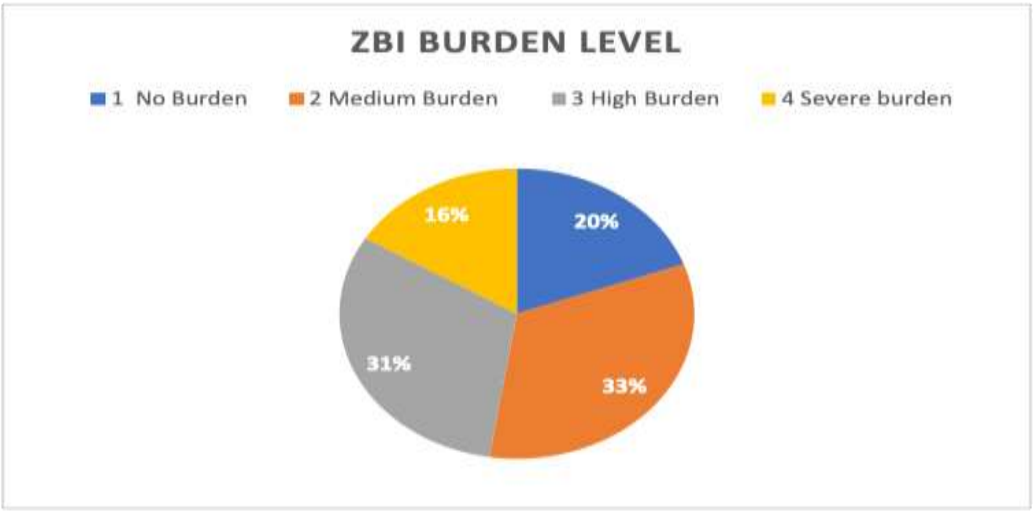


Figure 7-2. Burden level

A score of >40 means there is a high risk of depression. Thus, there were 165 (75%) participants at a high risk of depression.

7.3 Summary

This chapter discussed results of a survey of 227 patients with cancer and 227 family members in West Java. In the patient group, the most prominent physical symptoms include pain, weakness, a sore mouth, poor mobility and drowsiness. Top unmet needs were: discussing treatment with staff, having explanations of tests, being adequately informed about the benefits and side-effects of treatments before and having more cancer specialists. The majority of respondents marked the sexual domain as not applicable with the level of support needed. In the family caregiver group, the top highly need was finding out about life and travel insurance for a person with cancer, financial support, needing to discuss their concerns with the physicians, followed by obtaining adequate pain control. The sexual domain was was similar to the patients’ group answers, as not applicable. The biggest burdens as caregivers were that they felt strained around relatives and felt that they should do more to take better care of their family, with feeling suffered because of involvement with relatives, did not feel that the patient was asking for more help and feeling they should be doing more for the relative.

Chapter 8 The qualitative Study

8.1 Introduction

The fourth stage employs interview findings to provide overall descriptions of patients', family caregivers' and palliative care staff's views and expectations of palliative care. This chapter presents the findings of interviews with the participants. The aims of the research is to investigate the views and expectations of a participants of future nurse-led intervention to address the shortcomings of the current service. The research question is: what would stakeholders want this new intervention to offer, in addition to the current service? What are patients', family members' and healthcare providers' expectations of and preferences and priorities concerning an improved palliative care service, what should the system look like and how would an embedded nurse-led intervention improve the standard of the care provided? The result then constructed several themes below.

8.2 Rationale for qualitative research approach

The researcher collected qualitative data about stakeholders' views and expectations of palliative care services in Indonesia from the interviews. Qualitative data can be collected from interviews and focus group discussions that explore participants' depth of understanding (Malterud, Siersma and Guassora, 2016). A one-to-one interview is an effective method of uncovering health problems (Singh et al., 2023). The data findings constructed the meaning of participants' life experiences and identified what they needed to shape the palliative service to fit with their outcomes, needs and burdens. Interviews help to find data about people's thoughts, experiences or knowledge about something. They can be classified as semi-structured or structured. The structured interviews had a list of questions, while the non-structured ones gave options for participants to express their thoughts. Interview topic guides can be designed to help researchers ask the right questions (Alastalo et al., 2017). In-person interviews allow participants to express all their thoughts because they can feel the interviewer's presence (Krouwel, Jolly and Greenfield, 2019). However, people can use the telephone, emails, WhatsApp video calls, Skype, social media or other modern technology to conduct interviews. The interview data should be transcribed rather than analysed to construct themes for participants’ thoughts (Wemette et al., 2020). While quantitative research needs a fixed number of samples depending on the sampling technique, qualitative research does not require an exact number. As long as questions reach saturation, a few samples are enough (Heaslip et al., 2021).

8.3 Research design and setting

This study was a mixed-methods study and was carried out in Hasan Sadikin Hospital and shelters around Hasan Sadikin Hospital in Bandung, West Java Province, Indonesia. After finishing stages 2 and 3, the researcher conducted stage 4, interviews with the palliative care staff. The participants were invited to be interviewed in a place they felt comfortable in. Eight staff chose to be interviewed in their room at the hospital and two staff chose the teaching room in the Universitas Padjadjaran in front of the hospital complex. All staff finished interviews without any difficulty except one participant, who received three calls during the session. She is a nutritionist leader, and is constantly on stand-by, so she could only be interviewed during her break time.

8.4 Population and sample

8.4.1 Population

There were three populations for stage 4: patients, family caregivers and palliative care staff. The researcher recruited them in Hasan Sadikin Hospital and surrounding shelters. The patient and family caregiver population were made up of those who had been recruited as a sample in stage 3, 227 patients and 220 family caregivers, and there were 35 staff who had written instructions from the hospital director to work on the palliative team.

8.4.2 Sample

The sample was 10 palliative care staff, 10 patients and 10 family caregivers who were chosen from stage 3 findings regarding their characteristics: age, gender, needs, burdens and type of cancers. Patients and families also sample in stage 3 who fulfilled the sample criteria. The staff were recruited in stage 4 only. The researcher recruited 10 staff, who were chosen because of their characteristics: age, qualifications, formal education and multidisciplinary skills.

The researcher used the same data regarding the patient (demographic data: gender, age (but not date of birth), marital status, ethnicity, employment status, education level, distance from the hospital, duration of caregiving and clinical data: type of cancer, comorbidities, time since diagnosis). And this was the case for family caregivers too (demographic data: gender, age (but not date of birth), marital status, ethnicity, employment status, education level, relationship to the patient, duration of caregiving), but regarding the staff the demographic data was gender, age (but not date of birth), role (doctor, nurse, pharmacist) and how long they had been working in the team. The primary data from the interviews were participants' views and expectations of the nurse-led interventions.

8.4.3 Sampling technique and eligible criteria

The researcher used purposive sampling to recruit participants. The inclusion criteria for the patients were: 1) adult patients 18 years old and over and 2) adults with cancer who were accessing palliative care services in the hospital. The exclusion criteria for patients were: 1) patients who were too weak to answer questions or 2) patients with high cognitive dysfunction, diagnosis of delirium, or experiencing mental disorders. The inclusion criteria for the family were: 1) adult family members 18 years old and over, 2) have a relationship with the patient (spouse/children/parents/siblings/other relatives), 3) act as the main carer for the patient. There were no exclusion criteria for family members. Inclusion criteria for staff were: 1) member of the palliative care team, as confirmed by their letter of appointment or 2) a representative of the interdisciplinary palliative care team. There were no exclusion criteria for staff.

8.5 Data collection process

8.5.1 Data collection tools

The researcher used an interview topic guide to explore the participants' views and expectations of palliative care services. At this stage, the patients and family caregivers were interviewed and also ten of the staff were chosen by the team leader because of their role (physician, nurse, pharmacist, etc.). Semi-structured interviews were conducted to investigate all of these participants' views and expectations on a proposed nurse-led intervention. The participants who met the criteria were interviewed in a place and at a time requested by them. All interviews lasted around one hour. Patients and family caregivers were interviewed at different times. Ten questions explored the patients' views and expectations of palliative care in the hospital.

8.5.2 Pilot study

Regarding the topic guide, before interviewing the participant, the researcher did a role play as an interviewer of two lecturers from the Nursing Faculty of Universitas Padjadjaran using the list of questions. The researcher asked them whether they understood and could answer the questions. They said they could and that they believed potential participants would also be able to do so; therefore, the researcher did not make any modifications to the first version.

8.5.3 Data sources and sharing

Demographics were collected directly from patients and medical data was taken from medical records: the type of cancer and the treatment. Data will not be shared with a third party. The researcher used the patients' medical data (the diagnosis, how long ago they were diagnosed, the type of cancer) to recruit the participants. Demographics also collected from the family caregivers and staff. The participants were fully informed about this data before they agreed to participate.

8.5.4 Data analysis

The outcome was a list of views and expectations of the participants regarding the palliative care service. The researcher recorded the answers, transcribed them verbatim and then coded them using *NVivo* software version 12 to identify themes. The transcriptions produced a total of 66,369 words in the Indonesian language. The interview range was 15-60 minutes, with a total duration of 7.3 hours. The researcher used *NVivo* software tools to analyse the qualitative data. The purpose of qualitative data analysis is to describe and explain a pattern of experience. There are four stages for finding a pattern in qualitative research: collecting data, reduction, display and conclusion.

All data from the interviews was transcribed and analysed using *NVivo,* software that supports qualitative and mixed-methods research (Butler, 2017). The researcher followed Braun and Clarke's six steps for analysing data (Braun and Clarke, 2006, Braun and Clarke, 2012).

1) Familiarisation with the data: the researcher read and reread the articles until the answer was found and made it into a code.

2) Coding: the researcher created a code for the same answers from different articles.

3) Searching for themes: the researcher clustered the same coding into the same sub-subthemes, then grouped the same sub-subthemes into the same subthemes then into the same theme. All codes were grouped into similar themes. The same themes were then grouped until the researcher had the final themes. Headings were used that were direct answers to the research questions, then grouped similar findings under each heading so that the initial subthemes and themes could be identified.

4) Reviewing themes: the researcher found several themes for the first time; after reviewing them, some themes were merged, so these are the final themes.

5) Defining and naming themes: the researcher changed the name of the themes several times until the final names of the themes were decided on, which identified the answers to the research questions.

6) Writing up: writing up is an integral element of the analytic process in thematic analysis. The researcher wrote down all the processes used for building the themes.

The researcher did qualitative content analysis and thematic analysis by coding then generating the themes. The result is presented in the next chapter.

8.5.5 Trustworthiness

Validity and reliability are the main criteria for assessing the quality of the research (Streubert and Carpenter, 2011). Streubert explained that the term of trustworthiness is used to indicate the validity of data including credibility, dependability, confirmability, transferability and authenticity as explained below.

Credibility: The results are a representation of various reality related to the study. The reality is understood based on the subjects studied. The data credibility lies on the researchers' skills in exploring, recognising and assessing the veracity of the data. The researcher checks the whole process by validating the transcript with the informant. The informant reads the transcript and themes to confirm the suitability themes with their perception.

Dependability: The researcher checked the entire research process with the supervisors. This is done by consulting the transcripts, showing the consistency and reliability of the results in accordance with research procedures.

Transferability is related to the ability in generalising the results. The researcher is responsible for documenting data and writing detailed reports so that it can be evaluated whether the results are outside the context. The researcher archived the result in accordance with the ethics; clear, detailed and systematic.

Confirmability: The researcher's characteristics and subjectivity can influence the interpretations of the study. Therefore, the researcher should be neutral in order to ensure that the results are objective. The researcher confirms everything to the supervisors to keep the data interpretation free from the researcher's subjectivity. The researcher did this step so that the result came from data through confirmation and revisions.

Authenticity: The researchers checked the transcripts and the themes, whilst also showing the result to participants to confirm whether their meaning is relevant with the participant's meaning.

The result is the presentation of various realities related to the phenomena that are being studied. The reality is understood by researchers based on the information from the informant. The credibility data lies in the researcher's ability to recognise reality. To ensure the authenticity of data, the researcher had the skills to explore, recognise and assess the truth of participants.

According to critical realism, the main goal of this paradigm is to explain social events through references that form like layered icebergs (Fletcher, 2017b). The way patients or groups of service users place meaning on their health, wellbeing or experience is greatly valued in nursing. Patients' and communities' experiences can only be explored and investigated through in-depth processes that enable patients to explore and share their own experiences and perceptions. Therefore, critical theory research in nursing is of great value, but it should be fully considered and justified based on corresponding principles of the paradigms (Ryan, 2018). This study is relevant to critical realism because the researcher constructed the themes from what the informant expressed without putting her own perception.

8.5.6 Ethical issues

Ethics is to be done to ensure this research did not cause any harm to the informants. Several key ethical principles are applied during the research including confidentiality, justice, autonomy, balancing harm and benefit. This explanation can be found in chapter 6.

8.5.6.1 Confidentiality and anonymity

Subjects' privacy and confidentiality were respected by listing codes only on the questionnaire sheet; there is no patient identity (name, address) on the datasheet (anonymity) and data is not released to any third party. Participants revealed demographic data such as gender, age (but not date of birth, marital status, ethnicity, employment status, education level, distance from their home to the hospital), and medical data – (the type of cancer, comorbidities, and time since diagnosed).

The researcher and the investigator will protect participants' identity, original signed consent form, recorded and verbatim data and keep their data anonymous.

8.5.6.2 Interview topic guide

Interview topic guides can be designed to help researchers ask the right questions (Alastalo et al., 2017). In-person interviews allow participants to express all their thoughts because they can feel the interviewer's presence (Krouwel, Jolly and Greenfield, 2019).

8.5.6.3 Information and consent process

Eligible participants were invited to take part in the study via information sheets. The researcher gave them the Participant Information Sheet and Privacy Notice. They had the opportunity to ask further questions and 24-48 hours to decide whether they wanted to take part or not before confirming and signing a consent form. To maximise their ease of understanding, the researcher asked them to write their initials and date in the tick box and read the consent form aloud before signing. They signed two copies of the consent form, one for them and one for the researcher.

8.6 Conducting the interview

All patients and family caregivers agreed to be interviewed at their shelter. Eight out of ten patients were interviewed alone and two were accompanied by their caregiver because they said they were too weak to be alone without family support. The researcher interviewed nine caregivers alone. One participant cannot leave a patient for even five minutes for fear they will need help. The researcher allowed this participant to be interviewed with the patient beside her because the topic interviews did not include any privacy-related matters that would potentially affect patient-family relationships or make participants manipulate their answer. The researcher also interviewed eight staff in their ward and two in a university room because they did not have a private room in their ward.

The researcher keeps a journal and field note about the informant and verbatim. After having finished writing the themes, the researcher checked it with the participants to determine whether the result is the same as the information they gave. They agreed with the results.

This interview process is in line with a critical realist approach where the researcher made the views and expectations to be understood as social and personal self-worlds. Critical realism is a premise in which ‘reality is a social construct because, as human beings, we can only know what we have experienced or what has been represented to us’ (Schiller, 2016a). It has been postulated that critical realism allows the researcher to theorise the dynamic relationship between individual agency, organisational rules, regulation and the greater political and economic healthcare agenda and can facilitate the refinement of intervention (Parlour and McCormack, 2012b). Critical realists conceive that individuals have the power or agency to make decisions and change but that structural factors also constrain those decisions. Therefore, healthcare professionals must explore person and context (Harwood and Clark, 2012). Health outcomes and behaviour may be changed by interaction (DeForge and Shaw, 2012).

8.7 Summary

This chapter provides the rationale for using qualitative data for this study. The design was a one to one interview. The sample included the cancer patients, their family caregivers, and the palliative care staff in Hasan Sadikin Hospital. All participants received the informed consent and participant notice before agreeing to be recruited using purposive sampling. Data were collected using an interview topic guide and then analysed using thematic analysis. The key ethical principles applied during the research include confidentiality, justice, autonomy, and balancing harm and benefit. The interview was conducted in the hospital and the shelters around the hospital.

Chapter 9 Qualitative Study Findings

9.1 Introduction

This chapter provides the qualitative study findings from the interview sessions. The purpose of study is to investigate the views of patients, family members, health professionals and managers and their expectations of a future nurse-led intervention to address the shortcomings of the current service: what would stakeholders want this new intervention to offer in addition to the current service?

9.2 Demographic data for the participants

Thirty participants were involved. Two themes and four subthemes represent their views and expectations on what a nurse-led intervention must look like to improve palliative care services in West Java Province, Indonesia.

The researcher recruited ten patients and ten family caregivers. All patients were married and were staying in the shelters; half were female. The *mean* age was 36-55 and the ethnicity Sundanese (90%). Of these, five people's job status was housewife (50%), with an education level of junior school (60%). The average distance from the patients' hometown to the hospital is 96.2 km, with a range of 35-200 km. They represented nine cancers out of 32 types, all without comorbidities. They were very sick (60%), and the mean period of illness was 1.69 years.

Most caregivers were female (80%), the mean age was 38.4 and they were primarily aged <55 years old; are married (80%), worked as housewives (60%) and had an education at high school level (70%). The average distance from home to the hospital was 161.2km (60-300km). Duration as a caregiver was 2.03 years on average, mostly one to three years, and the relationship was as the patient's wife (30%).

The researcher also recruited ten palliative care staff with an interdisciplinary and palliative experience background. The most common occupations were nurses (40%) and physicians (30%). All female staff were married, the mean age was 38.4 and most were aged 40-50 years old (70%). Duration as a member of the team was

4.5 years. They had a formal education: master's level (70%), bachelor's (20%) and doctoral (10%). The main work unit varies such as working in a ward or clinic, as a supervisor, in quality assurance and or in hospital administration. Only three people (30%) learned about palliative care when studying at postgraduate level, when palliative care was a small credit in their curricula. Others learned during a short course. They are now having on-the-job palliative care training in collaboration with the Singapore Foundation and Indonesia Cancer Society. Table 9-1 compares the different demographic data for the three groups of participants.

Table 9-1 Descriptive statistics for the demographic and clinical characteristics of participants (n=30)

Variable/category	**Patient**	**Family caregivers**	**Staff**
	Frequency (%)		
Shelters • RK • RT • SS • DT	 2 4 3 1	 0 7 1 1	Nurse: 4 Physician specialist: 1 General Physician: 1 Psychiatrist: 1 Nutritionist: 1 Psychologist: 1 Pharmacist: 1
Gender • Female • Male	 5 5	 8 2	 10 0
Age • <50 • >50	 5 5	 9 1	 10 0
Marital status • Married • Single • Widow/er	 6 1 3	 8 2 0	 10 0 0
Education • Primary • High school • Bachelor's • Master's +specialist • Doctoral	 4 6 0 0 0	 3 7 0 0 0	 0 0 3 6 1
Distance to the hospital • <100 • >100	 7 3	 6 4	 10 0
Types of cancer	8 out of 33	N/A	N/A
Duration • <1 year • 1-3 • >3	Been sick 2 6 2	As caregiver 3 6 1	Work as team <5yr: 6 >5yrs: 4
• Pain level • Light • Moderate • Severe	• • 1 • 3 • 6	• • N/A	• • N/A
Other most common complaint	• Insomnia • Numbness • Headache • Itchy • Diarrhoea	• N/A	• N/A
Mean of score • IPOS • SCNS	 • 27.6 • 128.3	 • ZBI 39.9 • 170.8	 • N/A
Basic palliative care/ skills	• N/A	• N/A	• Inserted in curricula during • Master's: 2 • Doctoral studies: 1 • On-the-job training: 6 • Overseas training: 1

9.3 The themes

This section presents the results of interviews undertaken during data collection in Indonesia. The researcher made a code P, CG and S and continues with the code to identify the participants. For example, P1 means patient number 1, FC1 means family caregiver participant number 1, S9 means staff participant number 9. The overarching theme was barriers to and challenges of providing a nurse-led intervention in a resource-poor setting. The context was care in a resource-poor setting. The interviews generated data that were then grouped into three themes; views and expectations on nurse-led interventions in the future with five subthemes, barriers to and challenges in providing a nurse-led intervention with two subthemes and person-centred nursing theory with four subthemes. Each subtheme was supported with a minimum of two quotes from two different participants, as presented in Table 9-2. All themes and subthemes are presented in Appendix 15.

Table 9-2 Themes and subthemes; barriers to and challenges of providing a nurse-led intervention in a resource-poor setting.

Theme	Subthemes	Sub-subthemes	Research questions
1. Views and expectation on nurse-led interventions in the future	• Extend the service to the community. • The nurse is the closest one to the patient. • Nurse as manager. • The nurse is an information bank. • Nurse providing/administering painkillers.		1. What could nurses specifically do to better support patients/family caregivers with their different needs, physical, emotional, social, functional etc.? 2. How can nurses work differently in your hospital to better support patients/family caregivers? 3. Is there anything else you would like to discuss about nursing care in Hasan Sadikin Hospital palliative care? 4. What could be done to improve your care in Hasan Sadikin Hospital? 5. With regards to your own condition, to what extent do you feel your needs are being met?
2. Barriers to and challenges of providing a nurse-led intervention in a resource-poor setting	1. Experience in providing/receiving care • Patient participant	• Barriers in palliative care • Poor communication • Good and bad services	1. Have you had any involvement with palliative care in Hasan Sadikin Hospital? 2. Can you tell me about some of the people who care for you in palliative care in Hasan Sadikin Hospital? (e.g. Medicine Physician, Nurse, Pharmacist etc) 3. Can you tell me about your experience of receiving/providing cancer care/palliative care in Hasan Sadikin Hospital?
	• Family caregiver participant	• Poor information • Discrimination for patients in the third class	
	• Staff participant	• Teamwork • Patient rights	
	2. Palliative support needs	• Financial difficulties • Spiritual: God is the healing source, humans only the tool • Physical: Lack of painkillers • Psychological: To help the patient die in peace	1. Can you tell me about your views on how care is provided by nurses and other health professionals in your hospital, including strengths and weaknesses? 2. Do you have any ideas about how patients & their family caregivers would like care to be provided, including different ways (e.g., in the hospital and at home)?

			3. What kind of support do you expect nurses to offer to patients/ family caregivers? 4. Can you tell me about this support (what sort of needs did they have; how was care planned and implemented; which other interdisciplinary staff were involved in the care; were there any particular difficulties?)
3.Person-centred nursing theory	• Prerequisites	• Attributes of nurses include being professionally competent • Having developed interpersonal skills. • Being committed to the job • Being able to demonstrate clarity of belief. • Knowing themselves.	1. Can you tell me about your views on how care is provided by nurses and other health professionals in your hospital, including strengths and weaknesses? 2. How can nurses work differently in your hospital to better support patients/family caregivers? 3. Is there anything else you would like to discuss about nursing care in Hasan Sadikin Hospital palliative care?
	• The care environment	• Appropriate skill mix. • Workplace culture • Shared decision-making systems. • Power sharing and effective staff relationships. • Horizontal violence as a negative power relationship. • Potential for innovation and risk-taking. • The physical environment.	1. What could nurses specifically do to better support patients/family caregivers with their different needs, physical, emotional, social, functional etc.? 2. Do you have any ideas about how patients & their family caregivers would like care to be provided, including different ways (e.g., in the hospital and at home)?
	• Person centred care process	• Working with patients' beliefs and values. • Engagement • Having a sympathetic presence. • Sharing decision-making. • Providing holistic care.	3. What kind of support do you expect nurses to offer to patients/ family caregivers? 4. What could be done to improve your care in Hasan Sadikin Hospital? 5. With regards to your own condition, to what extent do you feel your needs are being met?
	• Person centred outcome	• Satisfaction with care. • Involvement in care. • Nurses' wellbeing. • Therapeutic culture.	Can you tell me about this support (what sort of needs did they have; how was care planned and implemented; which other interdisciplinary staff were involved in the care; were there any particular difficulties?)

9.4 Expectations of a nurse-led intervention to improve palliative care services in West Java Province

9.4.1 Extend the service to the community

The participants raised their expectation that cadres in the community would be empowered to provide frontline palliative care. This service would benefit patients because they could receive treatments earlier. They also wanted the team to provide the service in shelters and district hospitals as well as visit patients at home.

'Yeah... the idea of the project, the goal after we have finished the 6 modules is to enable West Java to provide palliative care to the people who need it, not only at this hospital but also in the community. So, to empower the cadre in the community to provide palliative care on the frontline.' (S4)

'That's right most of them didn't access palliative care services. Many of them are still untouched because most of them came to the poly and are still waiting for the chemo or radiotherapy list, even waiting for the diagnosis or test diagnosis result. Palliative volunteers are very limited.'(S6)

'I hope they are concerned about us family caregivers too. But this is our own problem, right? We stay here 24 hours care for our family without any support, money, food, emotion at all. I am afraid the hospital will review complaints and say, "We care for the patient, not their family." But maybe they can help us, give us food? Checking our health? I am sick too; provide us with information, ask about our emotions? Something like that? Or meeting session within the family caregivers? Supply us with relevant information?' (CG1)

Hasan Sadikin hospital is the referral hospital in West Province. Most district hospitals cannot treat cancer so send patients with cancer to Hasan Sadikin. Most of them in a severe condition were waiting for treatment in shelters. Some of them had the same concerns about their family's needs at home and their need at shelter. This meant all participants wanted to extend palliative care to the community. All patient participants expected the government to extend cancer treatment and palliative care to district hospitals, which would also be helpful to cut long waiting lists in the hospital.

'I hope they can provide the service in the village. Although the health insurance covered hospital expenses, we need money for transport and living costs in Bandung [province's capital city]. You know in Bandung everything is expensive. I really hope we can do chemo or radiotherapy in the village or at the district hospital. We should not have to wait nine months to get a surgery appointment. I hope they are treating all patients. Don't abandon the patient.' (P3)

'I think the patient should be treated at the hospital. It's impossible in the district. But I will be happy to do it at home as I can save money and energy. I am tired. I want to take a rest at home. If there is a nurse who can care for me at home, thank you very much. Of course, it will reduce my costs, my weakness and my pain.' (P8)

Almost all family caregivers (eight in ten) wanted the outpatient clinic to provide a one-stop service so patients can have all diagnostic tests and treatment in the hospital in one day. They also needed to be cared for at home.

'Very necessary they treat the patient at their GP. So far, poor people must come here from far, far away. It would cut the cost, the time and the energy, right? Look at me, we left home at 1 pm and arrived here at 8.30 pm. Stay at the shelter, then register in the outpatient clinic the next morning. If they could treat us at the GP, it would be constructive.' (FCG7).

'My first time here was when my Mom had breast surgery on September 24th, 2019. We came from Sumatra Island, 700 km away, because there is no cancer centre in my provincial hospital. The cancer treatment does not have to be centred on Hasan Sadikin. They should be in Lampung and the Puskesmas [primary healthcare] and even at home. Yes, I really expected. Yes, at the hospital, every village has a Puskesmas, it's the closest one, right? I really hope.' (FCG8)

Eight out of ten staff stated their expectation that palliative care should be extended to district and community levels and had ideas about training; to train caregiver how to care for patients at home. At the primary level, nurses could assess/care for patients at home and then the hospital team could collaborate with these nurses to visit patients at home. In the future, the team could extend palliative care training to the district, including social workers and cadres, to care for patients in their community. Owing to a limited budget, the team could encourage the private sector to run hospices. Ideally, palliative care should be done in the community, close to patients' families. Hospitals should only be for patients who need high levels of care and treatment.

'All health services should provide palliative care services. The fact is, the district hospitals don't have it yet and the health insurance scheme doesn't cover the costs. The patient who had palliative treatment in the hospital should be

referred to the GP to get treatment from the nurses in their community. But, the GP has not been aware of palliative care, so the patient has to stay longer in the hospital. Palliative volunteers are very limited.' (S6)

'The Ministry of Health has started to train the healthcare providers in West Java Health Centre. Hopefully, it will cover all the human resource needs over there. We will train the GP staff to care for the patients when they return home. Palliative care should be part of all health care providers/institutions and should include shelters and hospices and they should have nurses.' (S7)

9.4.2 The nurse is the closest one to the patient

The participants viewed nurses as being the closest person to patients. They expected that the nurse could assess any patient problems as well as give treatment. To support and cheer up the patient, they should not give up on the patient's condition and behaviour, should share everything with the patient and care for their emotional and physical needs. This kindness will make patients more robust.

'The support, cheers. Then we don't; we don't just give up. Don't give up on the patient; what should your support be? Yes, I still need nurse help. Everything is needed. From the patient, uhh from the nurse to what? Support physically, emotionally too, socially as well as from nurses. I expect all support from nurses.' (P4)

'Feeling. Care of their emotional and physical needs. These kinds of kindness will make me more robust; I am weak.' (P8)

'The doctor spends only 5-10 minutes beside the patient while nursing along the way. In addition to their duty, they should be more familiar with the patient, better understanding the patient's needs that might occur outside visit time.'(S1)

Five out of ten family caregivers viewed the nurse as the closest person to the patient. So the nurse should listen to patients, encourage and motivate them and make sure all of their signs and symptoms were communicated to physicians. Without saying anything, the nurse should understand what patients wanted to say. Their closeness to patients should make them aware of patients' needs.

'It's good for me to know that they take care of my wife. Their support... they listened to my wife, gave her help when she needed it. It's enough.' (FCG3)

'Handled the patient better. It's better. So, for example, without saying anything, the nurse should have understood what the patient wanted to say?'(FCG6)

‘Give us detailed information. Without information, the nurse should know what the patient is feeling. Their closeness to the patient can make them aware.' (CG8)

Two of ten staff said physicians only spent five to ten minutes beside patients while nurses treated them all the time. Hence, nurses should be more familiar with patients and understand their needs. They should know and be aware of what is happening to patients, not just visit at the start and end of their schedule. At the frontline, nurses can play a role in gaining the trust of patients and families, which will mean that patients will give them any information they need.

'The nurses in the team are already good enough, understand more about palliative care so that they can treat patients well. In addition to their duty, they should be more familiar with the patient, better understanding the patient's needs that might occur outside visit time' (S1)

‘Caring is the attitude of the nurse, ready to help. The sincerity of caring may be their nature. All the skills can be learned, but to serve with the heart is the most important.’ (S2)

‘The closest care providers to the patients and families are nurses. So, they must develop a level of trust with the patients. If they have trust between them, the patients will give them any information they need. The nurse is the frontline.' (S5)

Interestingly, one psychologist thought that nurses bore a heavy burden because all interventions are done by nurses.

‘Because my practice is psychosocial, there are often social problems too. I don't know much about the patients' social issues. And that maybe the nurse does? Or doesn't? Perhaps all the burden is placed on the nurses.' (S9)

9.4.3 The nurse as manager

Patient and family participants expected nurses to be managers who will manage everything for patients. The participants used powerful words about the nurse as manager, saying that nurses’ nature is to be caring, that they should serve with their heart, that they have intense contact, comfort the patient, are amiable and have integrity, are on the frontline, and have to master everything; it was noted that cancer is seen as something ‘creepy’. Patients appreciated nurses’ efforts and their sincerity. Four out of ten patients said the nurse as manager already provided an excellent service and expected the nurse to keep doing so. One participant valued the incredible humanity of the nurses and said they could handle all patients. Patients saluted the way nurses treated patients. Other participants said that the different services provided by nurses and other healthcare providers were caring, careful and thorough. Nurses cared for patients nicely and very gently, even when a patient behaved in a disgusting way.

'Huh… honestly, there was a lonely patient in the lower-class ward. He [patient] pooped and spread his poo in the bed, floor and wall and was swearing to the nurses weirdly. But the nurse cleaned him up, the nurse did it very gently. I appreciated her [nurse's] effort, her sincerity. So, I see it is incredible how their humanity, they can handle all patients. So, salute, I saw it with my own eyes. How can they treat patients like that? The different services between nurses and other healthcare providers? So many, but the important thing is they care for the patient. Caring…. Careful, thorough sense of the patient.' (P2)

'The nurse gives excellent service to the patients, greeting the patient and meeting their needs. Asking how they are feeling and checking their condition. Come as soon as possible when the patient needs their help. Oh, the nurse should be more friendly, or if the bell rungs, must come quickly. Oh yeah, like that, I want it to be fast. So, if anything happened, the nurse would come soon. If there is a complaint, they should get a response.' (P5)

Two out of ten caregivers expected nurses to overcome all patients' problems, like a manager, to be responsive, understand and be proactive by assessing patient before they tell their story and then solving their problems.

'Hehehe...[laughing] I don't understand. In my opinion, the nurse should overcome all patient problems. Yes, they should. Like a manager can resolve all issues. So, we family only get the result hah hahaaa...[laughing]. The nurse, doctor general and specialist should be friendly, give good service to the patient. I hope the nurse will come to the patient's house to check the patient. The nurse must be responsive and understand before the patient tells their story [and] that the nurse is proactive to assess the problem before the patient tells the story. That is what the patient needed. It's precisely what I need'. (CG1)

'The people who took care of my mother were the physician and nurse. The nurse is amiable. The nurse must be responsive and understand before the patient tells their story and that the nurse's is proactive to assess the problem before the patient tells the story.' (FCG8)

Seven out ten staff viewed nurses as managers for patients; nurses should refresh their skills in doing assessments and carrying out nursing care. Caring was the attitude of the nurse – their readiness to help. Their nature maybe to sincerely care. All the skills can be learned, but serving with the heart was the most important thing. 'To serve with your heart' was a prerequisite for providing the best service to patients. The difference between nurses and other healthcare professionals is that nurses had time when patients needed them.

'For nursing, we use the same steps in doing a nursing care plan. First, we do a comprehensive treatment plan. We learned this in nursing school; the hospital routine made us forget other aspects of care. We only focus on physical needs. We need enough time to gather all information about the patient. The nurse in the ward cares for many patients, so they don't have time to assess that, so we come to help' (S4)

Interestingly, one staff participant said patients arrived with deteriorating health, did not know their diagnosis and still hoped their illness could be cured. When they received a diagnosis, they were angry or in denial or depressed. If the patient knew that they had been diagnosed with a terminal disease, initially the nurse had enough time to assess their needs and discuss all aspects with them. One physician participant said nursing was challenging because there were practical aspects, medical aspects, nursing aspects and psychosocial aspects. The uniqueness of the nurses was partly because they were with the patient 24 hours a day. Also, it seemed as if they could do it all: physical, psychological and other necessary types of care. The nurse must be a master of everything.

'Caring is the nature of the nurse. Caring is the attitude of the nurse, a readiness to help. The sincerity of caring may be their nature. All the skills can be learned, but to serve with the heart is the most important. That is… to serve with your heart is a prerequisite for providing the best service to the patients.' (S2)

'The uniqueness of the nurses. Why are the nurses different from the other healthcare professionals in the palliative care field? Partly because they are with the patient 24 hours. Also, because it seems like they can do it all, physical, psychological and other necessary care types, that's the difference between the nurses and the others. The nurse must be a master of everything.' (S8)

9.4.4 The nurse as an information bank

As the closest person to patients, the participants saw nurses as information banks. They assumed the nurse would provide all information they needed. Moreover, one participant said that even before a patient asks, the nurse should inform them. Patients expected nurses not to be angry if a patient asked for more information. And nurses could put information in strategic places to protect them from being asked the same questions. Heartbreakingly, one participant thought that a diagnostic test was the definitive treatment because nobody had informed her otherwise.

'I understand it is frustrating for the nurses too. But please don't be angry with the patients. We need information too, right? I hope they write the information on the board so that the patient doesn't need to bother the nurse with so many questions. That's my expectation. At least ask how the patient is feeling and their condition. Sometimes I pressed the bell, but they didn't come as soon as possible. I understand that they are human too. Too many patients but only a few nurses. I also need the specialist to be in poly general, so we do not need to catch them in poly specialists. And they should visit the ward. Why have they sent the junior doctor? I hope I can discuss my condition with the specialist, not their assistant. Please support them [the patients] kindly. Listen to their complaints, smile for them. When we are sick, please comfort those suffering, cheer up the patient, support their spirit.' (P7)

One caregiver reported her dissatisfaction when nurses did not give her clear information. She expected them to use familiar words to explain something.

'The nurse should do comprehensive checks on the patient's condition so that all their complaints are dealt with. However, patients should not wait for the nurse to come to the bed. Sometimes the staff treats their favourite patient only. In my opinion, they should be doing it somewhat, right?' (CG3)

'Oh... I am a little bit confused. When I asked the nurse why my sister has consistently had blood in her faeces, the nurse said it's good, no problem. How can she say it's good? Her Hb is low and she needs a blood transfusion. She is still bleeding from the anus and the nurse says it's good.' (FCG9)

Six out of ten staff said nurses should have adequate skills to treat patients and should increase their skills. They should also explain medical aspects to patients and provide a good service and good communication. Communication skills are seen as essential in performing such tasks as breaking news, providing non-pharmacological therapies like hypnotherapy/complementary therapy and providing wound and stoma care. Nurses can inform patients and family members and approach issues early, including exploring taboo information like sexual problems. In addition, there is a perception that cancer is something creepy that cannot heal. Staff also expected nurses could improve awareness about cancer and give correct information.

'I never get complaints from the patients about nursing care. The thing they complained about was about the time it took to get the diagnosis.' (S1)

‘The nurse must be able to do palliative care nursing from the initial assessment until evaluation. Communication skills are essential in performing such tasks as breaking the news initially, providing non-pharmacological therapies like hypnotherapy/complementary therapy and providing wound & stoma care.’ (S2)

‘In the hospital, the nurse was the professional closest to the patient. They can assess information about health, whether they need palliative care or not. Is their status being in terminal illness? They can inform the patient and family. They can make an earlier approach.’ (S5)

On the other hand, palliative nurses did not have enough time to assess all of the information about a patient in one meeting. One participant illustrated that the nurse's role involved lots of listening, analysing and finding out a patient's needs to pass this information to the physician. Nurses met patients for longer than others. Consequently, patients looked for nurses more, expected more of them, asked them questions more often and complained more to them than to other staff.

‘It is possible to get as much information as possible from the patient, their condition. Owing to the intensity of nurses' contact with the patients, they will automatically expect to form a close relationship with the patient. The patient feels free to tell the nurse what their needs are and about their conditions. Other professionals do not always experience this. The nurse's role involves lots of listening, analysing and finding out the patient's needs to pass the information to the physician. Yes, the nurse meets patients longer than others, so the patient expects more, looking for them, asking them and complaining to them too.’ (S9)

‘The nurses are very active, communicative and proactive. When we want things done, the nurses do it right away. For me, it's good. They just need to improve their knowledge of palliative care. When I was doing the consultation, they missed the functional aspect. They were more focused on nursing, which is their field. The field of nursing is challenging, right? There are practical aspects, medical aspects, nursing aspects and psychosocial aspects.’ (S7)

9.4.5 The nurse providing/administering painkillers

This theme represents the kind of support needed, and being pain-free is the most common supportive need. The need for painkillers existed for all patient participants. Patients wanted nurses to check their condition and then give them painkillers.

‘Yes... Don't neglect the patient. For a patient in severe pain, could you not make them wait in a long queue? Patients suffer from pain, struggle with

diagnostic tests and spend a long-time queueing. When I felt pain, I wanted them to check my condition and then give me painkillers.' (P3)

Five caregivers reported their expectation regarding having enough painkillers for patients. Interestingly, they expected nurses could provide them. The participants reported pain as the most significant reason they went to the hospital and the most common problem they could not resolve. They did not receive morphine via the general practitioner nor in the district hospital. Only hospitals with specific criteria can prescribe morphine and only pharmacies in big cities can dispense morphine. As a result, most patients suffer from pain.

'The physician only gave us a prescription for one week of painkillers. We had to buy them ourselves, but we cannot buy this medicine without a prescription. So, I bought tramadol or paracetamol, but these don't work. He cannot sleep at night.' (FCG2)

'They gave painkillers to my grandma. Sometimes it is enough for her, but sometimes not. The surgeon said that it's a hard drug, she should not take it frequently, only when she feels pain.' (FCG7)

On the other hand, all staff believed that patients need a painkiller. Interestingly, four staff expected nurses to use nursing intervention, non-pharmaceutical therapies or distraction techniques to reduce pain. A pharmacist said the patient could get any painkiller if physicians prescribed them. However, sometimes the hospital ran out of painkillers, so when that happened, she expected nurses to use complementary therapy to reduce patients' pain.

'Yes. The nurse can do hypnotherapy or other complementary therapy to reduce the patient's pain or increase their quality of life. Teach the nurse how to give more nursing care intervention, for example how to reduce the pain with movement manipulation, distraction, or other nursing interventions.' (S1)

'The goal of the palliative care team is to make the patient as pain-free as possible, feel comfortable, get enough sleep and alleviate symptoms like nausea, vomiting and coughing. The nurse must be able to do palliative care nursing from the initial assessment until evaluation. Communication skills are essential in performing such tasks as breaking the news initially, providing non-pharmacological therapies like hypnotherapy/complementary therapy and providing wound & stoma care. The nurse must be able to do palliative care nursing from the initial assessment until evaluation.' (S2)

Another action was the sincere caring of the nurse as a strong nurse intervention to reduce pain. By understanding patient condition and explore their psychosocial aspect, the nurse could help release their pain burden.

'Caring and caring. Why? For instance, ask the patient what their need is. If the patient experiences pain, please treat the patient with painkillers and suited non-pharmaceutical therapies. Ask the patient regularly how they are, don't stop after the interventions. By doing this, we can learn more about their conditions and the patient is more able to express their feelings. Touching: sometimes, the patient is petrified by being touched. The nurse should take the initiative, checking the patient regularly, trying to sort out the problem.' (S6)

'Yes, it is not easy to let the patient know that they need palliative care because ordinary people, even some healthcare providers, do not understand palliative care. However, when we gave information about it, the patient becomes accepting of their situation. Their expectation of getting well soon decreases after that. Not as high as their first expectation anymore. Now they received that the patient's comfort is more important than it all.' (S6).

9.5 Barriers to and challenges of providing a nurse-led intervention in a resource-poor setting

The researcher generated two broad subthemes about barriers to and challenges in providing a nurse-led intervention. The subthemes were experience in providing/receiving care and palliative support needs.

9.5.1 Experience of providing/receiving care

Patients' experiences when receiving care were classified into three sub-subthemes, as explained above. The experiences were also divided into three groups' point of view: patients, family caregivers and staff.

9.5.1.1 Patients' experience of palliative care

a. The barriers in palliative care

From the patients' viewpoint, the barriers were mostly about physical support. They needed support because they were very tired or wanted a nurse to care for them at home; specialist physicians were too busy and had many patients so did not have time to have a consultation session with the patient, and they needed written information about the therapy. On the other hand, the specialist can decide on the cancer treatments for the patient, which made some patients find a shortcut to meet the specialist.

‘Sometimes I pressed the bell, but they didn't come as soon as possible. I understand that they are human too. Too many patients but only a few nurses. The specialist [physicians] is very busy as they did surgery in the theatre [surgery room], so they don't have enough time to visit patients.’ (P1).

'I went to the specialist outpatient clinic although I should pay for this service by myself. … I could pay for it. It costs 175,000 Rupiah (£9) for treatment in the specialist outpatient clinic. But not all people have money. The health insurance users cannot visit the specialist directly. The specialist will decide the subsequent treatment for the patient. But not all people have money to pay the specialist fee, right?’ (P7)

All the family caregivers gave their thoughts about patients’ barriers to receiving palliative care. The barriers were policy and information, including regulation regarding getting treatment, did not do early detection, difficulty getting painkillers, lack of information and a layer of bureaucracy when using the national health system. While seeking help, patients suffer from many signs and symptoms. However, they could spend a whole day waiting to see the physician at the outpatient clinic. All family caregivers talked about how several issues prevented prompt access to palliative care. Such barriers resulted in increasing the symptom burden. Along with their complaints, they also expressed their need for available care in their district or home visits, treatment tailored to patients’ needs and support and information for the family.

‘I hope they [hospital] can provide a room for patients because they [patient] suffer from so many complaints after chemo. So, we can stay several days then go home. I hope they can make one outpatient clinic [so] that we don't need to go to other places, just sit down there and they will do all diagnostic tests there? Is it too much?’ (FCG1)

'I hope for the best for him [son]. He needs surgery as soon as possible. But what can I do? I must wait. I hope they can do it at the district hospital, so we don't need to come here many times. It took so long to travel here from home. From our village to Sukabumi, it took 5 hours by a small transport car. We ride the public transportation [a small car in the village], we stay first to rest in Sukabumi. We stayed there for one night because my son was so tired. He had cancer in his knee and the transport car was so small, he couldn't rest his leg. He even collapsed and blacked out on the bus. Then from Sukabumi we continued by bus, which takes 6-8 hours depending on the traffic. My son is a brave fighter. I could see his tears while we were on the bus; he suffered from pain. I just touched

his leg gently and said, "Be patient, my son." He uses a stick because he cannot stand on his leg anymore. It's so painful for him when getting on and off the bus. We don't have enough money to rent a car.' (FCG2).

The barriers for the staff were the regulation and policy. The condition includes all staff have two jobs in the hospital, (in the palliative team as well as in their primary office), so the team cannot treat patients earlier. The patient also waits a long time to get a diagnosis, which delays treatment. In addition, the lack of healthcare provider training at the first level in the community means that all patients are sent to the hospital. Consequently, the physicians deal with many referral patients from district hospitals needing palliative care. Most of them will be sent back to the district hospital.

Nonetheless, the hospital's palliative care team still needs to collaborate with district hospitals, so the government needs to promote a general understanding of palliative care among hospital staff, provide facilities and restructure the policy in insurance health schemes.

The palliative staff said they still needed a clear vision of home care. One member of staff wanted an outpatient clinic with a room for complementary therapy, like music therapy. The team needed financial help from charities to help them with this issue and it also needed a cleric and priest. One participant hoped there would be a collaboration between the hospital and a minister of religion to arrange for dying people to talk to a priest, especially at the end of life.

'On the days I am on duty in my ward, when a patient needs palliative care treatment, I would play the role of the palliative care physician instead of a palliative psychiatrist. I would conduct palliative care needs assessment on this patient regarding their illness and needs.' (S1)

'I wish we had a private room to talk with the patient because some of them don't want their family members to know their wishes. Then we can discuss the follow-up in the ward, e.g., what to do after the patient goes home. We haven't talked about that yet. Most of them will be sent home to the district hospital. We don't have collaboration in palliative care with the district hospital yet. We have around 997 beds, 1100 on the website but 997 only. Nurses around 1200. One ward consists of 40 beds, with only 3 nurses. We want to have an outpatient clinic, with a room with complementary therapy, like music therapy, but we don't have funding yet. Home care, too, we don't have a clear vision about it. The legislation, the financing, we need people or charity help us with this issue.' (S4)

b. Poor communication

The patient and family participants experienced a lack of information during patients' treatment in hospital about procedures, diagnostic tools, the diagnosis, waiting times, medicines and other procedures. From the patient's perspective, their need for more information was related to staff attitude while caring for the patient. One patient participant raised his concerns when the physician did not tell him about the subsequent treatment. Others said that some physicians examined them without asking – just touched their body and left without any explanation.

One patient expected physicians to explain what they were assessing, the result and the subsequent treatment. She also said that staff did not explain what the procedure was for diagnostic tests. She waited for no reason in the hospital, they were not told that the results would not be available immediately and so they waited in the hospital until they eventually found out they could go home and results would arrive days or weeks later. She had hoped that the staff would explain the procedure and regarding waiting for the test results. One patient who lacked information disturbed the nurse by asking more and more questions, which made the nurse angry with him. He suggested it would be better if nurses provided an information board. Another participant did not even did not know the purpose of the treatment. When the physician carried out surgery to take a sample from her body, she thought they were going to cut the cancer out of her body.

'I know what the disease is, but I do not know what the next treatment is. Should I get chemo, radiotherapy? The physician knows and should have advised me about what to do next. Can they just give me medicine first while checking what treatment I should get? Can you do that? Before my illness more fatal?' (P2)

'Well, some are good, some are wicked. Some physicians just examined me without asking. They didn't ask how my condition is, then just left. I supposed they would ask about my condition. I expected they would explain what was happening to my body and what I should and shouldn't do. The nurse was good and many of the internship students were too. Hmmm, the Health Insurance likes that, hahaha well, especially for those people like me [3rd-class health insurance user]. It was my first time in the hospital. I was tired but [was told that] I should go to the anaesthesiologist downstairs. There I waited for so long. When I finally met the physician, they asked me where my ticket is? I said, what ticket? They said you should take a ticket first, so we went home because the outpatient clinic was closed already. It was awful. I felt pain all day. I had wasted my time there. I cried. They should explain clearly what we need to do so we don't waste time there.'(P3).

One family caregiver participant stated that outpatient clinic physicians even said they did not know what to do with the patient, which made them stressed. On the other hand, one participant said that the patient was hesitated regarding asking about or explaining their problems to physicians or nurses. Others said that physicians should understand patients' needs. Another reported that she was dissatisfied when the nurse could not logically explain her condition to the family.

'Look, my father only has one radiotherapy physician. But in ENT [ear, nose and throat] outpatient clinic, we met different physician every time we went there. They didn't know for sure what the next treatment would be. Every new physician asked us the history from the beginning and again seems like no progress. Even if they asked us, what should we do? It was horrible, the radiotherapist knowing the progress and what to do, but the ENT got confused. So, I think no use to visit the ENT.' (FCG10)

'The service for patients with cancer in the outpatient clinic is good already, but for patient in the ward is not good enough. It seems there is no communication between them. I guess the oncologist hadn't written down the details about my sister's condition and what treatment she should get on the ward. It annoyed the physician on the ward and he [physician] projected it on us. They should have good communication between them.' (FCG9)

The staff's experience when providing care for patients was that they thought they provided good care for patients despite the weakness in the system. The excellent parts were that they could coordinate with other teams, they knew their workflow and their team had members from different backgrounds. The weakness was that they focused more on managing pain than other symptoms, did not have a social worker that they believed could reach patients at any time and not all members were exposed to specific palliative care training.

'So far, we haven't had any difficulties because we have started to know the workflow. Even though not all the members are active. There are no significant difficulties because we already know the problems, the management, we have started to build up our chemistry.' (S4)

'Our team is almost complete, so for now, it's okay. We set the schedule for one month, usually one nurse and one physician with two or three patients every day. That team will look at the patient's primary needs. So, the first team will do an assessment then they can ask others for support. We don't need any more staff. But a social worker would be valuable too. They can be reach them out of our working hours and they can accompany the patient at any time.' (S5)

c. Good and bad services

All groups noted the good and bad services of the healthcare providers in the hospital. From a patient's point of view, the healthcare provider’s behaviour was excellent in the hospital. Some thought that physicians and nurses served them excellently by explaining what they would do during therapy. Inadequate services existed in the waiting system; they said, 'The queuing system in the hospital is boring and tiring’.

‘The queuing system in the hospital is boring and tiring. People from everywhere were crowded in the waiting room. Sometimes the clinic closed before my number was called. There are no fixed appointment times. Those who got low numbers number were seen first. You were unlucky if you got a higher number. I sat there and waited to be called by the nurse. In the chemo, the most trouble is getting an empty bed. When the appointment comes, we needed to find the room. First, the admissions [department] even sent us to the ward to ask them whether they had an empty bed. We searched in the wards, none… we went back to the admissions department. They said we should not have come back here. Ah… I was confused, we went home. Then when we found a bed, they said I should do the lab check again. When I got the lab results, there was no empty bed. I had to do the same steps again. When they found that my result did not fit the requirements, they sent me home to get therapy at the district hospital to get a blood transfusion or another treatment. After that, I had to start the same process again. My chemo appointment may be delayed for a month, 3 weeks, or 2 weeks like a ping-pong ball.’ (P1)

'The most serious difficulty is finding a room. I was lying sprawled in the waiting room from 8 am to 4 pm. There were no empty beds. We waited until one patient went home so that I could use their bed. It was terrible. Physician Naseh, an orthopaedic [surgeon], handled my treatment wholeheartedly and with a hiss, full attention. I felt their genuine care and concern for me when my wife was going home. The nurse in the clinic took care of me very well, although I waited from 9 am to 3.23 pm to access the service. It was difficult. I waited for 6 hours in severe pain, lying sprawled in the waiting room. I didn't know what to do. I cry when I remember that. I could see their [the staff's] feelings, their pity for me, but they couldn't do anything because they were also handling so many patients, some even worse off than me. Maybe they have rules and limitations too.’ (P2)

The family caregivers gave impressions that the bad things happened because of the queueing system. A participant told a story about having a high queue number in the outpatient clinic for the first time to seek cancer treatment. She received an appointment for surgery ten months later so she paid the specialist because she feared the cancer could spread in ten months.

‘The queueing time depends on the number of patients. It can be as little as 30 minutes if we get a lower number. I got number 474. At 9.30, I registered at the admission centre then went to the outpatient clinic. Some diagnostic tests can be done in one day. Others take a week or more, depending on the type of test. We

got an appointment for September 2020. [The interview was held in December 2019.] Oh… it's 9 months later? Pity, my wife, the growth in her womb is so big and she has nausea and vomiting almost every day. How will we manage? I voiced my objection to the delay, but they said they do not have any earlier slots; they have so many patients to treat. I think they gave good service at the clinic except on the queueing system.' (FCG3).

'The waiting list... you know I'm from far away. We left home at midnight and arrived here at 3 am. We didn't have any place to rest, then we were waiting in the hospital till midday.' (FCG5)

The staff write down all their work on the patient's form so that the primary physician should know what the treatment was.

'We [nurses] help patients with their hygiene problems, educate them in personal hygiene and wound care. If the wound gets worse, we refer them to the plastic surgery team. We visit the patients at our own expense. We call for help from the religious groups around patient homes to support them in this phase. They were delighted with that.' (S2)

'Commonly, the patients coming with pain, incontinence, bloating, gaping wounds and other complaints. We assessed and helped. At least it is reduced their symptoms 80%.' (S9)

9.5.1.2 Family caregivers' experience when their relative was receiving care in the hospital

a. Teamwork

Regarding the teamwork subtheme, patient participants and family caregivers talked more about the administration system and the staff behaviour. The participants viewed the staff as 'good staff'. Five out five patients said they experienced good care from physicians and nurses. They were satisfied when the nurse listened to their thought and gave them explanations about their care. Nevertheless, some patients experienced the opposite.

'The nurse should support our emotional feeling, don't argue with us. It makes us feel down. I hope the nurse can do that because they are with the patient 24 hours, compared to the physician only have a little time with the patient. The nurse should support our feelings.' (P1)

'Sometimes I am annoyed by my husband. So, I want the nurse to pay attention to my emotions, too. I was happy that I could express my feelings to them.

Sometimes I am overly concerned for my family, my husband. I need a nurse to listen to my complaints.' (CG5)

Eight out of ten family caregivers and three out of ten patient participants said the staff service in the hospital was good. The physicians and nurses were reasonable, gave treatment wholeheartedly even though they could not serve a significant number of patients.

'Physician Nasajarawan (name) is an excellent physician, physician Herry Herman, physician Maulana. They all are lovely and friendly. They told me the information, what to do, what the plan is and many more. So alhamdulillah, they all are good. The nurses, too, are friendly, polite. I hardly find their weakness. In the clinic and the ward are the same. So, I went there, he [the physician] cheers up my son, keeps his spirits up.' (FCG2)

'The physician, oncologist, nurse, laboratory officer, admin, pharmacist. The nurse called us if there is something we should do. Their support... they listened to my wife, gave her help when she needed it. It's enough.' (FCG3)

On the other hand, all the staff valued the fact that they could do their job well, and gave reasons why they could do so with the following reasons: they could coordinate with others, provide enough medicine, fulfil patients' right to have a comprehensive service, had no difficulty with their work, the team was solid and there nurses were in charge of patients.

'Most of the patients who were referred to the palliative team were in terminal cases with scores above three. Unfortunately, they were being treated for end-of-life care. They [physician] rarely sent us patients in the early stages. Usually sends the patient when they are confused about what treatment is suited for them. It is like we are the last choice that there's nothing more to do. When their diagnosis is cancer, there should be a collaboration with the palliative team to plan their care. It is more rational and more cost-effective.' (S6)

'My experience in Hasan Sadikin. First, the service is not palliatives but more end-of-life care because we are taking up the patient today and the next day the patient is gone/died. In my opinion, more should be done to better inform the physicians about palliative care. Because there are still many who do not know about or understand its purpose. So, they refer the patients to us when they are near death. Secondly, our team is solid enough where our team has someone on a shift. And to me, it is quite efficient. Third, we can discuss the findings in the group, at least in the beginning, we have data and then the expert or the competent physician can help provide a solution. That is what I am grateful for.' (S7)

The participants wanted the hospital to have a 'revolution' in the cancer services system. They wanted the hospital to make a new admission system so patients could have a fixed time for an appointment. Currently, they only had a date, not a fixed time. Patients took a queue number, which could be in the thousands, then waited hours before the officer called their number. Sometimes participants arrived at 4 am, hoping to get a low queue number. Patients from far away needed a low number of queuing, but the clinic was already closed when their number was called.

'In my opinion, there should be a revolution in the queueing system. There must be someone here who can solve that. I feel sorry for them too. I was concerned for the porters too, they transferred many patients and they were tired. To my mind, they should do the treatment as soon as possible. Why should we spend so much time just waiting for the diagnostic results?' (FCG10)

b. Patient rights

The patient and family caregiver participants commonly asked for their right to have a bed in the hospital, to receive treatments and be served by friendly staff. One participant raised the issue of a patient dying before receiving treatment because they arrived late and the hospital had limited beds. He wanted the hospital to sort out long waiting lists so that patients could receive treatment sooner. Interestingly, one participant thought that the high number of patients prevented staff from serving them well. He suggested that the government provides cancer treatment in district hospitals as the solution.

'I saw people die before they got their treatment. You know the lady in front of my room. You met her 2 weeks ago. She has died while waiting for her results. I know what happened to her since she was here. I help all the people in this shelter. One of them died while waiting for their biopsy result. They gave her a pain killer. So many… I transferred them to A&E and they were dying there. So, I understand all of it because they got treatment late. They suffered from pain and got bored because they were waiting for so long and became mentally disturbed. Those are the circumstances. Sort out the long wait to get treatment, respect the patients' emotions, consider, be aware of the patient feelings, don't make us think they have abandoned the patient.' (FCG10)

‘Please don't take too many patients a day. It makes they [staff; too tired to serve the patients] cannot treat us well. Hehe... if there is a chance, please check every person to find out the people in early stages.’ (FCG5)

On the other hand, staff said that patients have the right to receive skilful treatment, good service and communication, support in the mourning phase and to have their opinion and expectations listened to before receiving treatments.

'But when we visit the patient, there is no follow-up yet. We lost contact after that. Maybe we just did 60% [treatment]. The average patient comes here in the end-stage condition. Even their basic ability is worsening. I expect the family understands that palliative treatment aims not to heal the patient but to improve their quality of life at the end-of-life. Does the patient want to know more about their condition? Because some of them feel comfortable if they see that we have cared for patients like them and they got well. This keeps them motivated. '(S4)

‘I will explore more deeply into how much they understand their condition and encourage them to express emotions. The patient is having difficulty talking to the physicians or their families about it. If the patient feels a need to talk to someone, they come to me. Then, I rearrange how the family would like to talk together to solve the problem. So that's what I do.' (S9)

9.5.2 Palliative support needs

The next theme is palliative support needs. This theme has four subthemes: financial difficulties and spiritual, psychosocial and physical support.

9.5.2.1 Financial difficulties

Similar to family caregivers, patients experienced the same financial issues. Fifty per cent said they had financial difficulties. Health insurance covers treatment in the hospital. However, their family needs to pay their living costs. If they stay in a shelter, they also need to pay living costs.

'I hope they will help with my financial problems. My wife and I have been jobless for two years during my sickness. My wife cares for me because I cannot move, cannot stand by myself, I need 24 hours care. We have lived in the shelter for the last two years.' (P10)

‘My experience? Oh, everything went well, but money. Ummm, I am a poor woman. I work so hard to save money so I can come here to get chemo. 700,000 Rupiah [£35] is not enough to cover my transport and living costs on each chemo. I almost gave up. I had no money to go to Bandung. I am destitute. I have no money to go to Bandung. I am penniless.’ (P9)

Five out of ten family caregivers reported financial difficulties during their relative’s treatment in the hospital. If the relative was a breadwinner or a housewife, the money problem was more complex. They struggled to fund their expenses during their stay in or near the hospital and fund their family at home. Some patients/families requested to go home because they did not have money to buy food in Bandung.

'The cost too. I am a housewife; I have no money. After getting sick, my husband cannot work, my children need food at home and we do too here. It's too hard for me. We need transport here. We need social support. My neighbour? I hope I can borrow money from my neighbour.' (FCG1)

'Then we get the results the day after. It meant we could not go back home on that day. Before we knew there were shelters around, we slept on the hospital sidewalk to save money. And all that time, my sister suffered from pain and bleeding in her anus. Then one night, the security guard said we could not sleep on the sidewalk. We were sad. After that, we found out about the shelter and now, we are delighted with that. If they can make it possible to do it all in one day, that will be good. They could employ more physicians and nurses in the outpatient clinic so that we do not need to waste our time there.' (FCG9).

Four out of ten staff reported patients' difficulties during treatment. Some staff organised donations or treated patients free of charge because they could not pay fees or buy equipment. Patients even lied to physicians, saying they wanted to go home because they were missing their children when the reality was money problems.

'Well, we submitted the proposal a long time ago for home care, but until now, it doesn't get the result yet. Only capable patients can do home care. People who have benefit health insurance as poor people and the third-class scheme cannot access this service because it is classified as the private sector, the health insurance does not cover it.' (S3)

'Many times, I found that the patient had accepted their condition and were relatively stable. They wanted to be at home, but could not go home because of their family's concerns, for example, how they would cope if they relapsed? Those who have come from far away worry about how to get back here again if necessary. Yes, finance is also a barrier. It looks like not all people are aware of palliative care. What is an example for them? [no money, no services]. It's difficult for their daily needs to cover. Moreover, the caregiver is often also the breadwinner. If the patient's family is required to bring the patient home, they know the health insurance does not cover the reality that all the medical expenses are incurred at home. While in hospital, mostly are covered. Even though, some patient, firmly asks to be sent home. Some said the reason is just wanted to be home. So, when the costs are not covered, that is an obstacle to have cared for at home.'(S1)

9.5.2.2 Spiritual needs: God is the healing source, humans only the tool

Participants needed support in the spiritual domain to help them with religious rituals and to accept the illness and dying process as God's will. The participants said healthcare providers and family should not focus on the physical problems but on psychological and spiritual needs. It was crucial to make patients and their family understand that they were dying; they needed spiritual guidance to help them die peacefully. Patients and families needed to know their condition and prepare themselves to do religious rituals rather than receive medical treatment for the dying phase. By doing this, they could experience good dying and death and the family would be satisfied even if the patient died.

The family caregivers and patients also reported their need for spiritual support, especially regarding rituals. Three participants believed that the treatment process occurred with God's help. Their feeling regarding God's help was genuine.

'Finally, I got a date for surgery, in November 2019, 6 months from when I got the notification. My family thought it's just a trick that I will die in 6 months, so I will have already died when the surgery date comes. I cried to God in my prayers. Alhamdulillah, two weeks later, they called me. I was desperate. My cancer was dangerous. I lost weight, from 75 to 50 kilos, but now I am in full spirits and motivation. I will fight.' (P3)

'I talk to the physician. Yes, I was so sad, Ma'am. I was already seriously ill. Thank God, I thank God, we carried on, we were patient. We were given trials [from God to purify their faith] until we recovered. And it has been five years since we returned to this hospital.' (P6)

Seven out of ten family caregivers stated that God had power in all the healing processes. Their spiritual support needs included how to help patients make substitutions for their ritual prayers. They believe that failing to do a ritual has consequences by paying for the offering. This made patients stressed, because they could not pay. The code was created directly from a participant's comment; stated:

'I am sure God is the one who heals. The physician is just a medium and should treat the patient quickly.'(FCG10).

‘Thank God, the nurses took good care of him, giving him medicine, treating the wound, the food. God blessed him, provide him with health. Alhamdulillah Alhamdulillah, it's a little bit of progress. Even sometimes, she is angry but can accept the situation. Even though it's not 100% yet, but thank God there are behaviour changes.’ (FCG4)

The staff believed that patients’ spiritual needs involved helping them carry out religious rituals despite their illness and to treat them warmly. Patients tended to feel more peaceful if they had spiritual support. Nurses should help the patient remember Almighty God until their last breath: ‘Dying peacefully and calmly with prayer and remembering the Almighty God is more important for the patient at the end of life.’ One member of staff hoped there would be a collaboration between the hospital and the minister of religion to send the priest to provide end-of-life guidance. With spiritual guidance, patients were less nervous and would accept medicine or treatment more easily.

‘That is, serving with your heart is a prerequisite for providing the best service to the patients. Physical, psychosocial and spiritual. Patients tend to feel more peaceful if they have spiritual support.' (S2)

'For the patient near death, there is a final assessment of their life. We sometimes ignore the fact that this patient needs to be accompanied by their spiritual leader or priest. So, if I was there, I will prepare the Qoran with a prayer guide and act as one of their family. Hopefully, this can improve the patient's experience during the dying and death phase. We can say that the maximum possible medical treatment has been done. So, we can focus more on the patient's psychological needs by facilitating their spiritual needs. This decision is what families or patients cannot accept. They are still hoping the patient will get well soon. So, ask them to pray together with us. There must be “Taqil” for Muslims, which we believe ensure the benefit of remembering the Almighty God until the last breath. But, in a hospital, it is difficult if, at the exact times, the patient is being resuscitated. Nobody is concerned with the patient's spiritual needs. Dying peacefully and calmly with prayer and remembering the Almighty God is more important for the patient. We supplied patients with Quran to reduce their spiritual stress.' (S3)

9.5.2.3 Physical needs: lack of painkillers

Almost all participants need physical support. They experience changes in body shape and function, and fatigue and pain. Five out of ten caregivers reported the need for painkillers. All patients and families reported difficulty getting painkillers. The policy meant they had limited access to painkillers. Even if the patient was already at the hospital, there was no guarantee they could have them.

Outpatients needed a prescription to get painkillers for one month only. It should be possible to get the next prescription in the physician's clinic'. Some patients from far away have difficulty to travel to the hospital to have it. Some of them received painkillers, but they could not reduce their pain level, making them lose hope and be unable to stand the pain. Another participant said she was in pain all day, hardly slept and rolled around every night because of the absence of painkillers.

'Also, there was a problem in the pharmacy. The medicine didn't reduce my pain. I am not angry with them but, it didn't work. If I was in pain on the bus, there was nothing I could do. I blacked out on the bus. I was able to get the painkillers in the district, but they didn't give them to me. I went to the clinic in my village, the physician gave me "Piroksika", but it didn't work. The last time he gave me "tramadol", it doesn't work either, but it made me sleepy. I hope they give me painkillers or prescribe them, so I don't have to come here just to get painkillers.' (P1)

'Oh… I got ten prescriptions from the physician, but the pharmacist only gave me six. It happened twice. They said I should pay for several because the health insurance didn't cover it.' (P2)

One family reported that the physician gave her grandmother painkillers, but not enough to reduce her pain. The physician also advised patients not to use them frequently.

'The physician only gave us a prescription for one week of painkillers. We had to buy them ourselves, but we cannot buy this medicine without a prescription. So, I bought tramadol or paracetamol, but these don't work. He cannot sleep at night. The pain is still there. Yes, in the night, I didn't sleep. I gave him medicine to reduce his fever and pain. Yes, he is always patient; he cried.' (FCG2)

'Right, the patient has physical symptoms. He/she is sick. This symptom needs to be relieved. Needs help to sleep, eat, sad, angry, anxious, lost hope, right? Nurses should support patients in all areas. What the patient needs, the nurse immediately responds to that.' (FCG8)

Two out ten staff reported that patients needed painkillers. One participant emphasised that many things were needed to reduce patients' problems. As a treatment for life, painkillers should be free for patients and be easy to access.

'No, they are narcotics and can only be prescribed by a physician and many administration documents must be completed. The administration of the morphine is complicated and the patient must provide proof of address. We have limited oral morphine. There is painkiller injection in the district pharmacy. Still,

maybe patients cannot inject themselves, so they need oral morphine. Still, it is hard to get it at the district—possibly codeine to substitute that drug.' (S10)

'Painkiller and psychologist session can be worked together to release the pain. And this can help reduce the pain. When I see the patient, I make sure that they have gotten the medicine and the word/note from the physician whether they prescribe the medicine. Because I am a psychologist, I only glimpsed "Oh, it seems morphine has been given." In the counselling session, an emotional release made the patient feel more comfortable than before.' (S9)

9.5.2.4 Psychological support needs: to help the patient die in peace

All participants said patients and family caregivers needed psychological support. Some of the codes representing this were providing psychological support, helping patients die in peace, initiating discussion of sexual-life issues and the mourning period. Half of staff assumed that patients needed support from staff to cheer up patients who need help. Staff might not be able to predict when a patient will die. Nonetheless, they can estimate how much longer the patient will live so that they can help patients prepare everything. On the other hand, family caregivers needed to know how to care for patients at home and to help them accept that death is a natural process.

'We noticed some families found it upsetting when we explored the patient's psychological, social and economic problems. Sometimes they couldn't express their feelings. Maybe they feel like they are being told what to do or something. But then, a nurse with good communication skills makes the family express their feelings. On balance, the people complain about the physical aspects maybe because they have psychological problems. We teach them the basic principles of caring. The family will not be so worried if they know what it is and what to do. They can accept that death is a natural thing, that there is no need to worry.' (S5)

'That treatment will have an impact on the patients. However, suppose the patient's medical condition is of greater concern and has not been addressed. In that case, I will usually postpone psychological treatment. If there is a psychological condition and no effect, yes, the physical condition must be carried out first.' (S9)

9.6 Person-centred nursing theory

9.6.1 Framework 1. Prerequisites

Prerequisites focus on the context in which care is delivered (McCormack and McCance, 2006).

Element 1: Attributes of nurses include being professionally competent.

Attributes of nurses are being professionally competent and developing interpersonal skills to engage in emotional work. All nurse participants have a bachelor’s degree in nursing, had work experience in a palliative hospital team for a minimum of five years and had upskilled with palliative training. Patients, family caregivers and staff also noticed nurses’ competence; they claimed that nurses are the closest to patients and they served them with their heart. The elements of every framework can be seen in every quote below.

'I finished my Bachelor of Nursing in 2005, then worked as a nurse here. I joined modern dressing training in Jakarta. So, I have competence in doing modern dressing wound care. Then in 2011, I continued my studies and got my Master of Nursing degree. We did palliative care training in Thailand then a course in palliative training for caregivers and the palliative care training courses held by SIF and YKI.' (Staff 2; nurse)

Element 2: Having developed interpersonal skills.

Participants said that nurses showed their competence through caring for patients with one word and being an 'amiable nurse' who understands patients and families. A psychiatrist also stated that the nurse has excellent support in the palliative team. This finding supports ‘a person-centred focus on treating people as individuals: respecting their rights as a person; building mutual trust and understanding; developing a therapeutic relationship' (McCormack and McCance, 2017).

‘When I was in Fresia Ward, one patient got angry with the nurse, but the nurse cared for the patient nicely. What kind of person is she? I really liked this nurse; she didn't care about the patient's disgusting behaviour.' (Patient 10)

'I happened to work with nurses in the team who have the education and skill in palliative care background. Their knowledge and skill are excellent support for the team.' (S1, psychiatrist)

Element 3: Being committed to the job

Nurses confirmed their dedication to patients by emphasising patients' right to receive holistic care. Even if patients did not report symptoms, nurses said it was their job to assess patients holistically. This dedication showed the nurses' desire to provide the best care for patients. People should receive a standard of care that reflects their principles. They are committed to the job, skilled in emotionally engaging with the person and their family and provide space in which they, as well as clinical staff, can express difficult and sad feelings.

'The palliative care approach should be holistically integrated, covering the biological, psychosocial and spiritual aspects of care. If we do not examine patients' needs in these areas, it appears that there was not a need. Indeed, the patient's physical needs are addressed on the ward, while the need for psychosocial and spiritual support seems not to be explored as well. We want to emphasise that patients have the right to be cared for holistically and receive complete service.' (S2)

Element 4: Being able to demonstrate clarity of belief.

One nurse in this study stated her belief that patients have the right to be treated as individuals with their own lives. Good communication is the door to revealing the patient's hidden problems. As person-centred approach means that the patient needs medical treatment and support systems.

'As I see it, the patient needs not only medical treatment but also a support system. So, I can help them to over their psychosocial and spiritual problems. Palliative care courses have helped me understand how to examine patients' needs. Maybe the doctor has only told them about the medical aspects and the nurse on the ward only did the routine care and forgot the most profound thing. After receiving their information, I must provide them with the most reasonable intervention. Often, the patients can seem complicated, but after we talked, we found that the reason for this was anxiety about the changes in their bodies. They worry that they will not do normal activities afterward.' (S4)

Element 5: Knowing themselves.

Knowing themselves enables nurses to engage with others in a way that respects and values them as whole persons. One patient stated her feelings about how nurses engaged with her. Patients understand that nurses are always there for them; they only need to tell the nurse and the nurse will help them sort out their problem. The nurses themselves realise that they should build a close relationship with patients and spend extra time with them to show that they care.

‘I was happy that I could express my feelings to them [nurse]. Sometimes I am overly concerned for my family, my husband, I need a nurse to listen to my complaints. But sometimes I think I just bear it by myself hahaha…...[laughing]. The nurse gives excellent service to the patients, greeting the patient and meeting their needs. Asking how they are feeling and checking their condition. Come as soon as possible when the patient needs their help’. (CG5)

9.6.2 Framework 2. The care environment

The care environment focuses on the context in which care is delivered and focuses on their own and colleagues' wellbeing and contributes significantly to creating a working environment where everyone's experience, skills and knowledge are used to the full potential within the team (McCormack and McCance, 2017).

Element 1: Appropriate skill mix.

In hospital, all nurses have a local Registered Nurse certificate because it is a requirement when applying for a nurse role.

'I am a nurse. I finished my bachelor’s and master's degrees in nursing then continued with specialist training in oncology. I gained the Certificate in Palliative Care. I have done palliative care training overseas, in The Netherlands, Singapore and Bangkok.' (S2)

Element 2: Workplace culture.

Creative environments where individuals can flourish and generate energy from innovation and creativity are essential. The nurses in this study were concerned about holistic care for patients. Their desire to find problems and resolve them for patients authentically engaged with the person and his/her family to maximise autonomy and patients’ wishes about the place and level of care (McCormack et al., 2010).

‘The palliative care approach should be holistically integrated, covering the biological, psychosocial and spiritual aspects of care. Indeed, the patient's physical needs are addressed on the ward, while the need for psychosocial and spiritual support seems not to be explored as well. If we do not examine patients' needs in these areas, it appears that there was not a need. However, we found that there were problems. We want to emphasise that patients have the right to be cared for holistically, to receive the complete service.’ (S4)

Element 3: Shared decision-making systems.

The nurses were concerned about synergy between multidisciplinary staff when making decisions about interventions for patients. Care decisions are shared within the team and respect was evident for the individual knowledge, skills and experience of each team member regardless of grade (McCormack and McCance, 2017).

‘'I would conduct palliative care needs assessment on this patient regarding both their illness and their needs. These could be medical, nursing, psychosocial and spiritual needs. The results will be shared with the team, so everyone knows who will come next. For example, if the patient needs a nutritionist, the nutritionist will go next and will fulfil the patient's need. All the treatments we give are noted down on the patient's form. The primary doctor will then know what treatment the patient has received. We also keep our own team notes.' (S2, nurse)

‘Yes, we expect that we can do synergy, coordination and connect with each other. So, we cannot work alone. We must work together.’ (S6, nurse)

Element 4: Power sharing and effective staff relationships.

The nurses reported that physicians in the team still had more power than other professions, which made them dependent on physicians’ orders. Hence, power-sharing does not run smoothly in the team. Care-planning processes represent the agreed team vision for palliative care and include all domains of assessment.

'As for the treatment, I believe our work is already excellent. If we can do it all, the patients will be satisfied with our services. For us... Money, funding... at least if what work we have done can be calculated and remunerated, we would have much enthusiasm and do our best. We did this work outside of our working contract hours, so we should get a bonus. If not, we should be able to claim this as our main task. But there is no such scheme. So, this is charity work, hahaha...[laughing], so we can't do it optimally. We suggested that the hospital calculate our extra work into the remuneration system, but they rejected the suggestion. If everything is calculated with rupiah, surely everyone will be enthusiastic about visiting the patient. Sometimes, the patient has gone home or

even died before we visited them. Not everyone has the same passion for caring for the patient in the circumstances like that, right?' (S3)

Element 5: Horizontal violence as a negative power relationship.

Nurses find that physicians often delegate their tasks to the nurses. Physicians receive fees but other professionals do not, nor is their job appreciated in the team. Honest communication, highly developed interpersonal skills, colleagues' views on practice and supportively engaging in feedback with colleagues on their practice are needed to provide holistic palliative care. Thus, horizontal violence negatively impacted the nurses in this team.

'Doctors can instruct us to visit the patient directly. The doctor cannot come, but nurses have to come. Still... the gap is still looming heheh. The schedule consists of 1 doctor and 1 nurse. The doctor often asks, 'Nurse, please visit the patient first, then I will come. In fact, the patient's needs are met by a doctor rather than the nurses. Then, from a medical point of view, we cannot provide any therapy. The doctor can do direct therapy, no need to wait. The patients need a painkiller that can only be prescribed by the doctor. The payment for the nurse is less than the doctor. But the work should be done by the nurses. There are also those doctors who do not want to listen to the nurse in terms of communication. Pharmacists and nutritionists have no right to attend the consultation even though they also joining basic and advanced palliative training since beginning, which means that they can also answer the consultation. Well, maybe there is a separate policy for that. But the point is that nurses do more work than doctors, hehe.' (S3)

Element 6: Potential for innovation and risk-taking.

The nurses in this study reported their dissatisfaction with a limited infrastructure for supporting their job, such as a room, facilities for doing home care, and collaboration with district hospitals, NGOs and other innovations to reach more people. Nevertheless, the staff appreciated small things they had done, like charitable activities, when they visited patients at their own expense and arranged donations to help patients purchase medical equipment.

'We discussed with the YKI how best to reach the community. The plan is that not all of them can be sent to the hospitals, so we need to build a support system collaborating with the cancer foundation in West Java. For instance, in the Bandung area, cadres have gathered to capture or screen palliative care needs. The doctors or nurses then come to the patient's house through cadres. Hopefully, we will be able to do that.' (S4)

Element 7: The physical environment.

Care planning and practices could be done maximally with a supported physical environment. The nurses stated their concerns about having an appropriate room and medical equipment for patients to deliver care in a pleasant environment. Lacking adequate tools for handling the complexity of individuals, illness and evidence will damage the person-centred process.

'I wish we had a private room to talk with the patient because some of them don't want their family members to know their wishes. We want to have an outpatient clinic, with a room with complementary therapy, like music therapy, but we don't have funding yet.' (S4)

9.6.3 Framework 3. Person-centred care process

A person-centred process focuses on delivering care through a range of activities and engages with the person and his/her family from a position of knowing the personal autonomy of his/her values, beliefs and wishes about care (McCormack and McCance, 2017).

Element 1: Working with patients' beliefs and values.

Patients said that nurses should give emotional and spiritual support while family expected the nurse to show their sensitivity and provide most appropriate treatment. Furthermore, the staff said the quality of nurse enables them to explore patient needs and give reasonable care.

'The doctor visits the patient a few times and examines the physical response. The nurse has 24 hours with the patient. But depends on the nurse. Whether they examine the patient's needs or not depends upon the qualities of the nurse. Can they explore patient needs or not? If they examine the patient's needs, they can collaborate with other healthcare professionals to give a broader level of care. Cover each weakness.'(S8).

Element 2: Engagement.

One nurse said serving with your heart is a prerequisite for providing patients with the best service: knowing the person and his/her family, being attentive and available when present and demonstrating an appreciation for the loss of a future that may be felt. Being in the moment with the person is an opportunity for person-centredness no matter how brief the encounter (McCormack and McCance, 2017).

‘That is, serving with your heart is a prerequisite for providing the best service to the patients. Physical, psychosocial and spiritual. Patients tend to feel more peaceful if they have spiritual support.' (S2)

Element 3: Having a sympathetic presence.

Having this element means knowing the person and his/her family, being attentive and available when present, demonstrating an appreciation for the loss of a future that may be felt and understanding that one’s own actions and decisions are influenced by personal values (McCormack and McCance, 2017). The nurses said they believed that patients benefited from their presence because they provided holistic bio-psycho-socio-spiritual nursing interventions.

‘I believe psychiatric, psychologist, doctor who specialises in rehabilitation are diligent in visiting the patient. They must reduce patient distress and immobilisation/physical movement problems. We supplied patients with Quran to reduce their spiritual stress. We, nurses, visit them to do a nursing intervention. So, I believed they get a benefit for our team. Maybe 70%.’ (S3)

Element 4: Sharing decision-making.

The nurses emphasised their role in prioritising patient needs regarding their life care rather than the family or staff plan. For example, they said it is better to support spiritual needs than medical treatment in dying care. Nowadays, patients have autonomy and can decide on their healthcare process. This autonomy can be reached by adopting person-centred approach.

‘For spiritual care, access the patient, for Muslims ask whether they can perform sholat [ritual] prayer. Accompany them to pray. If they can perform the sholat ritual, teach them how to do it. Sometimes the patient doesn't understand how to do it with their conditions -the position limitation, but he really wants to worship. For non-Muslims, we refer to the nurse who is the same religion or give them a book guide. That's what we've been working on. Then we ask their family to get spiritual guidance within their religious group.’(S8).

Element 5: Providing holistic care.

The participants in this study emphasised that all interventions should ensure that patients die peacefully and remember almighty God. This holistic care has an insight into personal values and assumptions about palliative care, the views of service users and their family as whole human beings in all domains of needs, the views of colleagues on practice, and supportively engages in feedback with colleagues on their practice (McCormack and McCance, 2017).

'For the patient near death, there is a final assessment of their life. We sometimes ignore that this patient needs to be accompanied by their spiritual leader or priest. So, if I am there, I will prepare the Koran with a prayer guide and act as one of their family. Hopefully, this can be carried out to improve the patient's experience during the dying and death phase. We can say that the maximum possible medical treatment has been done. So, we can focus more on the patient's psychological needs by facilitating their spiritual needs. This decision is what families or patients cannot accept. They are still hoping the patient will get well soon. So, ask them to pray together with us. For Muslims, there must be the benefit of remembering the Almighty God until the last breath. But in a hospital, it is difficult if, at the exact times, the patient is being resuscitated. Nobody is concerned with the patient's spiritual needs. Dying peacefully and calmly with prayer and being able to remember the Almighty God is more important for the patient at this time.' (S3)

9.6.4 Framework 4. Person-centred care outcomes

A realistic approach to evaluating outcomes can be evaluating the satisfaction with care, involvement with care, nurses' wellbeing, the existence of therapeutic culture and enablement of person-centred cultures (McCormack and McCance, 2010a). Expected outcomes are the result of effective person-centred nursing. People should receive a standard of care that reflects their principles.

Element 1: Satisfaction with care.

Evaluations of nursing-specific outcomes that start by adopting a person-centred approach should show the stakeholders' satisfaction with care. Individuals within a team have a shared vision of palliative care and support each other to fulfil their vision. The participants believed patients were satisfied with care because nurses provided holistic and comprehensive care.

'With spiritual guidance, the patient is less nervous and will accept the medicine or treatment prescribed, they will be easier to treat. Medication is not the gate in palliative care, but it can be a good entry. It is difficult if the patient gets angry, or despairs and refuses the treatment.' (S8)

Element 2: Involvement in care.

The participants found that working together in a team enabled them to get involved with the team and with patients and families.

'The primary purpose of palliative care is to improve patients' quality of life and their families. This involves helping patients adapt to their illness and their families to accept their condition with minimal difficulties. The nurse prepares the patient psychologically to live with an extended illness for the rest of their life, or that the nurse will respond to the end-of-life care. We might not predict when the patient will die, but we can estimate how much longer the patient may have. They can explore the patient's psychosocial problems, although this is not always easy. In the last semester, there were cases of patients with terminal illnesses who committed suicide. An initial or mini-psychosocial assessment can help identify this tendency.' (S3)

Element 3: Nurses' wellbeing.

The nurses in this study expressed their dissatisfaction that the hospital system prevented them from giving holistic care. For example, they cannot follow up patients because of a lack of support for the home-care visit programme.

'There is no follow-up after we have visited the patient. We just answer the consultation request, visit the patient and perform the necessary intervention. There should be further follow-ups -when the patient goes home. We don't know if the patient has died at home. We can't follow the family mourning period's transportation. We are proposing that an ambulance be provided for palliative patients. Everywhere you need a ride now. Well, in Jakarta yesterday, I heard that they worked together with Grab (Uber) online. They use a Grab application with a cheaper tariff. The director ordered to unite several different teams such as home care, geriatrics, palliative care, wound care and pain team. They must be willing and able to visit the patient.' (S3)

Element 4: Therapeutic culture

Participants emphasised nurses' integrity in upgrading their knowledge and skills and thought that assessing patients comprehensively will create a therapeutic culture for patients. Nurses should avoid using a single method or need a more flexible method which could be doing routine task only.

'The integrity of the nurse, the nursing profession isn't just routine. There's a lot of work to do and other things we can learn. Is that possible? I don't know about the education process. I think there must be a role model at the hospital like that, right. One that shows that the nurse's job is not just a routine. I know some

nurses think they just do their routine. Yeah, they are stuck with the routine. Every patient is unique. They need a different approach to care. In my opinion, a role model can inspire others to learn. Maybe there should be refreshment, like a clinical lunch or access to the journals, to review the literature. With enough references, I assume the nurses will change their minds. We need to suggest informal events to raise awareness of palliative care and the need to improve nursing standards generally'. (S4)

9.7 Chapter summary

The overarching themes are the participants' views and expectations of the palliative care service and barriers to and challenges of providing a nurse-led intervention in a resource-poor setting. The context was care in a resource-poor setting. The first theme was views and expectations of nurse-led interventions in the future, with subthemes of extending the service to the community, the nurse as the closest one to the patient, the nurse as a manager, the nurse as an information bank and the nurse providing/administering painkillers. The second theme was barriers to and challenges of providing a nurse-led intervention in a resource-poor setting with two subthemes of experience in providing or receiving care, with sub-subthemes: teamwork and patient rights for staff participants; poor communication, barriers in palliative care, good and bad services for patient participants; discrimination for patients in the third class of health insurance and poor information for family caregiver participants. The second subtheme was palliative support needs, with sub-subthemes of financial difficulties, spiritual needs, physical needs, lack of painkillers and psychological needs. The third theme was person-centred nursing theory with four subthemes; prerequisites; the care environment; person centred care process; and person centred outcome.

Using person-centred nursing theory found that certain frameworks are already meeting the needs of patients, family caregivers and staff in terms of prerequisites and person-centred care processes. However, some aspects are still unmet in the care environment framework, such as shared decision making, power sharing and effective staff relationships. Additionally, unmet needs in person-centred outcomes are therapeutic culture and nurse wellbeing.

Chapter 10 Discussion of all Findings

10.1 Introduction

The overall purpose of this chapter is to integrate findings from all research stages to better understand what a nurse-led intervention must look like to be effectively implemented at Hasan Sadikin Hospital. The study answered all the research questions. Each finding contributes to increasing knowledge about what must be done to develop a feasible nurse-led intervention that addresses the current needs of patients and caregivers, the clinical requirements of the current palliative team and the expectations of the hospital from a management point of view. The nurse-led intervention deriving from this study supports the WHO conceptual model where the nurse is expected to have greater access to extend palliative care to the community. This will provide a low-cost intervention for both patient-family caregivers and the health system. Thus, assessing patient needs, outcomes and burden, training the family to care for their loved one at home, access the painkillers and facilitate the patient's needs across the palliative care team.

These findings show the needs and expectations of nurse-led intervention palliative care in West Java Indonesia. The results prove that both parties in palliative care could receive opportunities to be cared for somewhat with human touch and a comfortable environment so that the people could die in peace and dignity. These findings would benefit the patient, family caregivers, and staff, underpinned by person-centred nursing theory.

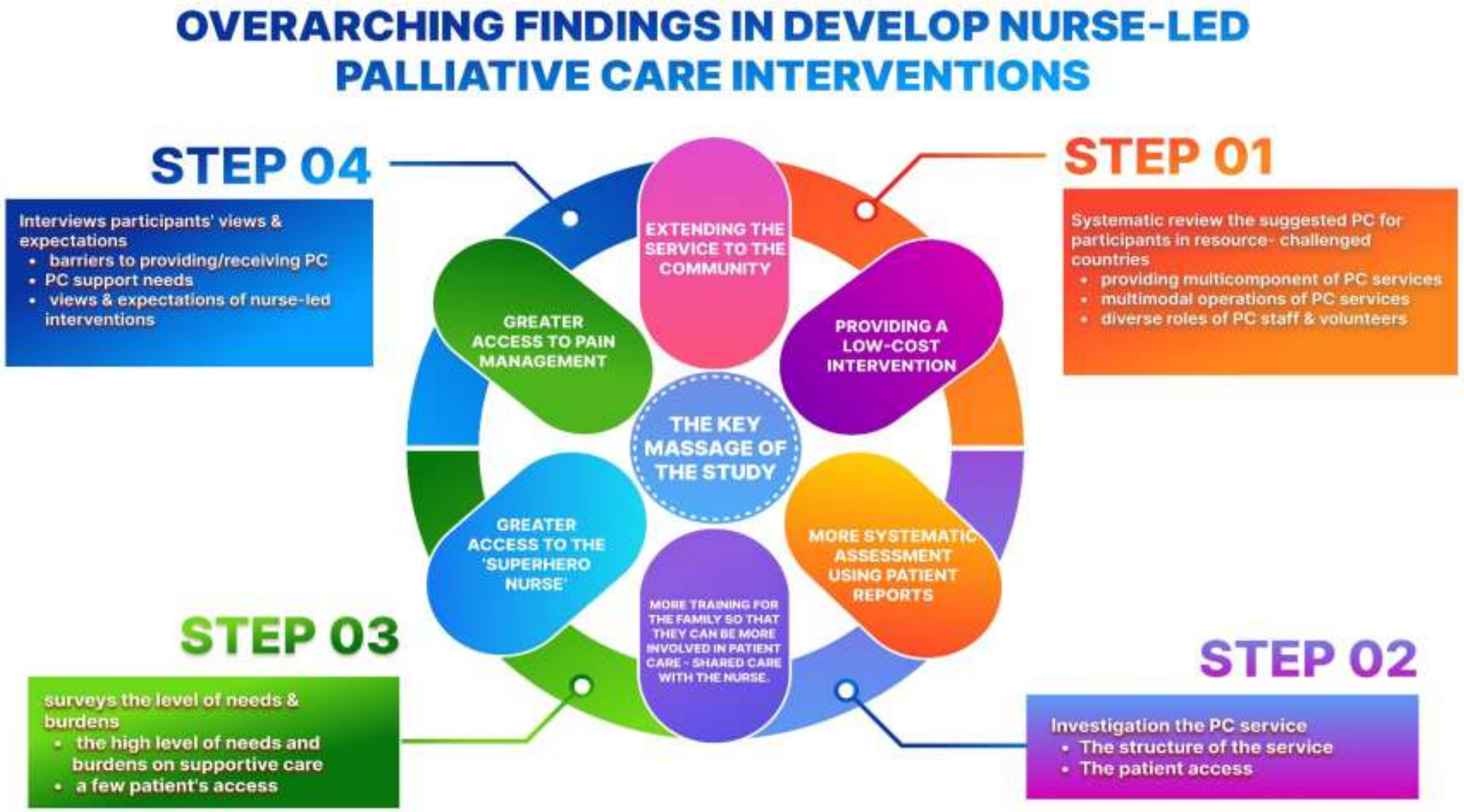
10.2 Theoretical contribution of the study

Mixing research methods has advantages regarding finding answers to complex questions. The quantitative study resulted in identifying participants' perceptions of need and burden, while the qualitative study explored their views and expectations in detail and depth. Collectively, these results help to develop action points that can translate into reasonable interventions and refinement of the service in the future. This study shows how the palliative care team in Hasan Sadikin Hospital Indonesia developed their palliative care services with their limited resources. This study added the information about; care for family members at home is common in Indonesia, little is known about their supportive needs, burdens, reported outcomes and what questionnaire to measure it. This is the first IPOS and SCNS Indonesian version tool that can measure their supportive needs. Meanwhile, patient & family caregivers needed all SCNS items except sexual domain. Thus, nurse-led interventions can provide care for family caregivers.

10.3 Synthesis of findings

There were similarities and complementary findings in the audit, survey results and interview analysis about the high burdens on patient and family caregivers as a result of cancer diagnosis, as well as the high need for supportive care. The variation in skill mix of palliative care providers in the health services allowed patients to suffer with severe signs and symptoms, especially in pain. There was also a limited amount of painkillers for patients with cancer. The expectation for the nurse to provide service for the patient and their family caregivers, and the barriers and opportunities of the team to provide fitting care for people with cancer. The interviews add further information to the findings in the survey responses, such as the time spent waiting for the treatment, the need for information about diagnosis, prognosis, laboratory tests, the supportive needs like how the healthcare workers treat the patient at the end of life. Overall, these studies' key findings can be summarised in six key findings below.

- Greater access to skilled and experienced nurses;
- Extending the service to the community;
- Providing a low cost intervention;
- Greater access to pain management;
- More systematic assessment using patient-reported outcomes;
- More training for the family so that they can be more involved in patient care.



OVERARCHING FINDINGS IN DEVELOP NURSE-LED PALLIATIVE CARE INTERVENTIONS

STEP 01

Systematic review the suggested PC for participants in resource- challenged countries
- providing multicomponent of PC services
- multimodal operations of PC services
- diverse roles of PC staff & volunteers

STEP 02

Investigation the PC service
- The structure of the service
- The patient access

STEP 03

surveys the level of needs & burdens
- the high level of needs and burdens on supportive care
- a few patient's access

STEP 04

Interviews participants' views & expectations
- barriers to providing/receiving PC
- PC support needs
- views & expectations of nurse-led interventions

THE KEY MASSAGE OF THE STUDY

EXTENDING THE SERVICE TO THE COMMUNITY

PROVIDING A LOW-COST INTERVENTION

MORE SYSTEMATIC ASSESSMENT USING PATIENT REPORTS

MORE TRAINING FOR THE FAMILY SO THAT THEY CAN BE MORE INVOLVED IN PATIENT CARE - SHARED CARE WITH THE NURSE.

GREATER ACCESS TO THE 'SUPERHERO NURSE'

GREATER ACCESS TO PAIN MANAGEMENT

Figure 10-1 Overarching findings in develop nurse-led palliative care interventions for adults with cancer and their family caregiver

10.3.1 Greater access to superhero nurses

Nurses are always central to palliative care because they are with patients 24 hours a day. The hospital clinic served thousands of people a day, all during office hours. These great numbers made some physicians treat patients hurriedly; they did not have time to explain test results. Vice versa, the patient could sense that the physicians did not have time for them. On the other hand, patients considered physicians to be the clever ones, who knew everything about them. This made them believe the physicians would treat them well, even without explanations. However, patients expected that nurses would explain anything related to their health issues and tell them how to continue their lives peacefully (Abdullah et al., 2021).

This great expectation is an excessive demand, leading to too much burden for nurses in a resource-challenged context. On the other hand, this high trust challenges the nurse to deliver better interventions. To support this unique position, nurses must build their capabilities to initiate a conversation with patients (Phillips, Johnston and McIlfatrick, 2020). One study suggested that healthcare providers in Indonesia should strengthen policy research, enhance the healthcare system and expand routine non-communicable disease surveillance to achieve good health for all (Schröders et al., 2017). This suggestion would help nurses provide a better service (Singh and Harding, 2015c). A comparison study in the Netherlands and Australia demonstrated that information needs did not exist in the Netherlands (Prins et al., 2011). This finding might be related to the high level of literacy in the Netherlands. The patients knew about their diagnosis, treatments and results, so there was no need for the information domain.

Participants believed that all matters in their lives were related to God's will and that only God could help them. This belief is represented by the participant's words that said ‘*God is the healing source and humans are only the tools’***.** In line with prior studies, people perceived their health as a spiritual condition that could be lifted by spiritual belief (Sokang, Westmaas and Kok, 2019). Many situations demonstrated the importance of religion for carrying burdens (Rochmawati, Wiechula and Cameron, 2018a). Prior studies found that religiosity was associated with quality of life, especially in Asian regions (Gayatri et al., 2021). The sense of spiritual care rooted in Southeast Asian people can be seen in their pain management, grief, self-value, faith and prayer (Subramaniam et al., 2018). This compassionate care focuses on spirituality to improve peace and quality of life and reduce depression. Thus, palliative needs in the spiritual domain are met by assistance with religious rituals and supporting the patient to accept the illness and dying process as God's will.

Nevertheless, one study reported the author’s frustration while seeing how medical care in Indonesia depends on spiritual process rather than comforting patients with an analgesic to reduce pain at the end of life (Wessner, 2018). Wessner reported that the absence of painkillers and lack of palliative care skills means staff cannot provide a good-quality death. Thus, she expected that medical care in Indonesia would provide end-of-life comfort. Moreover, staff should help patients maintain their dignity while delivering services (Brown, Johnston and Ostlund, 2011, Burke et al., 2018).

All participants need psychological support - to help patients die in peace and to help families in the mourning period. The patient has a right to have their needs met, to live in the here and now, to enjoy the moment and receive effective palliative care (Dönmez and Johnston, 2020). If they understood this concept, the staff could help patients live in the moment until they die in peace (Dönmez, Alici and Borman, 2021). Nurses could identify this stress by initially discussing how patients wanted to be treated at the end of life, including issues such as support while dying, autonomy, medication, respecting personhood and treating someone like a human being (Johnston et al., 2021a).

Patients and families expected nurses to support and cheer up patients. The patients identified the nurse as the closest person to them who gathered all data needed and wrote it in their medical record so that other healthcare staff could use it to prepare their intervention. This finding supported previous studies in which patient-reported outcomes were a significant element of reasonable care (Johnston et al., 2015a). Nowadays, patients are also confident about their desires and preferences regarding treatment provided by healthcare providers (Drummond, Johnston and Quinn, 2021). Nurses should realise patients’ have the right to choose what they want (McKinnell, 2008), should be open regarding patient freedom, dependency and meaning of life and have more desire to involve patients in decision-making (Udo et al., 2014). Patient and family participants expected nurses to manage everything for the patients. Nurses could help patients control their symptoms and prepare for the end of their life (Johnston et al., 2009). One study recommended that academics and policymakers be involved in narrowing the gap between uncoordinated services, health and social care (Finucane et al., 2021).

Participants assumed nurses should provide all the information they needed. This finding was similar to that of a prior study, where healthcare workers were the trusted information source (Farnood, Johnston and Mair, 2020). The study above mentioned that nowadays, people can easily find information online, and this improves patient-healthcare workers' relationships and helps discussions about everything with patients. One study reported that an intervention via the internet is feasible to reduce the hesitance among females with a sexually transmitted disease regarding an in-person consultation (Villegas et al., 2014). This might also be helpful for adults with cancer in their reproductive organs. Nonetheless, nurses cannot provide this information alone. They need to rely on their own expertise but also that of other multidisciplinary team members.

10.3.2 Extending the service to the community

All patient participants expected the government to provide cancer treatment and palliative care in district hospitals. Essential points for nurse-led interventions were accessible palliative care in the community, the value of nurses as managers and their ability to maintain friendships with participants. The palliative team realised this need by initiating palliative seminars and short courses for community nurses in primary healthcare. This would enable the hospital to refer patients back to the community. It was challenging for community nurses to increase their knowledge and skills in palliative care, research, information technology and communication to support patient care services (Johnston et al., 2012a). Different settings require nursing intervention skills, including humanity, relationship, dignity and advocating skills (McParland and Johnston, 2019).

In addition, staff expected they could serve patients comprehensively, provide earlier treatments and spread services to the community. This is partly because of the absence of home care and families lacking the skills to care for patients at home. Most patients are expected to be cared for in a hospital. However, choice and autonomy are the patient's rights; they might feel their rights have been abandoned if they are taken to hospital when they wanted to be cared for at home and vice versa (Pringle, Johnston and Buchanan, 2015).

From the patients' viewpoint, the barrier to receiving palliative care was more about physical support. Limited hospital beds forced patients to be cared for at home; family caregivers have minimum skills, meaning patients suffer from physical symptoms. Palliative care support only existed in the hospital's palliative care unit. These findings contrast that of a prior study. People in the United Kingdom, Ireland and the United States of America nowadays tend to be cared for and prefer to die at home because there is palliative care in the community or home-visit services programmes (Higginson et al., 2017).

Most of the participants in this study shared their feelings with family or friends as much as they wanted. This culture benefits patients. However, some families still believe in myths, traditional healing and stigma (Gamboa et al., 2020). Unhealthy people in Indonesia tend to receive information from their family or friends (Smith et al., 2021). Adults with cancer need supportive care to improve their quality of life, including the right information (Kotronoulas et al., 2017a, Kotronoulas et al., 2017b, Kotronoulas et al., 2017d). Accurate information contributes to better survival (Alexander and Murthy, 2020). Since families have a vital role in patient treatment and emotional support, they should also receive correct information. Healthcare professionals could offer them self-management programmes (Cheng and Kotronoulas, 2020).

10.3.3 Providing a low cost intervention

Most patient participants reported unmet financial supportive care needs, and family caregivers expected home care with a nurse's supervision and financial support. The greatest unmet financial need is a logical concern, because 83.7% of

Indonesia's health insurance users struggle financially (BPJS, 2019b). This unmet need mainly concerns balancing living costs and the budget allocated for cancer-related costs. Families also struggle to fund travel costs for a person with cancer. Travelling costs hindered patients in remote areas from getting painkillers. This finding supports an economists' quality ranking of death statistics, which stated that Indonesian cancer specialists are concentrated in only two cities on Java Island, leaving the rest of the countryside without access to a cancer specialist or palliative care specialist (EIU, 2015). Since the government does not pay extra costs for treatment, a specific training programme for family caregivers is recommended to enable families to care for family members at home (Rochmawati, 2016b). The local community could also make an economic contribution (Philip et al., 2019).

Caregivers felt they did not have enough money to care for their relatives. Most health insurance users were poor and unemployed, so the government funded their insurance prepayments (BPJS, 2019b). This study's participants were of working age and split their time between working and caring for family. Being jobless at a working age gave family caregivers an extra burden. This result aligns with prior studies in which the most challenging role for family caregivers was dealing with financial and emotional problems (Chiang et al., 2012).

Indonesia has a unique culture. If the patient is hospitalised, the family is also present 24 hours a day, helping them do daily activities. In public hospitals, the family also helps staff to take and collect samples/results to the laboratory, take prescriptions to the pharmacy, collect medicine/equipment, help the patient with performing personal hygiene and even look for or pick up blood packages from other cities. These additional tasks put burdens on them. Several hospitals facilitate this culture by providing extra beds beside patients in VIP-class rooms. Staying at the hospital with the patient was a burden for the family. They struggled to balance their daily life with their role as caregivers. Some districts' governments helped patients by providing free shelters (Dinillah, 2019). However, this capacity was relatively low compared to the number of people who needed care.

10.3.4 Greater access to pain management

Most patients could not access painkillers and expected nurses to provide them. All patients and families reported difficulty in getting painkillers and close to 72% of participants reported high pain levels. This finding was similar to that of an earlier study concluding that pain remained a common symptom among patients with cancer and was also a typical symptom in countries with limited access to painkillers (Silvoniemi et al., 2012). Even though the World Health Organisation (WHO) has already recommended reducing the number of steps needed to access painkillers, patients in Indonesia still encounter multiple layers of procedures before getting morphine (Setiabudy, Irawan and Sudoyo, 2015).

Regarding policy, only physicians in referral hospitals can prescribe morphine. It is dispensed only in pharmacies in big cities; patients should be present when it is prescribed and only one month's supply should be prescribed. Therefore, rural area patients face many barriers to getting painkillers (Knaul et al., 2017). Extending palliative care to around 17,000 islands in Indonesia could be a better way to disseminate painkillers to patients (Limardi et al., 2019).

Moreover, the annual consumption of morphine in Indonesia was only 0.054 mg/capita in 2014, as a result, people died in pain (Setiabudy, Irawan and Sudoyo, 2015). At the same time, half of the global population received only 1% of available morphine; this caused them to suffer from severe pain and health-related complaints. There was an enormous gap between high-income countries and low- and middle-income countries regarding painkiller availability; Vietnam consumed 9% of painkillers per capita, India 4% and China 16% (Knaul et al., 2017). In comparison, the United States of America, which has less than 5% of the world's population, consumed roughly 30% of the world's opioids in 2009, and nearly 40% were consumed in the European Union (Duff et al., 2021).

Although WHO has recommended that all countries decrease the barrier in getting analgesic, many countries still find it difficult to access morphine (WHO, 2020a). It has previously been found that people in small cities in Nigeria needed travel costs to find morphine (Osman et al., 2018). In Morocco, prescriptions could only be approved after the patients apply the exclusive applications (Consortium, 2021). Physicians in the Philippines had to pay for prescription forms (Jan et al., 2012). Physicians in Turkey had difficulties getting painkiller forms (Ozturk et al., 2021). In China, only referral hospitals could dispense opioids (Li et al., 2018). Most participants who need palliative care suffer from physical symptoms in early advanced cancer, then mobility and autonomy in the later stages (Coym et al., 2020). The pain reduced the quality of life, including sleep quality; females with cancer reported sleep problems relating to pain (Kotronoulas, Wengström and Kearney, 2012). Pain was the main reason for patients' presence in hospitals (Ozturk et al., 2021). Nurses' ability to assess this symptom enabled them to choose reasonable interventions (Rustøen et al., 2013). This can be seen in patient-reported outcomes', i.e. patients reported that the nurses had this ability (Lind et al., 2018). The nurse could plan complementary therapy to reduce the pain level and adverse side-effects of morphine (Rustøen et al., 2013).

10.3.5 More systematic assessment using patient-reported outcomes

Patients and family caregivers showed the same pattern of unmet supportive care needs in all domains, except in sexual needs. The common need regarding supportive care was discussing treatment with the staff. This finding was similar to that of many studies using the same tools in high-income countries, where the most common needs related to information and physical symptoms (Jie et al., 2020). This result might be related to low levels of education, self-awareness and literacy, limited cancer treatment and scarce painkillers. Data from the observations in this study showed that provincial referral hospitals received around 74,000 adults with cancer yearly, which meant the hospitals were unable to treat them promptly. It was six months on average before patients received the first cancer treatment. They met several healthcare providers during this time but could not find someone to talk to about their concerns. In addition, the staff did not explain the reasons for tests and the meaning of results. A similar study recommended that physicians give patients time to ask about their condition (Garvey et al., 2012).

Family members must balance their physical and psychological exhaustion to provide better care for their relatives better. The staff can assess patients' needs by using several supportive care tools to help them meet patient's needs continuously (Drummond, Johnston and Quinn, 2019a). The outcomes for family caregivers revealed that they were able to help patients express their needs and burdens in a way that could be understood by the clinicians (Drummond, Johnston and Quinn, 2019a).

The participants reported their anxiety about illness or treatment. Depression and anxiety in adults with cancer were commonly related to pain, treatment, bodily function and structural change, joblessness and feeling as though they had lost their authority (Hawkey et al., 2021). Hence, healthcare providers should be aware of these symptoms (Turaga et al., 2011). One study found that psychological support possibly increased a patient's constructive strategies (Janiszewska et al., 2013). Another study revealed that patients who had frequent sessions would receive enough support (Scheffold et al., 2018). Faith in God was the main component of patients' meaning of life that helped them cope with anxiety and death (Testoni et al., 2018).

Most patients reported feeling strained around relatives (53.6%). Understandably, people with pain and anxiety rarely feel at peace because they struggle with symptoms and emotional challenges. Adults with cancer are more likely to experience practical spiritual, physical and emotional problems (Nguyen, Do and Pham, 2021). A prior study stated that spiritual support and talking to someone could lift their anxiety (Ross and Austin, 2015). Regarding gender, females were more religious and participated more in religious rituals than males (Munoz et al., 2015). It was well known that spiritual support is an enormous support for people and helps them to feel peace (Büssing et al., 2013).

10.3.6 More training for the family so that they can be more involved in patient care that is shared with the nurse

Family caregivers' burdens were physical, psychological and financial. The feeling of guilt showed family's bonds; they felt they could provide better care for their ill relatives. This finding contrasted with a prior study where the patient's greatest fear was that cancer would recur (Kotronoulas et al., 2017d). Indonesia has a culture in which members should care for their relatives, especially their parents, including the nuclear and extended family (Effendy et al., 2015c). Parents will be taken care of by their descendants, who are obliged to provide a budget to care for the family, because the Indonesian government does not have a pension system. Family members may feel guilty when they fail to fulfil this role. Thus, nurses should teach family caregivers how to care for patients at home to reduce the length of the stay in hospital. In combination with telehealth and discharge planning, nurse-led transitional care could help family caregivers better organise their efforts and deal with caregiving demands and stress (Chiang et al., 2012).

Most participants had a medium to high burden. This result was similar to that for patients with breast cancer in China, where they experienced a moderate psychological burden that positively changed after they were diagnosed (Liu et al., 2018). A previous study in one hospital in Indonesia found that 82.8% of patients with cancer of the cervix received spiritual support from their families, which increased their spiritual wellbeing (Madadeta and Widyaningsih, 2016). The burden was higher on daughters and sons; however, the grief more commonly in spouses and daughters (Higginson et al., 2020). Family caregivers' burdens can be reduced by increasing their resilience. Resilience was found in the family's ability to adapt to sharp changes. Resilient coping lowers the stress and burden risks and promotes caregiver's ability to adapt (Palacio et al., 2019).

The family caregiver is a patient's emotional support, helping them to find meaning in their life and to cope with their treatment and diagnosis (Li et al., 2019). Three-quarters of respondents were at high risk of depression. Caregivers' burdens were higher in unemployed and lower-education groups and higher in the first six months after diagnosis (Rottmann et al., 2015). The patients needed caregivers' help to maintain their resilience and welfare (Kim, 2017) and adapt positively to the changes. Healthcare providers potentially encourage resilience in cancer survivorship (Gibbons et al., 2019). Thus, healthcare providers should develop interventions to strengthen family caregivers (Li et al., 2018).

The patient and family participants experienced a lack of information during their treatment in the hospital. The staff need to narrow the gap in knowledge of communication skills, mainly regarding terminal conditions (Jackson, McPeake and

Johnston, 2019). Receiving information was the primary support for a family in this situation (Papadopoulou, Johnston and Themessl-Huber, 2013). If patients learned about their diagnosis and treatments, nurses could facilitate their understanding of their illness journey. Dying in peace and dignity is a patient's right (Andrew, Johnston and Papadopoulou, 2013). Dignity is an essential element of the quality of care (Johnston et al., 2017). Hence, community nurses need more training to address dignity concerns (McIlfatrick et al., 2017).

Families want to provide care at home with a nurse's supervision. Sharing a home with patients and spending time together benefits family caregivers; they want to have some good memories of their loved one at the end of their life. During the pandemic, people with coronavirus died quickly without any family attendance, triggering more stress and grief. A photo/video or small things like their loved one’s hair or nails helped families to have something memorable. Memory-making was an intervention made to support bereavement (Bridget and Sandra, 2020). This intervention is expected in relation to babies, but it is helpful for all ages.

10.3.7 Person-centred nursing Theory

A patient-centred nursing framework comprises four constructs, whereas, a person-centred process focuses on delivering care through various activities (McCormack and McCance, 2010b) (Appendix 5). The researcher introduces the person-centred nursing framework in this study to see whether the care services are consistent with the international healthcare policy direction, which sets out a comprehensive framework for people-centred healthcare services. This study showed that the person-centred nursing theory could help nurses to embrace palliative care services.

10.2.7.1 Prerequisites

The Indonesia nursing association (INNA) embraces this challenge through healthcare policy (PPNI, 2005) and strategic initiatives focusing on reorganising people-centredness (McCormack and McCance, 2017). Thus, nurses are already professionally competent in providing care and making decisions (McCormack and McCance, 2006, McCormack and McCance, 2010a). The prerequisites focus on the context in which care is delivered (McCormack and McCance, 2006). The attribute of being professionally competent is reflected in this study in data which confirms that all nurses had a minimum education level of a bachelor's of nursing, work experience in a palliative team in a hospital for a minimum of five years and had upskill in palliative training. Patients, family caregivers and staff also noticed nurses' competence, claiming the nurse was the closest person to the patient and served them well. According to McCormack and McCance (2017), nurses should develop interpersonal skills, an awareness of their own emotion and respond sensitively and effectively to service users, families and colleagues (McCormack and McCance, 2017).

The nurses in the study had all passed the competence test run by the Indonesia Nursing Association (PPNI, 2005). These interpersonal skills are improved and continually developed through training and skills education. Patient participants said that nurses showed their competence through patient care. A psychiatrist in the team also stated that nurses had excellent support in the palliative team. This finding supports a person-centred focus on treating people as individuals; respecting their rights, building mutual trust and understanding; and developing therapeutic relationships (McCormack and McCance, 2017).

Even when patients did not report their symptoms, nurses said it was their job to assess patients holistically. This showed that they were dedicated to providing the best care for patients. A commitment to the job can be seen through skill in emotionally engaging with a person and their family and providing space for them to express complex and sad feelings. The nurses confirmed their dedication to patients by emphasising their right to receive holistic care. A person-centred process focuses on delivering care, including working with patients' beliefs and values (McCormack and McCance, 2016). Nurses can clarify their own beliefs by acknowledging the significance of the emotional work involved in palliative care and offering to support other team members when they feel emotionally challenged by their work. Their commitment can be demonstrated by prioritising the wellbeing and quality of life outcomes of service users and families in all the domains of palliative care assessment to enable wellbeing and flourishing (McCormack and McCance, 2017).

The nurses in this study had already 'developed awareness of emotion and can respond sensitively and effectively with service users, families and colleagues' (McCormack and McCance, 2017). Patients stated how they felt when nurses engaged with them. Patients understand that nurses are always there for them; they only need to talk to nurses and they will help them sort out problems. The nurses themselves realised that they should build a close relationship with patients and spend extra time with them. This shows that they care about being in the moment with the person and see it as an opportunity for person-centredness, no matter how brief the encounter is (McCormack and McCance, 2017).

10.2.7.2 The care environment

The care environment context focuses on one’s own and colleagues' wellbeing. It contributes significantly to creating a working environment where everyone's experience, skills and knowledge are used to improve the team's potency (McCormack and McCance, 2017). The nurses in this study were concerned about holistic care for the patients. Their desire to find and resolve patients’ problems authentically engages with each person and his/her family to maximise autonomy and wishes about the place and level of care (McCormack et al., 2010). Individuals in the team have a shared vision for palliative care and support each other to fulfil their vision (McCormack and McCance, 2017). The patients can decide on their healthcare process but care decisions are shared within the team. There is evident respect for each member's knowledge, skills and experience (McCormack and McCance, 2017).

10.2.7.3 The value of power-sharing

When the whole team agrees on the palliative care philosophy, principles and the existence of a healthful culture, the nurses reported that physicians still had more power than other professionals, which made them dependent on the physicians’ orders. The nurses’ experiences were that some physicians often delegated their tasks to the nurses. Also, the physicians received a fee, while other professionals did not. Thus, this horizontal violence negatively impacted the nurses on this team. Honest communication, highly developed interpersonal skills, considering colleagues’ views on practice and supportively engaging in feedback with colleagues on their practice leads to holistic palliative care. Hence, power-sharing still needs to be smoother in the team. Care-planning processes represent the agreed team vision for palliative care and includes all assessment domains.

The nurses in this study reported dissatisfaction with the limited infrastructure for supporting their job, like having a room and facilities for home care, and collaboration with district hospitals, NGOs and other innovations to reach more people. The lack of adequate tools for handling the complexity of individuals, illness and evidence decreases a person-centred process. Nevertheless, the staff appreciated every small thing they had done, like charitable activities, when they visited patients at their own expense and organised donations to help patients purchase medical equipment. A person-centred approach should contain creative environments where individuals can flourish and should generate energy from innovation and creativity (McCormack and McCance, 2017). The nurses stated their concerns about having an appropriate room and medical equipment for patients so that they could deliver care in a pleasant environment. The physical environment authentically engages with a person and his/her family to maximise autonomy and wishes about the place and level of care (McCormack et al., 2010).

10.2.7.4 Person-centred care process

The person-centred process focuses on delivering care through various activities; it engages the person and his/her family from a position of knowing the personal autonomy of his/her values, beliefs and wishes about care (McCormack and McCance, 2017). The patient shared their thought that nurses should provide emotional and spiritual support, while the family expected staff to show sensitivity and appropriate treatment. Furthermore, the staff said the quality of nurses enables them to explore patient needs and give care. Nurses should engage authentically with the person and his/her family by encouraging them to make decisions based on their values, beliefs and wishes and their clear values and beliefs (McCormack et al., 2017).

One nurse said serving with the heart is a prerequisite for providing the best service to patients. Knowing the person and his/her family and being attentive and available when present demonstrates an appreciation that there is a feeling that the future has been lost. Engaging with others in a way that respects and values them as whole persons enables nurses and colleagues to transform practice and develop positive energy for change and human flourishing (McCormack and McCance, 2017). The nurses believed patients benefited from nurses' presence when providing a holistic nursing intervention. A compassionate presence means knowing the person and his/her family and being attentive and available when present, demonstrating an appreciation of feeling of loss of their future and understanding that their actions and decisions are influenced by personal values (McCormack and McCance, 2017). Care-planning processes represent the agreed team vision for palliative care in all domains, including decision-making (McCormack and McCance, 2017).

The nurses emphasised their role in prioritising patient needs. For example, they said it was better to support spiritual needs than provide medical treatment when caring for those who were dying. Care decisions are shared within the team and respected. People who are important to the patient are involved in decisions about care that fit with the patient's wishes (McCormack et al., 2010). Nurses in Indonesia are involved in decision-making in three ways: paternalistic, shared and informed decision-making (Fauzan et al., 2019). The participants in this study emphasised that all interventions should ensure the patient dies peacefully and remembers almighty God. This holistic care has an insight into personal values and assumptions about palliative care, views service users and their families as whole human beings in all the need domains, considers colleagues' views on practice and supportively engages in feedback with colleagues on their practice (McCormack and McCance, 2017).

10.2.7.5 Expected outcomes

People should receive a standard of care that reflects their principles (Kennedy and Connoly, 2018). Outcomes are the result of practical person-centred nursing (McCormack, 2020). All participants expected the staff to help them to fulfil their basic needs during the treatments. A realistic approach to evaluating outcomes can be ascertained by considering the level of satisfaction with care: the level of involvement with care, nurses' wellbeing, whether there was a therapeutic culture and whether a person-centred culture was enabled (McCormack and McCance, 2010a). The nurse participants believed the patients were satisfied with holistic and comprehensive care. They found that working together enabled them to get involved with the team and the patient/family. A person-centred nursing practice is about developing, coordinating and providing healthcare services that respect the uniqueness of individuals by focusing on their belief, value, desire and wishes, independent of age, gender, social status, economic status, faith, ethnicity, cultural background and a context that includes collaborative and inclusive practices (McCormack et al., 2017). The challenges to practice can be overcome by looking to disciplines that are relevant for best meeting patients' complex needs? having a correct understanding of biology, psychosocial judgement and clinical and personal experience (McCormack and McCance, 2017).

Patients view nurses as being with them for their whole lives, while staff generally view patients as angry or anxious (McCormack, 2004). The nurses in this study expressed dissatisfaction because the hospital system prevented them from giving holistic care. For example, they could not follow up patients because they cannot do home-care visits. Nursing outcomes arise from the changes made in the care environment in residential settings for older people (McCormack et al., 2010). Participants emphasised that they thought nurses had integrity because they upgraded their knowledge and skills to assess patients comprehensively. Nurses should avoid reducing a single method to routine work only. Effective teamwork, workload management, time management and good staff relationships are essential to creating a democratic culture in people-centred relationships (McCormack et al., 2010).

These findings are in line with the person-centred nursing theory. The results show that people with cancer and their family caregivers community in Indonesia can accommodate the healthcare issues as long as 'the superhero nurses' are present next to the patient and family and treat them warmly as members of the family. Those high beliefs and expectations are the model for developing nurse-led interventions in Indonesia.

10.3.8 Unanswered questions

The observations made by the researcher alone are not sufficient enough to address the complexities of the palliative care team required. However, a comprehensive mixed-methods study effectively tackled all research inquiries, providing valuable insights. The findings derived from this study can be utilised as actionable recommendations to fortify the proposed nurse-led intervention for the palliative care team, especially in resource-constrained settings.

10.4 Conceptual model development framework

The study's findings enabled the researcher to create a conceptual framework rooted in these results, which can be utilised by others. The overarching findings indicated that the development of nurse-led interventions in West Java, Indonesia could be achieved by strengthening the role of the patients, family caregivers, volunteers, and stakeholders by addressing their needs and burdens. Compared to the conceptual model of palliative care development WHO 2021 below, the development of palliative care in West Java still widely differs (WHO, 2021). The WHO's latest conceptual model of palliative care development consists of a house component for people suffering from deteriorating signs and symptoms of health problems. The component’s indicators monitor palliative development from the initial stages and development across countries (Nair, Paul and Raveendran, 2023). The WHO inquired about components that should be included in national care plans (Sánchez-Cárdenas et al., 2022). However, the financial resources made by only a few countries included the components in their national plans, including Indonesia. The palliative care development in West Java is still far from this model with challenges in several components.

Figure 10-2 Conceptual model of palliative care development WHO 2021 (WHO, 2021)

The development of nursing-led intervention palliative care in Indonesia is slow with several components already being started. The development looks like building a house with a strong basement, strong pillars to reduce their symptoms and burdens, enough comfort room for the sick people and a strong roof to protect the people. However, the Indonesian traditional house presents the development process with a different shape but the same aim. Empowering people and communities is a big support because of the communal culture among Asians, specifically West Java people, where the people belong to the community. The responsibility of the neighbourhood to care for others still exists nowadays. The insufficiency of policy and research in palliative care looks like the stairs of this house; small and without handrails that make the house look vulnerable. The lack of essential medicines, and education and training in palliative care is presented by the pillars that are too short compared to the high roof. The high space between the pillars and roof deputises the provision that still needs a long time to have those components. In the WHO framework, those pillars should be the strong pillars to support this house. The Indonesian big house, which could traditionally foster hundreds of people, deputises the existing shelters around the hospital. The woman in the open window looking outside reflects the sick people's cries for help. Meanwhile, the man outside looking at the house reflects the community that is eager to help.

10.4.1 Provision of palliative care

The palliative care referral hospital in West Java has been active since 2005. However, at the time, the healthcare institutions did not yet have curricula in palliative care. As a result, not all the staff were familiar with palliative care. They then invited the healthcare professionals who attended palliative care courses abroad to teach them anything about palliative care as part of the provision to run the palliative services. Due to the lack of manpower, facilities and regulations, the palliative care team opened the service in 2016. From this data, it can be concluded that the progress of palliative care is slow. Nonetheless, the team is continuing to work in order to increase their services with education and training, opening the services for inpatient and outpatient clinics, with their limited resources. There are many NGOs who provide shelters for people with chronic illnesses. These shelters can be a new model for services developing palliative care such as in India, where the society successfully established community based palliative care services (Murali et al., 2020). The previous study recommended that home-based care is the most reasonable palliative model in challenging resource countries with prioritising the existence of education, essential medicines, policies, and social and political support (Wallner et al., 2024).

10.4.2 People with palliative need in West Java

Around 61,000 people with cancer need palliative care in West Java every year. However, less than 100 of them receive palliative care services due to the structure of service, regulations and non-existing early palliative care services. Together with patients with other chronic illnesses, this data could be five to ten times more. The participants in this study showed that all of them needed supportive care and reported outcomes more in pain. This vulnerable group needs the government to prioritise their services by providing services to the community to reduce their burdens (Murali et al., 2020).

10.4.3 Use of essential medication

Even though the WHO already asked the government to ease the painkiller regulations, the participants reported pain as the most common outcome and many layers for them to receive the painkillers. Patients cannot buy it in the district because the dispensing is mostly in the big cities while the patient should present in the referral hospital before the physician prescribing the painkillers. These problems still happen even when the patient is inpatient ward because the pharmacy often runs out of morphine. Therefore, the patient suffers from severe pain. The annual consumption of morphine in Indonesia is 0.054 mg/per capita (Setiabudy, Irawan and Sudoyo, 2015).

10.4.4 Education and training

The palliative care team in the hospital supports the members of the team to join the palliative care courses at national and global levels. However, the team reported that the other staff outside the palliative team tend to send the patient to the team when the patient is already at the very end of life care. Thus, the team expected the hospital would also train all the health workers about palliative care so that they could receive earlier services. No one university in Indonesia has formal education in palliative care at the bachelor, master's and doctoral levels. The health workers who graduated with palliative subjects mostly studied in Europe and Australia. The palliative care curriculum at bachelor level in Indonesian nursing academia was started in 2016 (Agustina, 2021), so that the nurses who could deliver palliative care are the ones who graduated after 2021. In comparison, India has had a palliative medicine doctoral programme since January 2011 in Tata Memorial Hospital, Mumbai (Murali et al., 2020).

10.4.5 Research

To our knowledge, this is the first study about the palliative care team development in West Java. Moreover, we could not find enough data about palliative care in Indonesia, we found limited publications about it. In addition, there is no nursing journal with palliative care. Also, there are no national seminars or congress on palliative care yet. If there are palliative care topics, most are presented under the chronic diseases specific umbrella such as seminars in oncology. Similarly, India also reported limited subjects of palliative care, however, India already has the Indian Journal of Palliative Care (Murali et al., 2020). Compared to data in Scotland, there were 1919 shreds of evidence in palliative care (Finucane et al., 2018). Scotland had health care support workers and untrained nurses who could care for the patient at home and do regular visits. They also could treat patients under the community nurse's supervision (Herber and Johnston, 2013). Hence, the data for this study recommended further research to find the gap between the needs and the services, and how research can be used to change policy.

10.4.6 Health policy

The government has not integrated palliative care into national health insurance yet. There is no collaboration between the referral hospital and the district hospital to supervise the patient at home. Also, the national health policy did not have national guidelines for palliative care. Data from this study is expected to be presented to the stakeholders so it could help to change the regulations. This study result is expected to be submitted to the government to propose the national strategies for palliative care. India successfully collaborated with expert groups so that they could influence the government to make integration of services (Murali et al., 2020).

10.4.7 Empower people and community

There are no NGOs or dedicated groups for palliative care yet in Indonesia. Also do not have respite care, hospice care and home care. However, Indonesia has a group of cancer societies, Diabetic societies, autoimmune, and other chronic illness societies. The palliative team in the hospital could start collaborations with shelters to empower the community on how to care for the patient. There is a cadre, ordinary people who are chosen by the Ministry of Health to be the supervisors to visit people with health-related problems and report to the nurse in the community health care provider. These cadres can be trained to deliver basic care for patients at home. The team stated they want to empower the cadres along with the family, the nurse in the community and the nursing student so that in the future, more people could deliver the services. The role of palliative care is a significant key in this study. Most care was delivered by the unpaid family caregivers. The family caregivers’ journey, challenges, motivations and suffering can be a model for understanding the communication between patients, families and clinicians (Furlong et al., 2019).

Chapter 11 Conclusions and Recommendations

11.1 Merits and limitations of the study

11.1.1 Systematic review

Using a mixed-methods systematic review and the SWiMS technique regarding the risk of bias resulted in using high-quality relevant articles that provide up-to-date information. The researcher followed PRISMA systematic guidance to identify and select all the relevant, high-quality articles.

Nonetheless, the researcher overlooked evidence of palliative care in research-constrained countries that have already established their services, such as Uganda, due to the criteria outlined in 3a of the palliative care map.

11.1.2 Audit

The audit shows the development of the palliative care services provided by the team in the hospital. The research step ensures the data collection till data analysis is rigorous. The documents provide real information about their structure, patient access, the evaluation, the approaches and the fee services so that there is no hidden data that cannot answer the research questions. In terms of the audit of current services, the researcher could only describe how the service operates based on written documents (retrospective data) and not by doing observations (prospective data) to witness how people work, because the service was closed when the researcher did the data collection. Moreover, data were only available from 2016 to 2020. So that it can only be generalised from 2016. The documents provided comprehensive information about the palliative care team's structure, the kind of their services and access to it.

11.1.3 Surveys

This study was the first mixed-methods study using validated questionnaires translated into Indonesian to measure the IPOS and SCNS for family caregivers' needs in the context of advanced cancer. Although a convenience sample was recruited from a single region in Indonesia, wide diversity in their demographics reflects the wider Indonesian family caregiving population. The researcher followed current guidance to translate and linguistically validate the IPOS & SCNS-P&G. However, full validation was beyond the scope of this project. Additional research is warranted to test the Indonesian IPOS's and SCNS-P&CG's psychometric properties for the researcher did back translation, validity and reliability test. Non-response bias is likely minimal given our high response rates, 91% for patients and 88% for family caregivers. Since more than 85% of respondents had a Sundanese ethnic background, the findings may be skewed towards the cultural practices and needs of this ethnic group. However, approximately 34 million Sundanese people live in 27 districts of West Java Province with varied demographics because the hospital is the only referral centre for West Java Province; therefore, it is likely that data accurately represents the target population in West Java.

Regarding the surveys, the differences between participants reflected those in the wider Indonesian population. There is heterogeneity in the demographic data. Their varied backgrounds could represent around 46 million people in West Java Province. The questionnaires can picture outcomes, needs and burdens as critical points that can be used to provide better intervention for patients and family caregivers. The results confirmed the family caregiver's role in Asian culture as a communal system. Unpaid family caregivers need to fulfil patients' needs during illness. Their critical role needs to be supported by servicing their needs.

11.1.4 Interviews

Thirty patients, family caregivers and multidisciplinary palliative staff groups came from diverse districts in the province. The selection of stakeholders can reflect all stakeholders' expectations for improving the service. The research rigour is done by ensuring the participants establish authenticity, their thoughts give a rich impression of how they think they should be treated. It resulted in the same themes representing the population's thoughts. It will be vital to consider their thoughts about the services in the future. The findings answer the research questions: what are patients', family members' and healthcare providers' expectations of and preferences and priorities concerning an improved palliative care service. A nurse-led intervention was reported as the most convenient approach for patients because nurses stay with them longer, have a good relationship with them and understand their problems. A nurse-led intervention has proven to be the best approach when there are insufficient resources because the nurse has qualities as a caring person, spends a long time with patients and can work with patients and family caregivers. In addition, ordinary people with low education levels expected nurses to explain better what doctors had said about their treatment plan.

At the interviews stage, participants upset the interviewer because they tended to talk deeply about their emotions. However, the interview topic guide and role-play mock interviews before sessions helped the interviewer to lead the talking sessions. In sum, participants' thoughts answered all research questions.

Both qualitative and quantitative research answers all the research questions with pros and cons. Quantitative research helps describe the participants' real needs, burdens and reported outcomes and provides data about what should be done to develop palliative care for the patients. Qualitative research helps explore the deep meaning of participants' views and expectations of nurse-led intervention in palliative care. Knowing their desires, hopes, needs, and burdens will help palliative care workers provide interventions to their feelings. The numerical and word data from the result provide the action needed to bespoke the palliative care programme to the West Java, Indonesia patient.

11.2 Key findings

The key message from this PhD study is a suggested mode of operation for developing nurse-led palliative care in the resource-challenged context of West Java, Indonesia. The suggested nurse-led intervention is the presence of nurses to address participants' physical, psychological, financial, spiritual and information needs. They expected nurses to be a master of everything for them. The study also notes the critical role of family caregivers in care treatment. This study is novel in approaching the problems from different angles and using diverse perspectives to give broad and in-depth understanding of how and why a nurse-led intervention should be develop in a certain way to be meaningful or useful in resource-challenged countries. Stages 1-4 of the study, the observation, survey, interviews and systematic review, overall require a nurse-led intervention that focuses on the following issues:

- greater access to the 'superhero nurse'
- extending the service to the community
- providing a low-cost intervention
- greater access to pain management
- more systematic assessment using patient reports
- more training for the family so that they can be more involved in patient care shared with the nurse.

These key findings add information about the needs and burdens of people with cancer and their family caregivers. It suggested the Indonesian government's plans to fund palliative care through health insurance so that the patient can access the service, reduce the layer of administration involved in purchasing painkillers so that the patient can reduce suffering, and provide basic training for family caregivers to care for the family with cancer at home.

11.3 Recommendations

From those findings, it can be recommended to several stakeholders below to provide palliative care including

11.3.1 Recommendations for government and health and social care practice

- Those recommendations are what governmental strategy and planning should focus on to impress the government's solid effort to provide palliative care to healthcare providers. It also impresses the skill and knowledge of the nurse to perform patient-centred care for adults with cancer and their family caregivers.
- Offer a joint outpatient clinic and inpatient ward setting.
- Provide consultation and tailored interventions in the outpatient clinic.
- Restructure the staff's work time, freeing them from having two separate jobs on their on-call day.

- Set a goal to increase referral rates to 10% and palliative care rates services to 65% in the next year.
- Perform a full review of budget, with attention to equipment, facilities and infrastructure development.
- Introduce systematic assessment of supportive care needs via PROMs in local practice.
- Provide time to discuss any questions and concerns of patients and families using simple language.
- Provide palliative care services as early in the cancer trajectory as possible, in line with current clinical recommendations.
- Pay extra attention to thorough pain assessment, ensuring patient access to appropriate pain management.
- Reduce patients’ feeling that they are being ‘discriminated against’.
- Acknowledge and celebrate the achievements of the staff (fee or reward).
- Manage waiting times and introduce an online system to prevent overcrowding in the hospital.
- Train families to confidently provide care at home under supervision.
- Initiate collaboration with the shelters.
- Recruit and train volunteers.

11.3.2 Recommendations for policy makers in West Java

These points raise the stakeholders' focus on collaborating with the government, NGOs, and volunteers to provide palliative care for all people with terminal illnesses.

- Facilitate online communication between all hospitals in Indonesia that patients could access.
- Cover home-care fees through national health insurance.
- Reduce the number of steps that need to be taken to get morphine.
- Improve the referral system to ensure patients receive early treatments.
- Extend cancer treatment and palliative care services to primary care institutions.
- Collaborate with the shelters.

- Palliative care networking between the government, non-government organisations and volunteers.
- Action needed to prevent a financial burden.
- Restructure the current policy to develop more responsive palliative care services.

11.3.3 Recommendations for local education initiative

- Local education could raise awareness of palliative care through webinars, courses, activities and skills training
- Enable access to formal education provision for all members of staff involved in palliative care.
- Enable training in decision-making in palliative care.
- Enable training in health budgeting for palliative care.
- Promote the concept of palliative care in Puskesmas through training programmes.
- Engage in local public awareness activities.

11.3.4 Recommendations for local future research

- Future research can explore many issues in providing and running a palliative care system, including cultural barriers and facilitators in running the palliative care services.
- Explore cultural barriers and facilitators to providing / accessing / seeking palliative care.
- Investigate provision of ‘mobile’ palliative care services in shelters.
- Explore end-of-life perspectives for tribal people and in different geographical areas.
- Explore requirements for bereavement support for tribal people and in different geographical areas.

11.4 Conclusions

The purpose of this study is to bespoke palliative care services in Hasan Sadikin Hospital Indonesia by mixed-methods research. This study is novel in using mixed methods to explore a current palliative care service and recommendations to improve the service in the future based on the data. To my knowledge, this systematic review is the first to synthesise the suggested mode of operation of palliative care in level 1-3 of palliative care development. The observation study is novel in explaining the service's history and providing a summary of the service. It is the first study to use the IPOS questionnaire and the SCNS P&C in Bahasa Indonesia (language). The interview study is the first to explore views and expectations across three stakeholder groups in the hospital. This work is so important because it provides the provision for developing palliative care in the hospital in low- and middle-income countries. This study shows the need to change the patient access to the palliative services and to integrate palliative care into the health system.

This project has revealed current gaps and contributed new evidence to advance development of palliative care services for people affected by advanced cancer in West Java province. Operating within a challenging context, the current palliative care team is developing slowly and serves only a few patients. Patients and family caregivers may experience considerable physical, psychological and financial burden, which requires careful attention and assessment of supportive care needs and a plan for management. The project has identified a wide range of views and expectations with regards to improving the existing service, reaching out to more people, and raising awareness of cancer and palliative care through policy. Importantly, nurses were nominated as being the key people to deliver all supportive care interventions, which increases the expectation on the profession in West Java province. However, a nurse-led intervention in West Java province cannot be a nurse-only intervention. The project has revealed a specific need for a multidisciplinary intervention that is coordinated by nurses to better align resources to the financial challenges posed to the local system, health professionals, and the public. The implications for future practice and policy development are evident, while additional research should further investigate implementation, feasibility, and sustainability of the nurse-led intervention, before long-term efficacy can be investigated.

The data from all stages provide essential data about the hospital's development of palliative care services. The team’s goals, skills, training needs and outcomes had never been measured since they started the service. The team operated in line with palliative care guidelines, took up upskilling opportunities and trained others in West Java Province. However, regular evaluation of practice is vital. Nurses can play a crucial role in service delivery and evaluation.

The educational strategy for palliative care nurses in resource-poor countries was training of trainer approach (Bassah, Seymour and Cox, 2014). This training aims to train the staff with skills and knowledge in palliative care. In turn, they will transfer their skill by training the nurses in their village. The team at Hasan Sadikin Hospital had already applied this strategy by starting to train staff in community and primary health care. Partnerships with medical schools, local clinics, local culture and partner institutions is a better approach to increasing staff skills (Rhee et al., 2018). Furthermore, intensive training will effectively increase palliative care delivery (Daubman et al., 2021). The requirement for a nurse-led intervention for adults with cancer and their families in West Java Province, Indonesia

The most prominent physical symptoms patients experienced were pain, and the top emotional concerns reported were the anxiety of family or friends. Both patients’ and family caregiver'' groups reported unmet needs in all domains of supportive care needs. More than 80% of family caregiver participants had a medium-level burden and 75% were at high risk of depression. The family caregiver'' burdens were physical, psychological and financial. The most relevant things that patients expected were painkillers, psychological support and good communication. Family caregivers expected home care with a nurse's supervision and financial support. In contrast, staff expected they could serve the patient comprehensively, provide earlier treatments and extend services to the community.

I have learned that establishing a palliative care service is quite a challenging endeavour. Despite this, the palliative care team managed to launch the service with limited resources. Key points for a nurse-led intervention included providing accessible palliative care in the community and recognising the significance of nurses, both as managers and confidants for the patients. Upon completing the study, I will become a member of Indonesia's nursing palliative care association and will organise a series of free webinars on various palliative care topics. The participants included people with cancer, family caregivers, volunteers, students, government officials and stakeholders. Additionally, we are planning to host the first national conference in palliative care in 2024, where I will be part of the research-hospital services teamwork. My colleague and I also received a research grant from the Indonesian higher education minister to establish a £5000 laboratory setting for palliative care in 2024. As this is the first grant of its kind in palliative care education, we are immensely proud to be organising the laboratory setting. We hope that our laboratory will become the leading centre for palliative care research studies in Indonesia. My prior research experience will be instrumental in carrying out the research in Indonesia.

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Appendices

Appendix 1 Prospero registration

National Institute for
Health Research

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UNIVERSITY of York
Centre for Reviews and Dissemination

Systematic review

A list of fields that can be edited in an update can be found here

1. * Review title.

Give the title of the review in English

Organisational and operational characteristics of palliative (cancer) care services developed for and

implemented in resource-challenged countries: a systematic review

2. Original language title.

For reviews in languages other than English, give the title in the original language. This will be displayed with

the English language title.

3. * Anticipated or actual start date.

Give the date the systematic review started or is expected to start.

24/11/2021

4. * Anticipated completion date.

Give the date by which the review is expected to be completed.

24/08/2022

5. * Stage of review at time of this submission.

This field uses answers to initial screening questions. It cannot be edited until after registration.

Tick the boxes to show which review tasks have been started and which have been completed.

Update this field each time any amendments are made to a published record.

The review has not yet started: No

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Review stage Started Completed

Preliminary searches Yes No

Piloting of the study selection process Yes No

Formal screening of search results against eligibility criteria No No

Data extraction No No

Risk of bias (quality) assessment No No

Data analysis No No

Provide any other relevant information about the stage of the review here.

6. * Named contact.

The named contact is the guarantor for the accuracy of the information in the register record. This may be any member of the review team.

Chandra Isabella Hostanida Purba

Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:

Mrs Purba

7. * Named contact email.

Give the electronic email address of the named contact.

xxxxxxx@student.gla.ac.uk

8. Named contact address

Give the full institutional/organisational postal address for the named contact.

57 Oakfield Avenue, Glasgow, Scotland, G20 8LP

9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

xxxxxxxxxxxxxxxxxxxxx

10. * Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

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University of Glasgow.

Organisation web address:

Website: http://www.gla.ac.uk/schools/medicine/nursing

11. * Review team members and their organisational affiliations.

Give the personal details and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong. **NOTE: email and country now MUST be entered for each person, unless you are amending a published record.**

Mrs Chandra Isabella Hostanida Purba. University of Glasgow, School of Medicine, Dentistry & Nursing, Glasgow, United Kingdom

Professor Bridget Johnston. University of Glasgow, School of Medicine, Dentistry & Nursing, Glasgow, United Kingdom, NHS Greater Glasgow & Clyde, Glasgow, United Kingdom,

Dr Grigorios Kotronoulas. University of Glasgow, School of Medicine, Dentistry & Nursing, Glasgow, United

Kingdom

12. * Funding sources/sponsors.

Details of the individuals, organisations, groups, companies or other legal entities who have funded or

sponsored the review.

Universitas Padjadjaran, Indonesia

Grant number(s)

State the funder, grant or award number and the date of award

Surat Perjanjian Tugas Belajar nomor (Study Agreement Letter number) 5011/UN6.WR2/KP/2018

13. * Conflicts of interest.

List actual or perceived conflicts of interest (financial or academic).

None

14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are

not listed as review team members. **NOTE: email and country must be completed for each person,**

unless you are amending a published record.

1[15 . c*h Ranegviee]w question.

State the review question(s) clearly and precisely. It may be appropriate to break very broad questions down

into a series of related more specific questions. Questions may be framed or refined using PI(E)COS or

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similar where relevant.

Research question

1. What is the main component of palliative care service in resource-challenged countries?
2. What is the mode of operation of palliative care service in resource-challenged countries?
3. What is the need for palliative staff and volunteers when providing palliative services for people with

cancer and their family caregiver in resource-challenged countries?

Aims:

1. To identify the main components of palliative care services for adults with cancer and their family

caregivers in resource-challenged countries.

2. To identify the mode of operation of palliative care services for adults with cancer and their family

caregivers in resource-challenged countries.

3. To identify the barriers and requirements for palliative care staff and volunteers in order to provide

palliative services in resource-challenged countries.

16. * Searches.

State the sources that will be searched (e.g. Medline). Give the search dates, and any restrictions (e.g. language or publication date). Do NOT enter the full search strategy (it may be provided as a link or attachment below.)

MEDLINE, CINAHL, Embase, Web of Science, Cochrane Library will be searched from their inception until the present for a combination of subject headings and keywords related to (1) adult (2) cancer (3) palliative care (4) Developing countries list as Global Atlas palliative care.

1[17 . cUhRanLg teo] search strategy.

Upload a file with your search strategy, or an example of a search strategy for a specific database, (including the keywords) in pdf or word format. In doing so you are consenting to the file being made publicly accessible. Or provide a URL or link to the strategy. Do NOT provide links to your search **results**.

https://www.crd.york.ac.uk/PROSPEROFILES/220499_STRATEGY_20210906.pdf

Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Do not make this file publicly available until the review is complete

18. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied in your systematic review.

The Global Atlas Palliative Care reported that advanced integration of palliative care with broader health services had been achieved in 20 countries only (8%) as group four: Australia, Austria, Belgium, Canada, France, Germany, Hong Kong, Iceland, Ireland, Italy, Japan, Norway, Poland, Romania, Singapore, Sweden, Switzerland, Uganda, United Kingdom, United States of America (Baxter, 2018). Palliative care services in the world can be categorised into four groups from no activity to comprehensive services. Groups 1-3 commonly developing countries. These groups face barriers in policy, education, medicine availability, and implementation in palliative care. How these countries develop their services for patients with cancer will help enhance other countries' development. Therefore, we need to review the organisational and operational characteristics of palliative care services developed in these groups for West Java Province implementation as the same context poor resource country.

19. * Participants/population.

Specify the participants or populations being studied in the review. The preferred format includes details of both inclusion and exclusion criteria.

Inclusion criteria:

- Patients with cancer and their family caregivers who receive palliative services/supportive needs/end-of-life care treatments/interventions.
- Staff palliative and volunteer who provides palliative care services/supportive needs/end-of-life care treatments/interventions for adult adults with cancer.

Exclusion criteria:

- The patient is children or elderly
- Palliative service for patient non-cancer (HIV/AIDS, Covid-19, other chronic illnesses)
- The patient has been diagnosed with other chronic illnesses/infections/ Covid-19.

20. * Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the interventions or the exposures to be reviewed. The preferred format includes details of both inclusion and exclusion criteria.

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This review is concerned with Palliative care services that provide the intervention, implementation, evaluation of palliative care services for adults with cancer in developing countries including what part or method of operation, the main component, how they work, how they developed.

The palliative care intervention including in this review must satisfy one or more criteria:

Inclusion criteria:

- All types of subject experiments: patient with cancer, family caregivers, staff palliative care/health care providers, volunteer in developing countries.
- Patients with cancer and their family caregivers need/receive Palliative care/Supportive/ End of life care in developing countries
- Studies that provide the intervention, implementation, evaluation of palliative care services for people with cancer in developing countries.

Staff palliative and volunteer who provides palliative care services/supportive needs/ end-of-life care

treatments for adult adults with cancer.

Exclusion criteria:

- Treatment/service does not include a palliative care approach.

Patient/family caregivers receive non-palliative care approach/services such as medicine, diagnostic

procedures, professional training.

Staff/volunteers do not provide a palliative care approach

Studies that apply the palliative care approach for people without cancer (HIV/AIDS, Covid-19, and other

chronic illnesses) in developed countries.

2[1 . c*h Canogmep]arator(s)/control.

Where relevant, give details of the alternatives against which the intervention/exposure will be compared

(e.g. another intervention or a non-exposed control group). The preferred format includes details of both

inclusion and exclusion criteria.

Not applicable

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22. * Types of study to be included.

Give details of the study designs (e.g. RCT) that are eligible for inclusion in the review. The preferred format

includes both inclusion and exclusion criteria. If there are no restrictions on the types of study, this should be

stated.

IAnncylu msioenth:odology and any study design of primary and secondary research published in a peer-reviewed

journal and in English.

Exclusion:

Case series, case report, letters to the editor, Congress abstract, expert opinion, Organisation

report/WHO/NHS group.

23. Context.

Give summary details of the setting or other relevant characteristics, which help define the inclusion or

exclusion criteria.

Studies conducted in any primary, secondary, and tertiary healthcare setting will be considered eligible for

iTnhcelu rseiosno.urce-challenged countries in this study are the countries in the category group of 1-3 as Global Atlas

of Palliative Care at the End of Life (CONNOR, et.al. 2021)

- Group 1: No known hospice-palliative care activity, current work has been unrecognised.
- Group 2: Capacity building activity: there is evidence of wide-ranging initiatives designed to create the organisational, workforce, and policy capacity for hospice-palliative care services to develop, no service yet.
- Group 3: Isolated palliative care provision and Generalised palliative care provision.

These groups do not have advanced palliative care yet. Thus, the studies will include all the palliative care settings in countries groups 1-3. There are 127 countries in the group 1-3.

Inclusion criteria:

- Palliative service for adult adults with cancer in 172 countries in the Global map palliative care list.

Exclusion criteria:

- Palliative service for adult adults with cancer in Australia, Austria, Belgium, Canada, France, Germany, Hong Kong, Iceland, Ireland, Italy, Japan, Norway, Poland, Romania, Singapore, Sweden, Switzerland, Uganda, United Kingdom, United States of America

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2[24 . c*h Managine so]utcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

Increase in the number of patients accessing palliative care services from baseline to the maximum number, measured using the number of visits in the palliative care services in the hospital.

Exclusion criteria: Outcomes unrelated to palliative care.

Measures of effect

Please specify the effect measure(s) for you main outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.

2[25 . c*h Aadndgietiso]nal outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state ‘None’ or ‘Not applicable’ as appropriate to the review

Change in patient-reported outcomes from baseline to the minimum score in supportive care need and

burden measured using Integrated Palliative care Outcomes (IPOS) Supportive Care Needs Survey
(SCNS),
and Zarit Burden Interview (ZBI).

Measures of effect

Please specify the effect measure(s) for you additional outcome(s) e.g. relative risks, odds ratios, risk
difference, and/or 'number needed to treat.

2[16 . c*h Danagtae]extraction (selection and coding).

Describe how studies will be selected for inclusion. State what data will be extracted or obtained. State how
this will be done and recorded.

TAhueth foorllowing data will be extracted:

Year
Title
Country

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Aim or question
Design: data collection, methods, analysis.
Population:demographic, participants
Sample
Setting/location

including data regarding:

-How the services are structured
-What they provide
-Whom they serve
-How they operate
-How many clinicians do they involve
-How much they cost
-What are their intervention outcomes.

These data will be extracted from each study by one reviewer (CP) and verified by a second (GK) and a third
reviewer (BJ). A mutual discussion will undertake to reach an agreement. The result of the data extraction
will available in the appendix.

2[17 . c*h Ranisgke o] f bias (quality) assessment.

State which characteristics of the studies will be assessed and/or any formal risk of bias/quality assessment
tools that will be used.

TWhee uMseM AthTe iMs IaX cErDiti cMaEl aTpHpOraDisSa lA tPooPlR thAaISt iAs Ld eTsOigOnLe d(M foMr AthTe) VapEpRraSiIsOaNl s 2ta0g1e8 otof saysstesmsa tthice mrisixke odf sbtuiadsi.es reviews, i.e., reviews that include qualitative, quantitative, and mixed methods studies. It permits to appraise the methodological quality of five categories to studies: qualitative research, randomised controlled trials, nonrandomised studies, quantitative descriptive studies, and mixed methods studies (HONG et al 2018).

This tool has an Algorithm for selecting the study categories to rate as quantitative, qualitative, or mixed-method.

One reviewer and critical appraisal will be piloted for the first three papers so that consensus can be reached among the three reviewers.

2[18 . c*h Satnrgaete]gy for data synthesis.

Describe the methods you plan to use to synthesise data. This **must not be generic text** but should be **specific to your review** and describe how the proposed approach will be applied to your data. If metaanalysis is planned, describe the models to be used, methods to explore statistical heterogeneity, and software package to be used.

We will use narrative data synthesis to interpret the data. Qualitative and quantitative outcomes studies focusing on palliative care service delivery for cancer patients, family caregivers, and staff will be analysed together.

We will follow the Synthesis Without Meta-analysis guidelines in the methods section by grouping studies for synthesis to describe populations, interventions, and outcomes. Then we will explain why the metric(s) was chosen, describe any methods used to transform the intervention effects, justify the methods used to synthesise the effects for each outcome when it was not possible to undertake a meta-analysis of effect estimates. We will provide the criteria used to prioritise results for summary and synthesis with supporting justification, select the studies for the main synthesis or to draw conclusions from the synthesis, explain the method(s) used, describe the methods used to assess the certainty of the synthesis findings then describe the graphical and tabular methods used to present the effects.

The results section will describe the synthesised findings and the certainty of the findings and present them

in graphics and tables. These include how the services are structured, what they provide, whom they serve,
how they operate, how many clinicians they involve, how much they cost, and the impact on Quality of life/
pain/suffering/cost-effectiveness/care outcomes in this review. Then in the discussion section, we will report
the limitations of the synthesis methods used and how these affect the conclusions concerning the original
review question.

29. * Analysis of subgroups or subsets.

State any planned investigation of ‘subgroups’. Be clear and specific about which type of study or participant will be included in each group or covariate investigated. State the planned analytic approach.

None

30. * Type and method of review.

Select the type of review, review method and health area from the lists below.

Type of review

Cost effectiveness

Yes

Diagnostic

No

Epidemiologic

No

Individual patient data (IPD) meta-analysis

No

Intervention

Yes

Living systematic review

No

Meta-analysis

No

Methodology

No

Narrative synthesis

Yes

Network meta-analysis

No

Pre-clinical

No

Prevention

No

Prognostic

No

Prospective meta-analysis (PMA)

No

Review of reviews

No

Service delivery

Yes

Synthesis of qualitative studies

Yes

Systematic review

Yes

Other

No

Health area of the review

Alcohol/substance misuse/abuse

No

Blood and immune system

No

Cancer

Yes

Cardiovascular

No

Care of the elderly

No

Child health

No

Complementary therapies

No

COVID-19

No

Crime and justice

No

Dental

No

Digestive system

No

Ear, nose and throat

No

Education

No

Endocrine and metabolic disorders

No

Eye disorders

No

General interest

No

Genetics

No

Health inequalities/health equity

No

Infections and infestations

No

International development

No

Mental health and behavioural conditions

No

Musculoskeletal

No

Neurological

No

Nursing

Yes

Obstetrics and gynaecology

No

Oral health

No

Palliative care

Yes

Perioperative care

No

Physiotherapy

No

Pregnancy and childbirth

No

Public health (including social determinants of health)

No

Rehabilitation

No

Respiratory disorders

No

Service delivery

No

Skin disorders

No

Social care

No

Surgery

No

Tropical Medicine

No

Urological

No

Wounds, injuries and accidents

No

Violence and abuse

No

31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.

English

There is an English language summary.

32. * Country.

Select the country in which the review is being carried out. For multi-national collaborations select all the
countries involved.

Scotland

33. Other registration details.

Name any other organisation where the systematic review title or protocol is registered (e.g. Campbell, or
The Joanna Briggs Institute) together with any unique identification number assigned by them. If extracted
data will be stored and made available through a repository such as the Systematic Review Data Repository
(SRDR), details and a link should be included here. If none, leave blank.

34. Reference and/or URL for published protocol.

If the protocol for this review is published provide details (authors, title and journal details, preferably in
Vancouver format)

Add web link to the published protocol.

*Page: 14 / 17***PROSPERO**

International prospective register of systematic reviews

Or, upload your published protocol here in pdf format. Note that the upload will be publicly accessible.

No I do not make this file publicly available until the review is complete

Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

35. Dissemination plans.

Do you intend to publish the review on completion?

Yes

Give brief details of plans for communicating review findings.?

This review is part of Chandra Isabella Hostanida Purba PhD thesis. The findings will disseminate in academic conferences or academic press.

36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line.

Keywords help PROSPERO users find your review (keywords do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

Adult*Cancer OR Carcinoma OR Neoplasm OR metastases cancer OR malignant, “Palliative care” OR “supportive care” OR hospice OR “End of life care” OR “terminal care” OR “supportive oncology” OR “End stage disease” OR “terminally ill”“Developing countr*” OR “poor countr*” OR “low income countr*”

BOrRu n“leoiw OeRr mKidridblaet ii nOcRo mLaeo cso OunRtr *“M” OarRs h“uapll plselra nmdidsd” lOe Rin cMoicmroen ceosuian*tr O*”R Nauru* OR Palau* OR 'Solomon Islands*' OR Tonga OR Tuvalu* OR Vanuatu* OR Bhutan OR Maldives* OR “North Korea” OR “Timor Leste” OR Andorra OR Kosovo* OR Monaco OR Montenegro OR “San Marino*” OR Turkmenistan OR “Vatican City” OR Djibouti OR Iraq OR Somalia OR Somaliland OR Syria* OR Yemen OR “Antigua and Barbuda” OR Cuba OR Dominica* OR Grenada* OR Guyana OR “Saint Lucia” OR “St Kitts and Nevis*” OR “St Vincent and the Grenadines*” OR Suriname* OR “Cape Verde” OR “Central African Republic” OR Chad OR Comoro OR “Congo Republic” OR “Guinea-Bissau*” OR Lesotho OR Mali OR Seychelles OR “South Sudan” OR Uzbekistan OR Samoa OR “United Arab Emirates” OR Bahamas OR Haiti OR Algeria

OR Benin OR Botswana OR Cameroon OR Congo OR Ethiopia OR Ghana OR Guinea OR Madagascar OR

Mauretania OR Mauritius OR Mozambique OR Namibia OR Niger OR Nigeria OR Rwanda OR Senegal OR

“Sierra Leone” OR Tanzania OR Togo OR Bolivia OR “Dominican Republic” OR Ecuador OR Guatemala

OR Honduras OR Jamaica OR Nicaragua OR Paraguay OR Peru OR “Trinidad and Tobago” OR Venezuela

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OR Armenia OR Azerbaijan OR “Bosnia and Herzegovina” OR Croatia OR Estonia OR Greece OR

Kyrgyzstan OR Moldova OR Tajikistan OR Turkey OR Bangladesh OR India OR Indonesia OR Myanmar OR

Nepal OR “Sri Lanka” OR Cambodia OR Fiji OR Malaysia OR “Papua New Guinea” OR Philippines OR

Vietnam OR Gambia OR Kenya OR Zambia OR Belize OR Brazil OR Colombia OR “El Salvador” OR

Panama OR Jordan OR Oman OR Qatar OR “Saudi Arabia” OR Albania OR Belarus OR Bulgaria OR

Cyprus OR Finland OR Luxembourg OR Macedonia OR Malta OR Serbia OR Slovenia

3[17 . cDheatnagiles] of any existing review of the same topic by the same authors.

If you are registering an update of an existing review give details of the earlier versions and include a full

bibliographic reference, if available.

Not applicable

3[18 . c*h Canugrree]nt review status.

Update review status when the review is completed and when it is published.New registrations must be

ongoing so this field is not editable for initial submission.

Please provide anticipated publication date

Review_Completed_not_published

3[29 . cAhnayn gaedsd]itional information.

Provide any other information relevant to the registration of this review.

There is only one cancer treatment and palliative care in West Java Province, Indonesia, for 46 million

people. However, the existing palliative team served very few patients. This review's findings will help us find

the organisational and operational characteristics of palliative (cancer) care services developed and

implemented in resource-challenged countries. It will suggest the main component of enhanced palliative

care service and mode of operation for implementation in the West Java province Indonesia to increase

patient access and decrease their need and burden during illness and cancer treatment. The qualitative

reviews will help us mitigate the barriers for staff and volunteers to provide palliative services in resourcechallenged
countries.
As part of the theses, we did a baseline data survey in 2019: the total number of hospitalised patients with
cancers who received palliative care was only 0.23% in 2017, 0.29% in 2018, and 0.6% in 2019. Moreover,
the total number of adult patients who received the services (outpatient clinics and wards) compared to the
total number of cancer patients who visited the hospital was only 0.05% in 2017-2018. Also, we did a
baseline survey in 2019 with the result almost 80% of participants reported high need and burden in

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supportive care needs. After receiving the services by 2025, we expect the number of patients accessing
palliative services will be increased to 20% and the needs and burden will be increased to the less need and
burden.

4[01 . cDheatnagiles] of final report/publication(s) or preprints if available.

Leave empty until publication details are available OR you have a link to a preprint (NOTE: this field is not
editable for initial submission). List authors, title and journal details preferably in Vancouver format.

Give the link to the published review or preprint.

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Appendix 2 PICO evidence

PICO	Description / Definition	Synonyms / Keywords
Population / Problem	Adult patients with cancer Inclusion criteria: • Patients with cancer and their family caregivers who receive palliative services/supportive needs/end of life care treatments/interventions. • Staff palliative and volunteer who provides palliative care services/supportive needs/end of life care treatments/interventions for adult people. Exclusion criteria: • Palliative care services for children and the elderly.	Adult*
	Cancer	Cancer OR Carcinoma OR Neoplasm OR metastases cancer OR malignant
Intervention / Exposure	Palliative care This review is concerned with Palliative care services intervention/implementation in developing countries, including what part or method of operation, the main component, how they work, how they developed. The findings can enhance the service in other countries with the same background as low resources countries. The intervention including in this review, must satisfy one or more criteria: Inclusion criteria: • Palliative care for adults with cancer and their family caregivers in developing countries • Supportive care for adults with cancer and their family caregivers in developing countries • End of life care intervention for adults with cancer and their family caregivers in developing countries. Exclusion criteria: • Intervention does not include palliative care intervention	"Palliative care" OR "supportive care" OR hospice OR "End of life care" OR "terminal care" OR "supportive oncology" OR "End stage disease" OR "terminally ill"
Context / Setting	Studies conducted in any primary, secondary, and tertiary healthcare setting will be considered eligible for inclusion. The resource-challenged countries in this study are the countries in the category group of 1-3 as Global Atlas of Palliative Care at the End-of-Life 2nd Edition, 2020	"Developing countr*" OR "poor countr*" OR "low income countr*" OR "lower middle income countr*" OR "upper middle income countr*" Brunei OR Kiribati OR Laos OR "Marshall Islands" OR Micronesia* OR Nauru* OR Palau* OR 'Solomon Islands*' OR Tonga OR Tuvalu* OR Vanuatu* OR Bhutan OR Maldives* OR "North Korea" OR "Timor

	• Group 1: No known hospice-palliative care activity. Current work has been unrecognised. • Group 2: Capacity building activity: there is evidence of wide-ranging initiatives designed to create the organisational, workforce, and policy capacity for hospice-palliative care services to develop, no service yet. • Group 3: Isolated palliative care provision and Generalised palliative care provision. These groups do not have advanced palliative care yet. Thus, the studies will include all the palliative care settings in countries groups 1-3, almost all countries in the world except 20 countries.	Leste” OR Andorra OR Kosovo* OR Monaco OR Montenegro OR “San Marino*” OR Turkmenistan OR “Vatican City” OR Djibouti OR Iraq OR Somalia OR Somaliland OR Syria* OR Yemen OR “Antigua and Barbuda” OR Cuba OR Dominica* OR Grenada* OR Guyana OR “Saint Lucia” OR “St Kitts and Nevis*” OR “St Vincent and the Grenadines*” OR Suriname* OR “Cape Verde” OR “Central African Republic” OR Chad OR Comoro OR “Congo Republic” OR “Guinea-Bissau*” OR Lesotho OR Mali OR Seychelles OR “South Sudan” OR Uzbekistan OR Samoa OR “United Arab Emirates” OR Bahamas OR Haiti OR Algeria OR Benin OR Botswana OR Cameroon OR Congo OR Ethiopia OR Ghana OR Guinea OR Madagascar OR Mauretania OR Mauritius OR Mozambique OR Namibia OR Niger OR Nigeria OR Rwanda OR Senegal OR “Sierra Leone” OR Tanzania OR Togo OR Bolivia OR “Dominican Republic” OR Ecuador OR Guatemala OR Honduras OR Jamaica OR Nicaragua OR Paraguay OR Peru OR “Trinidad and Tobago” OR Venezuela OR Armenia OR Azerbaijan OR “Bosnia and Herzegovina” OR Croatia OR Estonia OR Greece OR Kyrgyzstan OR Moldova OR Tajikistan OR Turkey OR Bangladesh OR India OR Indonesia OR Myanmar OR Nepal OR “Sri Lanka” OR Cambodia OR Fiji OR Malaysia OR “Papua New Guinea” OR Philippines OR Vietnam OR Gambia OR Kenya OR Zambia OR Belize OR Brazil OR Colombia OR “El Salvador” OR Panama OR Jordan OR Oman OR Qatar OR “Saudi Arabia” OR Albania OR Belarus OR Bulgaria OR Cyprus OR Finland OR Luxembourg OR Macedonia OR Malta OR Serbia OR Slovenia
	All relevant palliative care outcomes. This review is concerned with the main component and mode of palliative care service development in resource-challenged countries for adults with cancer. Inclusion criteria: All outcomes in palliative care: how the services are structured what they provide whom they serve how they operate how many clinicians do they involve? how much they cost Exclusion criteria: All outcomes without palliative care approach.	Quality of life OR pain OR suffering

Appendix 3 Search strategy history

Embase <1996 to 2021 Week 32>

Table 1. Search Embase (OVID)

ID	Term	Result
1	exp Adult/	7885238
2	adult*.tw.	1562445
3	1 or 2	8377739
4	Cancer.mp.	3416916
5	Cancer*.tw.	2473140
6	Carcinoma/	39007
7	Carcinoma.tw.	679439
8	Neoplasms/	18142
9	Neoplasm*.tw.	154648
10	metastases cancer.mp.	115
11	metastases cancer*.tw.	119
12	malignant.mp.	540955
13	malignan*.tw.	719011
14	4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13	3913223
15	exp Palliative Care/	113121
16	Palliative care.tw.	48779
17	supportive care.mp.	31956
18	supportive care.tw.	30372
19	exp Hospices/	11885
20	hospice*.tw.	19229
21	End of life care.mp.	17214
22	End of life care.tw.	15138
23	exp Terminal Care/	60615
24	terminal care.tw.	1157
25	supportive oncology.mp.	238
26	supportive onco*.tw.	238
27	End stage disease.mp.	1787
28	End stage disease.tw.	1760
29	exp Terminally Ill/	7624
30	terminally ill.tw.	5594
31	15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30	198661
32	exp Developing Countries/	65805
33	Developing countr*.tw.	74445
34	poor countries.mp.	2669
35	poor countr*.tw.	2876
36	low income countries.mp.	8719
37	low income countr*.tw.	9144
38	lower middle income countries.mp.	965
39	lower middle income countr*.tw.	1236
40	middle income countries.mp.	25870
41	middle income countr*.tw.	26931
42	32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41	139772
43	Brunei/	526
44	Kiribati.mp.	207

45	Laos/	2112
46	Marshall Islands.mp.	330
47	Micronesia/	705
48	Nauru*.mp.	140
49	Palau/	298
50	Solomon Islands.mp.	846
51	Tonga/	351
52	Tuvalu*.mp.	82
53	Vanuatu/	461
54	Bhutan/	887
55	Maldives*.mp.	511
56	North Korea.mp.	1602
57	Timor-Leste/	627
58	Andorra/	55
59	Kosovo/	612
60	Monaco/	887
61	Montenegro/	802
62	San Marino/	65
63	Turkmenistan/	275
64	Vatican City/	99
65	Djibouti/	312
66	Iraq/	9566
67	Somalia/	1722
68	Somaliland.mp.	133
69	Syria/	2517
70	Yemen/	1864
71	(Antigua and Barbuda).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]	156
72	Cuba/	5293
73	Dominica/	194
74	Grenada/	288
75	Guyana/	832
76	Saint Lucia/	90
77	(St Kitts and Nevis*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]	101
78	(St Vincent and the Grenadines*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]	77
79	Suriname/	898
80	Cabo Verde/	407
81	Central African Republic/	699
82	Chad/	710

83	Comoros/	352
84	Congo/	3247
85	Guinea-Bissau/	919
86	Lesotho/	694
87	Mali/	3231
88	Seychelles/	466
89	South Sudan/	360
90	Uzbekistan/	1446
91	Samoa/	548
92	United Arab Emirates/	3512
93	Bahamas/	728
94	Haiti/	3804
95	Algeria/	4306
96	Benin/	2510
97	Botswana/	2672
98	Cameroon/	6792
99	Congo/	3247
100	Ethiopia/	18859
101	Ghana/	12210
102	Guinea/	1946
103	Madagascar/	4081
104	Mauretania.mp.	4
105	Mauritius/	883
106	Mozambique/	3815
107	Namibia/	1631
108	Niger/	2037
109	Nigeria/	34135
110	Rwanda/	3646
111	Senegal/	5367
112	Sierra Leone/	2327
113	Tanzania/	14664
114	Togo/	1293
115	Bolivia/	3277
116	Dominican Republic/	2349
117	Ecuador/	5604
118	Guatemala/	3725
119	Honduras/	1816
120	Jamaica/	2850
121	Nicaragua/	2019
122	Paraguay/	1400
123	Peru/	11899
124	(Trinidad and Tobago).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]	1690
125	Venezuela/	4996
126	Armenia/	1528
127	Azerbaijan/	1348

128	(Bosnia and Herzegovina).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]	3344
129	Croatia/	10442
130	Estonia/	3875
131	Greece/	24854
132	Kyrgyzstan/	1031
133	Moldova/	983
134	Tajikistan/	750
135	Turkey/	2380
136	Bangladesh/	16497
137	India/	132524
138	Indonesia/	19524
139	Myanmar/	4109
140	Nepal/	12539
141	Sri Lanka/	7855
142	Cambodia/	5014
143	Fiji/	1470
144	Malaysia/	21004
145	Papua New Guinea/	3914
146	Philippines/	9733
147	Vietnam/	14627
148	Gambia/	2233
149	Kenya/	19900
150	Zambia/	5842
151	Belize/	695
152	Brazil/	113295
153	Colombia/	19952
154	El Salvador/	1834
155	Panama/	2440
156	Jordan/	7190
157	Oman/	3153
158	Qatar/	3538
159	Saudi Arabia/	22006
160	Albania/	1838
161	"Republic of Belarus"/	2026
162	Bulgaria/	6070
163	Cyprus/	2432
164	Finland/	30937
165	Luxembourg/	1295
166	Macedonia.mp.	2282
167	Malta/	1640
168	Serbia/	6237
169	Slovenia/	5454
170	43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80 or	703172

	81 or 82 or 83 or 84 or 85 or 86 or 87 or 88 or 89 or 90 or 91 or 92 or 93 or 94 or 95 or 96 or 97 or 98 or 99 or 100 or 101 or 102 or 103 or 104 or 105 or 106 or 107 or 108 or 109 or 110 or 111 or 112 or 113 or 114 or 115 or 116 or 117 or 118 or 119 or 120 or 121 or 122 or 123 or 124 or 125 or 126 or 127 or 128 or 129 or 130 or 131 or 132 or 133 or 134 or 135 or 136 or 137 or 138 or 139 or 140 or 141 or 142 or 143 or 144 or 145 or 146 or 147 or 148 or 149 or 150 or 151 or 152 or 153 or 154 or 155 or 156 or 157 or 158 or 159 or 160 or 161 or 162 or 163 or 164 or 165 or 166 or 167 or 168 or 169	
171	42 or 170	799901
172	3 and 14 and 31 and 171	1553
173	limit 172 to (yr="2011 - 2021" and "all adult (19 plus years)")	1359
174	exp Adult/	7885238
175	adult*.tw.	1562445
176	174 or 175	8377739
177	Cancer.mp.	3416916
178	Cancer*.tw.	2473140
179	Carcinoma/	39007
180	Carcinoma.tw.	679439
181	Neoplasms/	18142
182	Neoplasm*.tw.	154648
183	metastases cancer.mp.	115
184	metastases cancer*.tw.	119
185	malignant.mp.	540955
186	malignan*.tw.	719011
187	177 or 178 or 179 or 180 or 181 or 182 or 183 or 184 or 185 or 186	3913223
188	exp Palliative Care/	113121
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190	supportive care.mp.	31956
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192	exp Hospices/	11885
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195	End of life care.tw.	15138
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200	End stage disease.mp.	1787
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202	exp Terminally Ill/	7624
203	terminally ill.tw.	5594
204	188 or 189 or 190 or 191 or 192 or 193 or 194 or 195 or 196 or 197 or 198 or 199 or 200 or 201 or 202 or 203	198661
205	exp Developing Countries/	65805
206	Developing countr*.tw.	74445

207	poor countries.mp.	2669
208	poor countr*.tw.	2876
209	low income countries.mp.	8719
210	low income countr*.tw.	9144
211	lower middle income countries.mp.	965
212	lower middle income countr*.tw.	1236
213	middle income countries.mp.	25870
214	middle income countr*.tw.	26931
215	205 or 206 or 207 or 208 or 209 or 210 or 211 or 212 or 213 or 214	139772
216	Brunei/	526
217	Kiribati.mp.	207
218	Laos/	2112
219	Marshall Islands.mp.	330
220	Micronesia/	705
221	Nauru*.mp.	140
222	Palau/	298
223	Solomon Islands.mp.	846
224	Tonga/	351
225	Tuvalu*.mp.	82
226	Vanuatu/	461
227	Bhutan/	887
228	Maldives*.mp.	511
229	North Korea.mp.	1602
230	Timor-Leste/	627
231	Andorra/	55
232	Kosovo/	612
233	Monaco/	887
234	Montenegro/	802
235	San Marino/	65
236	Turkmenistan/	275
237	Vatican City/	99
238	Djibouti/	312
239	Iraq/	9566
240	Somalia/	1722
241	Somaliland.mp.	133
242	Syria/	2517
243	Yemen/	1864
244	(Antigua and Barbuda).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]	156
245	Cuba/	5293
246	Dominica/	194
247	Grenada/	288
248	Guyana/	832
249	Saint Lucia/	90
250	(St Kitts and Nevis*).mp. [mp=title, abstract, heading word, drug trade name, original title, device	101

	manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]	
251	(St Vincent and the Grenadines*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]	77
252	Suriname/	898
253	Cabo Verde/	407
254	Central African Republic/	699
255	Chad/	710
256	Comoros/	352
257	Congo/	3247
258	Guinea-Bissau/	919
259	Lesotho/	694
260	Mali/	3231
261	Seychelles/	466
262	South Sudan/	360
263	Uzbekistan/	1446
264	Samoa/	548
265	United Arab Emirates/	3512
266	Bahamas/	728
267	Haiti/	3804
268	Algeria/	4306
269	Benin/	2510
270	Botswana/	2672
271	Cameroon/	6792
272	Congo/	3247
273	Ethiopia/	18859
274	Ghana/	12210
275	Guinea/	1946
276	Madagascar/	4081
277	Mauretania.mp.	4
278	Mauritius/	883
279	Mozambique/	3815
280	Namibia/	1631
281	Niger/	2037
282	Nigeria/	34135
283	Rwanda/	3646
284	Senegal/	5367
285	Sierra Leone/	2327
286	Tanzania/	14664
287	Togo/	1293
288	Bolivia/	3277
289	Dominican Republic/	2349
290	Ecuador/	5604
291	Guatemala/	3725
292	Honduras/	1816
293	Jamaica/	2850

294	Nicaragua/	2019
295	Paraguay/	1400
296	Peru/	11899
297	(Trinidad and Tobago).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]	1690
298	Venezuela/	4996
299	Armenia/	1528
300	Azerbaijan/	1348
301	(Bosnia and Herzegovina).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]	3344
302	Croatia/	10442
303	Estonia/	3875
304	Greece/	24854
305	Kyrgyzstan/	1031
306	Moldova/	983
307	Tajikistan/	750
308	Turkey/	2380
309	Bangladesh/	16497
310	India/	132524
311	Indonesia/	19524
312	Myanmar/	4109
313	Nepal/	12539
314	Sri Lanka/	7855
315	Cambodia/	5014
316	Fiji/	1470
317	Malaysia/	21004
318	Papua New Guinea/	3914
319	Philippines/	9733
320	Vietnam/	14627
321	Gambia/	2233
322	Kenya/	19900
323	Zambia/	5842
324	Belize/	695
325	Brazil/	113295
326	Colombia/	19952
327	El Salvador/	1834
328	Panama/	2440
329	Jordan/	7190
330	Oman/	3153
331	Qatar/	3538
332	Saudi Arabia/	22006
333	Albania/	1838
334	"Republic of Belarus"/	2026
335	Bulgaria/	6070

336	Cyprus/	2432
337	Finland/	30937
338	Luxembourg/	1295
339	Macedonia.mp.	2282
340	Malta/	1640
341	Serbia/	6237
342	Slovenia/	5454
343	216 or 217 or 218 or 219 or 220 or 221 or 222 or 223 or 224 or 225 or 226 or 227 or 228 or 229 or 230 or 231 or 232 or 233 or 234 or 235 or 236 or 237 or 238 or 239 or 240 or 241 or 242 or 243 or 244 or 245 or 246 or 247 or 248 or 249 or 250 or 251 or 252 or 253 or 254 or 255 or 256 or 257 or 258 or 259 or 260 or 261 or 262 or 263 or 264 or 265 or 266 or 267 or 268 or 269 or 270 or 271 or 272 or 273 or 274 or 275 or 276 or 277 or 278 or 279 or 280 or 281 or 282 or 283 or 284 or 285 or 286 or 287 or 288 or 289 or 290 or 291 or 292 or 293 or 294 or 295 or 296 or 297 or 298 or 299 or 300 or 301 or 302 or 303 or 304 or 305 or 306 or 307 or 308 or 309 or 310 or 311 or 312 or 313 or 314 or 315 or 316 or 317 or 318 or 319 or 320 or 321 or 322 or 323 or 324 or 325 or 326 or 327 or 328 or 329 or 330 or 331 or 332 or 333 or 334 or 335 or 336 or 337 or 338 or 339 or 340 or 341 or 342	703172
344	215 or 343	799901
345	176 and 187 and 204 and 344	1553
346	limit 345 to (yr="2011 - 2021" and "all adult (19 plus years)")	1359

Table 2. Search Strategy in CINAHL (Ebsco) 19/08/21

No	40Term	Result
S1.	(M41H "Adult+")	1,909,679
S2.	TI (42 Cancer OR Carcinoma OR OR Neoplasm OR metast43ases cancer OR malignant) OR AB (Cancer OR Carcinom44a OR OR Neoplasm OR metastases cancer OR malignant) 45	460,558
S3.	TI (“Palliative46 care” OR “supportive care” OR hospice OR “End of life c47are” OR “terminal care” OR “supportive oncology” OR “E48nd stage disease” OR “terminally ill”) OR AB (“Palliative car4e” OR “supportive care” OR hospice OR “End of life care” OR “terminal care” OR “supportive oncology” OR “End stage disease” OR “terminally ill”)	52,109
S4.	TI (“Developing countr*” OR “poor countr*” OR “low income countr*” OR “lower middle income countr*” OR “upper middle income countr*”) OR AB (“Developing countr*” OR “poor countr*” OR “low income countr*” OR “lower middle income countr*” OR “upper middle income countr*”)	19,479

S5.	TX Brunei OR Kiribati OR Laos OR “Marshall Islands” OR Micronesia* OR Nauru* OR Palau* OR 'Solomon Islands*' OR Tonga OR Tuvalu* OR Vanuatu* OR Bhutan OR Maldives* OR “North Korea” OR “Timor Leste” OR Andorra OR Kosovo* OR Monaco OR Montenegro OR “San Marino*” OR Turkmenistan OR “Vatican City” OR Djibouti OR Iraq OR Somalia OR Somaliland OR Syria* OR Yemen OR “Antigua and Barbuda” OR Cuba OR Dominica* OR Grenada* OR Guyana OR “Saint Lucia” OR “St Kitts and Nevis*” OR “St Vincent and the Grenadines*” OR Suriname* OR “Cape Verde” OR “Central African Republic” OR Chad OR Comoro OR “Congo Republic” OR “Guinea-Bissau*” OR Lesotho OR Mali OR Seychelles OR “South Sudan” OR Uzbekistan OR Samoa OR “United Arab Emirates” OR Bahamas OR Haiti OR Algeria OR Benin OR Botswana OR Cameroon OR Congo OR Ethiopia OR Ghana OR Guinea OR Madagascar OR Mauretania OR Mauritius OR Mozambique OR Namibia OR Niger OR Nigeria OR Rwanda OR Senegal OR “Sierra Leone” OR Tanzania OR Togo OR Bolivia OR “Dominican Republic” OR Ecuador OR Guatemala OR Honduras OR Jamaica OR Nicaragua OR Paraguay OR Peru OR “Trinidad and Tobago” OR Venezuela OR Armenia OR Azerbaijan OR “Bosnia and Herzegovina” OR Croatia OR Estonia OR Greece OR Kyrgyzstan OR Moldova OR Tajikistan OR Turkey OR Bangladesh OR India OR Indonesia OR Myanmar OR Nepal OR “Sri Lanka” OR Cambodia OR Fiji OR Malaysia OR “Papua New Guinea” OR Philippines OR Vietnam OR Gambia OR Kenya OR Zambia OR Belize OR Brazil OR Colombia OR “El Salvador” OR Panama OR Jordan OR Oman OR Qatar OR “Saudi Arabia” OR Albania OR Belarus OR Bulgaria OR Cyprus OR Finland OR Luxembourg OR Macedonia OR Malta OR Serbia OR Slovenia	640,732
S6.	S4 OR S5	650,537
S4.	S1 AND S2 AND S3 AND S6	494

Table 6. Search Strategy in Medline (Ebsco) 18/08/21

ID	Term	Result
S1	(MH "Adult+")	7,551,522
S2	TI (Cancer OR Carcinoma OR OR Neoplasm OR metastases cancer OR malignant) OR AB (Cancer OR Carcinoma OR OR Neoplasm OR metastases cancer OR malignant)	2,191,508
S3	TI (“Palliative care” OR “supportive care” OR hospice OR “End of life care” OR “terminal care” OR “supportive oncology” OR “End stage disease” OR “terminally ill”) OR AB (“Palliative care” OR “supportive care” OR hospice OR “End of life care” OR	67,301

	"terminal care" OR "supportive oncology" OR "End stage disease" OR "terminally ill")	
S4	TI ("Developing countr*" OR "poor countr*" OR "low income countr*" OR "lower middle income countr*" OR "upper middle income countr*") OR AB ("Developing countr*" OR "poor countr*" OR "low income countr*" OR "lower middle income countr*" OR "upper middle income countr*")	70,986
S5	TX Brunei OR Kiribati OR Laos OR "Marshall Islands" OR Micronesia* OR Nauru* OR Palau* OR 'Solomon Islands*' OR Tonga OR Tuvalu* OR Vanuatu* OR Bhutan OR Maldives* OR "North Korea" OR "Timor Leste" OR Andorra OR Kosovo* OR Monaco OR Montenegro OR "San Marino*" OR Turkmenistan OR "Vatican City" OR Djibouti OR Iraq OR Somalia OR Somaliland OR Syria* OR Yemen OR "Antigua and Barbuda" OR Cuba OR Dominica* OR Grenada* OR Guyana OR "Saint Lucia" OR "St Kitts and Nevis*" OR "St Vincent and the Grenadines*" OR Suriname* OR "Cape Verde" OR "Central African Republic" OR Chad OR Comoro OR "Congo Republic" OR "Guinea-Bissau*" OR Lesotho OR Mali OR Seychelles OR "South Sudan" OR Uzbekistan OR Samoa OR "United Arab Emirates" OR Bahamas OR Haiti OR Algeria OR Benin OR Botswana OR Cameroon OR Congo OR Ethiopia OR Ghana OR Guinea OR Madagascar OR Mauretania OR Mauritius OR Mozambique OR Namibia OR Niger OR Nigeria OR Rwanda OR Senegal OR "Sierra Leone" OR Tanzania OR Togo OR Bolivia OR "Dominican Republic" OR Ecuador OR Guatemala OR Honduras OR Jamaica OR Nicaragua OR Paraguay OR Peru OR "Trinidad and Tobago" OR Venezuela OR Armenia OR Azerbaijan OR "Bosnia and Herzegovina" OR Croatia OR Estonia OR Greece OR Kyrgyzstan OR Moldova OR Tajikistan OR Turkey OR Bangladesh OR India OR Indonesia OR Myanmar OR Nepal OR "Sri Lanka" OR Cambodia OR Fiji OR Malaysia OR "Papua New Guinea" OR Philippines OR Vietnam OR Gambia OR Kenya OR Zambia OR Belize OR Brazil OR Colombia OR "El Salvador" OR Panama OR Jordan OR Oman OR Qatar OR "Saudi Arabia" OR Albania OR Belarus OR Bulgaria OR Cyprus OR Finland OR Luxembourg OR Macedonia OR Malta OR Serbia OR Slovenia	3,382,169
S6	S4 OR S5	3,416,004
S7	S1 AND S2 AND S3 AND S6	601

Table 3. Search Strategy in Web of science (Medline) 18/08/21

ID	Term	Result
#1	TI=(adult*)	286590
#2	TS=(Cancer OR Carcinoma OR Neoplasm OR "metastases ca ncer" OR malignant)	266943 3

#3	TS=("Palliative care" OR "supportive care" OR hospice OR "End of life care" OR "terminal care" OR "supportive oncology" OR "End stage disease" OR "terminally ill")	66402
#4	TS=("Developing countr*" OR "poor countr*" OR "low income countr*" OR "lower middle income countr*" OR "upper middle income countr*")	783443
#5	TI=(Brunei OR Kiribati OR Laos OR "Marshall Islands" OR Micronesia* OR Nauru* OR Palau* OR 'Solomon Islands*' OR Tonga OR Tuvalu* OR Vanuatu* OR Bhutan OR Maldives* OR "North Korea" OR "Timor Leste" OR Andorra OR Kosovo* OR Monaco OR Montenegro OR "San Marino*" OR Turkmenistan OR "Vatican City" OR Djibouti OR Iraq OR Somalia OR Somaliland OR Syria* OR Yemen OR "Antigua and Barbuda" OR Cuba OR Dominica* OR Grenada* OR Guyana OR "Saint Lucia" OR "St Kitts and Nevis*" OR "St Vincent and the Grenadines*" OR Suriname* OR "Cape Verde" OR "Central African Republic" OR Chad OR Comoro OR "Congo Republic" OR "Guinea-Bissau*" OR Lesotho OR Mali OR Seychelles OR "South Sudan" OR Uzbekistan OR Samoa OR "United Arab Emirates" OR Bahamas OR Haiti OR Algeria OR Benin OR Botswana OR Cameroon OR Congo OR Ethiopia OR Ghana OR Guinea OR Madagascar OR Mauretania OR Mauritius OR Mozambique OR Namibia OR Niger OR Nigeria OR Rwanda OR Senegal OR "Sierra Leone" OR Tanzania OR Togo OR Bolivia OR "Dominican Republic" OR Ecuador OR Guatemala OR Honduras OR Jamaica OR Nicaragua OR Paraguay OR Peru OR "Trinidad and Tobago" OR Venezuela OR Armenia OR Azerbaijan OR "Bosnia and Herzegovina" OR Croatia OR Estonia OR Greece OR Kyrgyzstan OR Moldova OR Tajikistan OR Turkey OR Bangladesh OR India OR Indonesia OR Myanmar OR Nepal OR "Sri Lanka" OR Cambodia OR Fiji OR Malaysia OR "Papua New Guinea" OR Philippines OR Vietnam OR Gambia OR Kenya OR Zambia OR Belize OR Brazil OR Colombia OR "El Salvador" OR Panama OR Jordan OR Oman OR Qatar OR "Saudi Arabia" OR Albania OR Belarus OR Bulgaria OR Cyprus OR Finland OR Luxembourg OR Macedonia OR Malta OR Serbia OR Slovenia)	606124
# 6	#5 OR #4	1226861
# 7	#6 AND #3 AND #2 AND #1	21

Table 4. Search Strategy in Cochrane 07 August 21

ID	Term	Result
#1	MeSH descriptor: [Adult] explode all trees	476600
#2	MeSH descriptor: [Neoplasms] explode all trees	83140

#3	(Cancer OR Carcinoma OR Neoplasm OR "metastases cancer" OR malignant):ti,ab	172787
#4	(Connor et al.-#3)	198139
#5	MeSH descriptor: [Palliative Care] explode all trees	1684
#6	("Palliative care" OR "supportive care" OR hospice OR "End of life care" OR "terminal care" OR "supportive oncology" OR "End stage disease" OR "terminally ill"):ti,ab	7004
#7	(Nuranna et al.-#6)	8089
#8	MeSH descriptor: [Developing Countries] explode all trees	878
#9	(Developing countr* OR poor countr* OR low income countr* OR lower middle income countr* OR upper middle income countr*):ti,ab	7760
#10	(Brunei OR Kiribati OR Laos OR “Marshall Islands” OR Micronesia* OR Nauru* OR Palau* OR 'Solomon Islands*' OR Tonga OR Tuvalu* OR Vanuatu* OR Bhutan OR Maldives* OR “North Korea” OR “Timor Leste” OR Andorra OR Kosovo* OR Monaco OR Montenegro OR “San Marino*” OR Turkmenistan OR “Vatican City” OR Djibouti OR Iraq OR Somalia OR Somaliland OR Syria* OR Yemen OR “Antigua and Barbuda” OR Cuba OR Dominica* OR Grenada* OR Guyana OR “Saint Lucia” OR “St Kitts and Nevis*” OR “St Vincent and the Grenadines*” OR Suriname* OR “Cape Verde” OR “Central African Republic” OR Chad OR Comoro OR “Congo Republic” OR “Guinea-Bissau*” OR Lesotho OR Mali OR Seychelles OR “South Sudan” OR Uzbekistan OR Samoa OR “United Arab Emirates” OR Bahamas OR Haiti OR Algeria OR Benin OR Botswana OR Cameroon OR Congo OR Ethiopia OR Ghana OR Guinea OR Madagascar OR Mauretania OR Mauritius OR Mozambique OR Namibia OR Niger OR Nigeria OR Rwanda OR Senegal OR “Sierra Leone” OR Tanzania OR Togo OR Bolivia OR “Dominican Republic” OR Ecuador OR Guatemala OR Honduras OR Jamaica OR Nicaragua OR Paraguay OR Peru OR “Trinidad and Tobago” OR Venezuela OR Armenia OR Azerbaijan OR “Bosnia and Herzegovina” OR Croatia OR Estonia OR Greece OR Kyrgyzstan OR Moldova OR Tajikistan OR Turkey OR Bangladesh OR India OR Indonesia OR Myanmar OR Nepal OR “Sri Lanka” OR Cambodia OR Fiji OR Malaysia OR “Papua New Guinea” OR Philippines OR Vietnam OR Gambia OR Kenya OR Zambia OR Belize OR Brazil OR Colombia OR “El Salvador” OR Panama OR Jordan OR Oman OR Qatar OR “Saudi Arabia” OR Albania OR Belarus OR Bulgaria OR Cyprus OR Finland OR Luxembourg OR Macedonia OR Malta OR Serbia OR Slovenia):ti,ab	37443
#11	{OR #8-#10}tr	42489
#12	#1 AND #4 AND #7 AND #11 with Publication Year from 2011 to 2021, with Cochrane Library publication date Between Jan 2011 and Jan 2021, in Trials	16

Appendix 4 Data extraction

Author (year) Country/Region /Study design	**Description of the study sample /setting**	**Objectives**	**Findings**			**Quality appraisal**
			Main components	Mode of operation	Requirements	
1. (Hartwig et al., 2014) Tanzania/Africa Mixed-methods quantitative: survey patients. Qualitative: interview nurses.	145 adults with cancer across 13 hospitals and 6 nurses who had worked in palliative care (PC) minimum 7 years.	To demonstrate the effectiveness of palliative care teams in reducing pain and increasing other positive life qualities in the absence of morphine and to document the psychological burden of clinical providers, trained the morphine delivery.	Integration of palliative care	Hospital-based teams with transport that provided home-based care. Home visit: nurses visit patients with cancer at home and measure their POS and monitor pain and the quality of care.	Organise care support: the staff could reduce the pain level, increase other positive life qualities, document the burden and trained in morphine delivery.	5-High
2. (Shabnam et al., 2018) Bangladesh/Asia Mixed-methods quantitative: analyses patients' calls. Quantitative: interview the staff who answer the calls.	A literature scoping review Descriptive analysis: 4,195 calls. A semi-structured group interview was conducted with the PC physicians on the development of the service and their experiences of delivering it. One clinical pharmacist and four physicians answered the phone calls.	1st: To answer the question 'What is the existing literature on 24/7 telephone consultation in PC for patients and their carers subsequently?' 2nd: To analyse the calls to the services. A retrospective descriptive analysis of the total number of calls (4,195 calls). 3rd: To explore the staff's feelings when	Integration of palliative care consultation free call, the patient/family should register as patient/ users in the hospital.	Hospital-based consultations; commonly callers asked about medication usage, symptom management, psychologist support, anxiety, admission, ambulances, food and other problems.	Provide direct care work. The staff could make the patients feel they had someone on the telephone to whom they could talk if there were any problems.	5-High

Author (year) Country/Region /Study design	Description of the study sample /setting	Objectives	Findings			Quality appraisal
			Main components	Mode of operation	Requirements	
		delivering the services.				
3. (Chacko et al., 2014b) India/Asia Mixed-methods quantitative; self-administered questionnaires, qualitative: interview.	Questionnaires for 140 patients and 40 healthcare professionals. Interviews: structured interviews with patients and a self-administered questionnaire from healthcare professionals.	To explore the end-of-life care perspectives both of patients with advanced carcinoma and of healthcare professionals in a tertiary healthcare setting in India.	Integration of palliative care and cancer rehabilitation. Chemotherapy and radiotherapy.	Community-based palliative care. Patient outcomes reported. Interviewed patients about their emotional, social, physical and spiritual dimensions on end-of-life preferences. The healthcare professional filled out a similar questionnaire.	Work in a unidisciplinary and an interdisciplinary way. Nurses and physicians should be proactive in offering key support services to ensure patient autonomy and facilitate a good death.	3-Moderate
4. (Kapoor et al., 2017b) India/Asia Quantitative: RCT	Adult female patients with advanced cancer were divided into 2 groups: the intervention group (30 patients) and the control group (33 patients). Both groups were provided with nutritional counselling. The intervention group received 100 g of flour to be consumed.	To assess the efficacy of nutritional addition (with counselling) in enhancing the health status of cachexia patients. Counselling regarding nutrition can improve the anthropometric status and quality of life of adults with cancer who also have cachexia.	Integration of palliative care and consultation Counselling	Hospital-based. Provided nutrition and counselling.	The staff could give nutritional advice plus a consultation. Patient/family could prepare the nutrition from sustainable ingredients/local food with minimum training.	3-Moderate
5. (Rozman et al., 2021a) Brazil/Latin America	A data analysis of the prospective healthcare facility, formal healthcare sector costs of 2,985 adult patients who received PC.	To identify the sociodemographic and clinical variables that could explain the cost per day of PC for cancer in	Clinical consultations, interdisciplinary consultations, hospital admissions, emergency	Hospital-based services. The PC services are provided by a	Organise care support. Partnership organisation regarding providing palliative services.	5-High

Author (year) Country/Region /Study design	**Description of the study sample /setting**	**Objectives**	**Findings**			**Quality appraisal**
			Main components	Mode of operation	Requirements	
Quantitative: description of costs.	The unit cost values level was collected from a database.	Brazil. Measuring the cost of treatment for patients with cancer during hospitalisation.	department visits, intensive care unit admissions, surgical procedures, chemotherapy, medication, laboratory tests, medical supplies, hospital supplies and hospice care.	multidisciplinary team organised for outpatient, inpatient and hospice care.	Patient care in formal healthcare can be integrated into oncologic care or can be provided separately. Works in a formal partnership with other institutions.	
6. (Shamieh et al., 2017) Jordan/Middle East Quantitative	182 adult patients with advanced cancer; they had consultations in outpatient palliative care clinic	To examine the symptom changes among adults with cancer at a palliative care clinic in Jordan.	Integration of palliative care: the palliative care outpatient clinic, inpatient consultation service, palliative care unit and home palliative care programme.	Hospital-based services. Outpatient palliative care consultation associated with improvement on ESAS, particularly for patients with moderate-severe symptoms	Interdisciplinary trained staff provide the services (American Board Certified in Hospice and Palliative Medicine, registered nurses trained in palliative care and wound management, and a clinical pharmacist, social worker and spiritual advisor).	5-High
7. (Krishnan et al., 2018b) India/Asia Quantitative	3,270 patients with cancer who visited the Trivandrum Institute of Palliative Sciences (TIPS) between 2014 and 2016.	To describe the delivery of care by the TIPS in Trivandrum, India, including case volumes, care setting, and organisational expenditures. An estimate of the cost ($) per clinical encounter was derived from	Integrating palliative care and cancer rehabilitation psychiatric consultation involves the social workers and family. TIPS is a WHO collaborating centre for training and policy regarding access to pain relief.	Home-based community. Provide inpatient, outpatient and home-based community-oriented palliative care.	Organisation has a fund for training staff and providing interventions via policies or the palliative service. TIPS Policymakers must address palliative care as an essential entity and take necessary steps to improve access by establishing palliative care.	5-High

Author (year) Country/Region /Study design	**Description of the study sample /setting**	**Objectives**	**Findings**			**Quality appraisal**
			Main components	Mode of operation	Requirements	
		monthly clinical expenditures by the number of patient visits.	Pallium India was instrumental in the adoption of the Palliative Care Policy by the government of Kerala.		TIPS works closely with other NGOs to form a link centre in the community. TIPS provides a 13-bed inpatient service at Arumana Hospital (AH).	
8. (Damani et al., 2020a) India/Asia Quantitative	80 of the 102 PC centres provide information about PC services. The respondents: 31 PC staff (34.8%), 2 hospital administrators (2.1%), 47 oncology service staff (53.3%) and 9 clinicians (9.8%). They have no dedicated funds for PC, have no support from the hospital administration, and a staff shortage: no social workers, no counsellors and no volunteers. Although end-of-life care is recognised, there is a lack of institutional support.	To identify gaps in palliative care provision across National Cancer Grid centres in India.	Integration of palliative care and cancer rehabilitation. Doctors with generalist PC training, full-time PC physicians; nurses with 6 weeks of PC training, and an outpatient PC unit with the facility to provide inpatient PC, a hospice referral offers concurrent cancer therapy alongside PC, a licence to procure, store and dispense opioids, and have an uninterrupted supply of oral morphine for patients; policy; taking part in quality control measures.	Home-based PC services.	Need collaboration between oncologists, PC specialists, executives from the public and private sectors, and government to enhance the delivery of high-quality PC for patients with cancer in India. The National Cancer Grid mandate is to have uniform standards of cancer care across the country (and globally) and to work towards reducing inequities in care. NCG now covers almost the entire length and breadth of the country and is among the most extensive cancer networks in the world.	5-High
9. (Tapela et al., 2016b)	The hospital had 152 beds and the following departments: emergency,	To describe programme-level experience of	Integration of palliative care and cancer care.	Hospital-based. Collaboration between two organisations to	The partnership will enhance the PC services. Butaro Cancer	5-High

Author (year) Country/Region /Study design	Description of the study sample /setting	Objectives	Findings			Quality appraisal
			Main components	Mode of operation	Requirements	
Rwanda/Africa Quantitative	general medicine, paediatrics, surgery, maternity, two operating theatres and a neonatal intensive care unit. It had 160 employees (including 67 medical and 30 paramedical). Butaro hospital suitable for a model oncology programme. A 27-bed cancer ward was converted for inpatient care, and a weekly cancer outpatient clinic was integrated into the non-communicable diseases clinic roster.	implementing, patient characteristics and challenges encountered.	Histopathology-based diagnosis, X-ray and ultrasound imaging, chemotherapy, selected surgical procedures, palliative care, and socioeconomic support delivered by a multidisciplinary team.	provide palliative care. With no oncology specialists on-site, care was delivered through task-shifting, structured twinning and long-term collaboration between organisations. Generalist physicians prescribed chemotherapy and performed biopsies. Nurses mixed and administered chemotherapy. Clinicians followed standardised protocols-based experts through weekly 'tumor board-like' conference calls and emails.	Centre demonstrates that, with partnerships and support, complex cancer care can be delivered in the most commonly provided infrastructure by staff using non-specialised consumables complementary to oncology services. The average cost per patient receiving a 6-week course of chemoradiation amounts to over USD 500,000 per year. Patients paid 10%; 90% was covered by funding from grants, foundations and private donations.	
10. (Kristanti, Setiyarini and Effendy, 2017a) Indonesia/Asia Quantitative	41 family caregivers entered the study; 30 participants completed the study. The family caregivers were those of patients with stage 3 or 4 cancer,	To evaluate how basic skills training (BST) given to family caregivers could enhance the quality of life (QoL) of the palliative	Involve the social workers and family meetings. Three training sessions for the family caregivers were provided. Two weeks later, the nurse educators visited	Home-based services. Trained the family caregiver who would care for the patient with cancer at home.	Organise care support. Staff developed an intervention centred on an educational package to encourage interaction	4-High

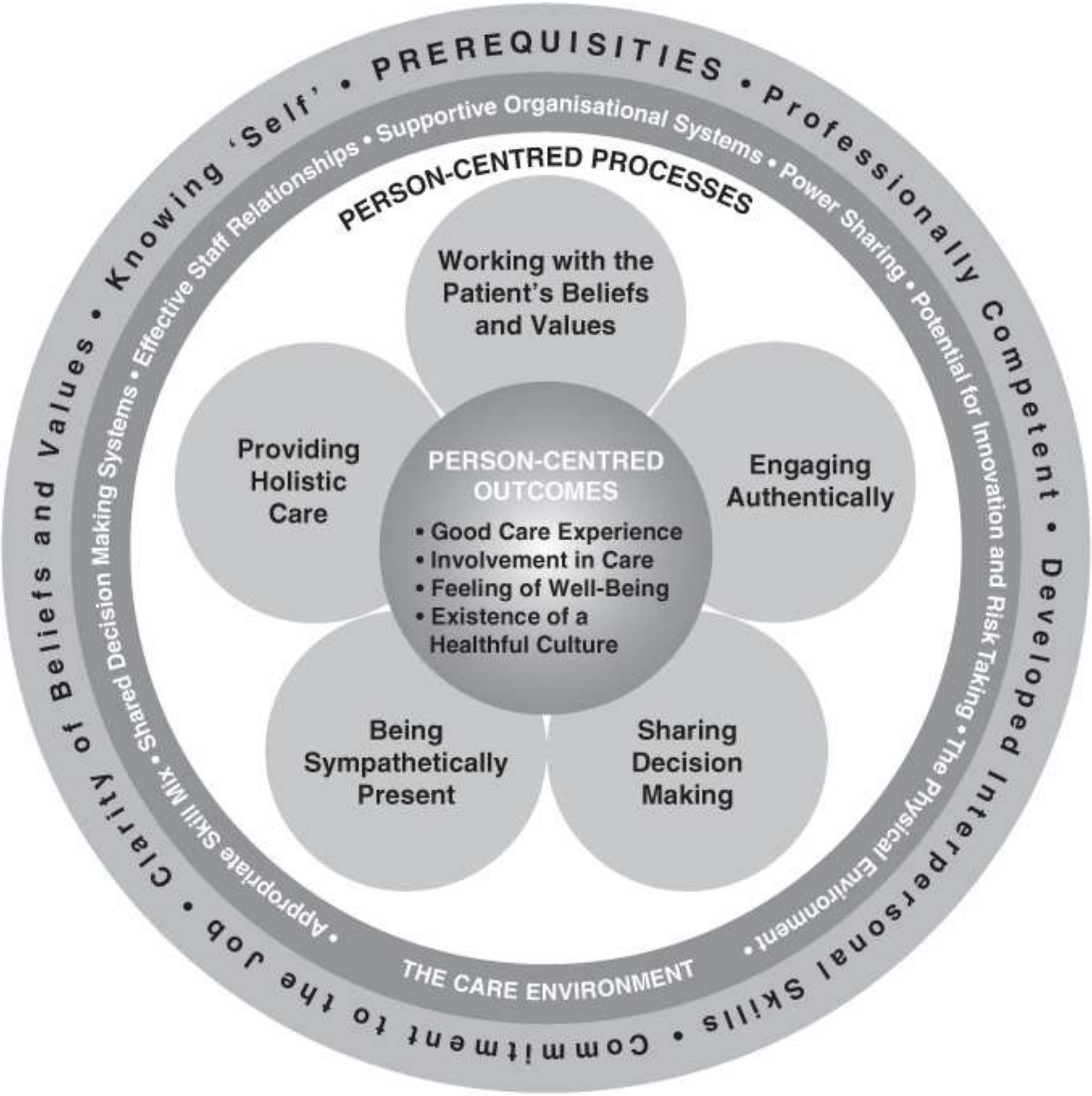
Author (year) Country/Region /Study design	Description of the study sample /setting	Objectives	Findings			Quality appraisal
			Main components	Mode of operation	Requirements	
	with a Palliative Performance Scale score of <60, who went to the hospital.	care of adults with cancer in Indonesia.	patients' homes to encourage the family caregivers and assist them to develop their skills in providing personal care and to provide further information if required. During the third visit 1 month after patients' discharge from hospital, nurse educators visited the patients' homes and collected further data on the patients' QoL.		between family caregivers and nurse educators. The package included a 1-hour video (on CD) and a module consisting of five chapters on skills for assisting a bedridden patient at home. The skill to measure the meaningful change in patients' global health status/ QoL and financial hardship after receiving the service from skilled family.	
11. (Silbermann et al., 2015) Middle Eastern countries Quantitative	15 Middle Eastern countries	To determine knowledge, beliefs, barriers, and resources regarding palliative care services in the Middle Eastern countries and to use findings to inform future educational and training activities.	Integration of palliative care and cancer care. Pain management consultative team, Quality improvement for pain management, symptom management, discharge planning for patients with chronic illness, consultation service, quality improvement for end-of-life care, interdisciplinary care	Hospital-based. Most were satisfied. The delivery of pain and symptom management; least satisfied with the discussion around advanced directives.	Work in a unidisciplinary and an interdisciplinary way. The staff's ability to offer the palliative care services is related to pain management using non-pharmacologic therapy, multimodal therapy, nonsteroidal anti-inflammatory drugs, limited doses of injectable opioids and complementary alternative medicine	5-High

Author (year) Country/Region /Study design	**Description of the study sample /setting**	**Objectives**	**Findings**			**Quality appraisal**
			Main components	Mode of operation	Requirements	
			programme for dying patients, contractual relationship with other hospice progras, promote advanced care planning, Programme for staff to support caring for dying patients; bereavement programme.		due to the limited painkillers available. In many Middle Eastern countries, symptom management of mild cancer pain is controlled without medication, while moderate to severe pain appears to be controlled using painkillers.	
12. (Abdulla et al., 2021) Malaysia & Indonesia/Asia Qualitative	12 PC staff in the hospital, 6 nurses with >2 years of palliative care experience, and 6 physicians with work' experience of >2 years and had receive any palliative care training within preceding 6 months.	To explore the perspectives of palliative care decision-making for palliative patients and families in Indonesia and Malaysia.	Care culture and spirituality. Spiritual end-of-life approach. Hospital applies a palliative care service that includes a good death concept for their patients' care management with the Muslim concept, which is related to the palliative care goals of care.	Hospital-based service.	Family caregivers are involved as volunteers. Nurses played a supportive role in ensuring that the patients' and families' care was effective and efficient. Their role involved the following: 1) being a caregiver for the patients and their families, 2) being an educator 3) being a facilitator 4) being an advocate 5) providing information 6) being a coordinator 7) giving suggestions to doctors during discussions about patients' care management	5-High

Author (year) Country/Region /Study design	Description of the study sample /setting	Objectives	Findings			Quality appraisal
			Main components	Mode of operation	Requirements	
					8) obeying all patient care plans with confidence and competency.	
13. (Adejoh et al., 2021) Nigeria, Uganda, and Zimbabwe/ Sub-Saharan Africa Qualitative	48 adult caregivers as: 'unpaid, informal providers who provide one or more physical, social, practical, and emotional tasks'.	To determine optimal mechanisms through which patient-level data can be used in the development and delivery of palliative cancer care.	Integration of palliative care: 1) Caregivers are coordinators of emotional, practical and health service matters 2) Caregiving comes at a personal, social and financial cost across countries 3) Practical and emotional support received and required 4) Experience in interacting and liaising with palliative care services 5) Recommendations relating to improving access to palliative care.	Home-based services. The challenges of caregiving for adults with cancer in these countries were context-bound features such as the financial, transport and nutritional information needs of informal caregivers in Sub-Saharan Africa.	Provide direct care. The study confirms that caregivers are a crucial partner in the provision of palliative care for people with advanced cancer, taking care of the majority of patients' medical, physical, financial (fundraising for treatment), emotional and spiritual (prayer) needs. The caregiver burden across the three countries involve varying sacrifice relating to employment, finances and their own health and social life.	5-High
14. (Ndiok and Ncama, 2021) Nigeria/Africa Qualitative	19 nurse managers in 2 hospitals based on the prominence of their roles in each hospital in policy	To identify barriers to and benefits of establishing a model for integration of palliative care of adults with cancer in	Provision of palliative care. Participants were asked about their barriers to achieving the PC model.	Hospital-based. Challenges in implementing PC services in hospitals can be overcome by instituting workable	Work in a unidisciplinary and an interdisciplinary way. Social supports play a pertinent role in buffering emotional distress and need	5-High

Author (year) Country/Region /Study design	Description of the study sample /setting	Objectives	Findings			Quality appraisal
			Main components	Mode of operation	Requirements	
	formulation and in conveying the policies of the major actors in caregiving.	daily clinical practice in tertiary health institutions by focus group discussions and individual interviews with stakeholders.	The resulting themes: barriers, potential benefits, patient and family outcomes.	models and policies, adequate allocation of funds, and appropriate monitoring of PC activities.	investment to ramp up mental health workforce capacities.	
15. (Rajah et al., 2021a) Malaysia/Asia Qualitative	102 patients diagnosed with primary colorectal, prostate, cervical or breast cancer.	To explore the sources of emotional distress, the related support, and the unmet needs of cancer survivors in Malaysia, where cancer survivorship services are presently limited.	Community-based palliative care. Compassionate and holistic care approach in an integrated system. Financial problems in setting up a PC team, denial or rejection by patient or family of cancer diagnosis (based on ignorance, religious beliefs or culture) and inadequate knowledge or inappropriate attitude of nurses; fault in check-in barriers to palliative care model appointments; lack of staff; monitoring and supervision of funds and programmes.	The barriers to the adoption of a PC model included financial problems in setting up a PC team.	Organise care support. Lack of staffing, monitoring and supervision of funds and programmes.	5-High

Appendix 5 Person centred nursing theory



Appendix 6 Ethics approval

KEMENTERIAN KESEHATAN REPUBLIK INDONESIA
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rshs

PERSETUJUAN ETIK
ETHICAL APPROVAL

NOMOR : LB.02.01/X.6.5/344/2019

Yang bertanda tangan di bawah ini, Komite Etik Penelitian Kesehatan Rumah Sakit Umum Pusat Dr. Hasan Sadikin Bandung, setelah dilaksanakan pembahasan dan penilaian pada tanggal 28 November 2019, dengan ini memutuskan dan menyetujui protokol penelitian berjudul :

"Pengembangan Intervensi Keperawatan Paliatif Oleh Perawat Untuk Pasien Kanker dan Pengasuhnya Dengan Keterbatasan Sumberdaya di Jawa Barat Indonesia"

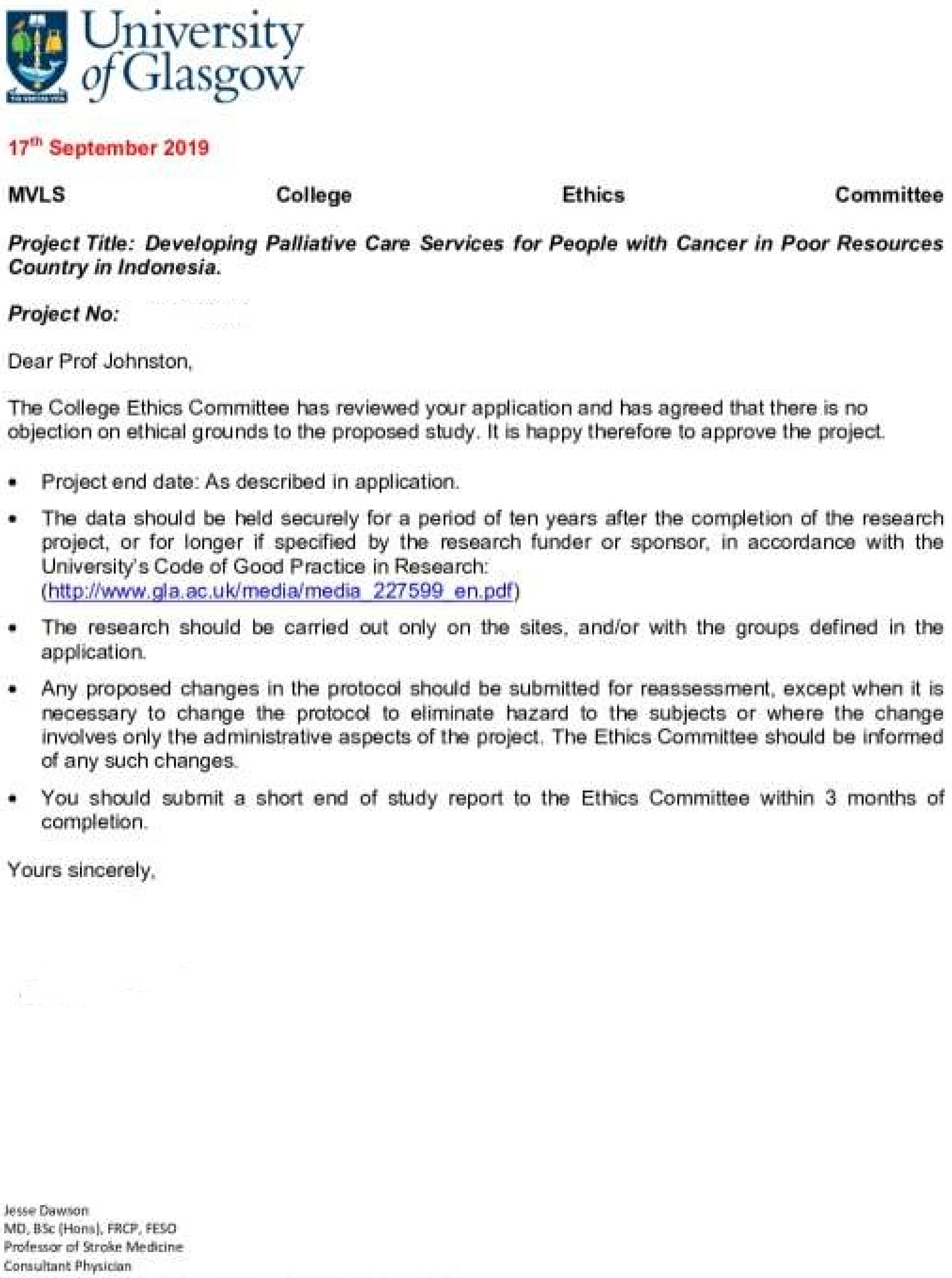
Nama Peneliti Utama : Chandra Isabella Hostanida Purba, S.Kp., M.Kep
No. NPM
Nama Institusi : PhD Nursing
School of Medicine, Dentistry and Nursing
College of Medical, Veterinary & Life Sciences
University of Glasgow Scotland, United Kingdom
Perbaikan diterima tanggal : 2 Desember 2019

Protokol tersebut dapat disetujui pelaksanaannya.

Pada akhir penelitian, **laporan pelaksanaan penelitian harus diserahkan kepada Komite Etik Penelitian Kesehatan RSUP Dr. Hasan Sadikin Bandung.** Jika ada perubahan protokol dan/atau perpanjangan penelitian, harus mengajukan kembali permohonan kajian etik penelitian (amandemen protokol).

***_Ethical approval_ berlaku satu tahun dari tanggal persetujuan**
**Peneliti berkewajiban :

1. Menjaga kerahasiaan identitas subjek penelitian
2. Memberitahukan status penelitian apabila :
    a. Setelah masa berlakunya keterangan lolos kaji etik, penelitian masih belum selesai, dalam hal ini *ethical approval* dan surat izin penelitian harus diperpanjang
    b. Penelitian berhenti ditengah jalan
3. Melaporkan kejadian serius yang tidak diinginkan (*serious adverse events*)
4. Melaporkan pelaksanaan penelitian secara berkala
5. Peneliti tidak boleh melakukan tindakan apapun pada subyek sebelum penelitian lolos kaji etik, *informed consent* dan surat izin penelitian.



University of Glasgow

17th September 2019

MVLS College Ethics Committee

Project Title: Developing Palliative Care Services for People with Cancer in Poor Resources Country in Indonesia.

Project No:

Dear Prof Johnston,

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project.

- Project end date: As described in application.
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research: (http://www.gla.ac.uk/media/media_227599_en.pdf)
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely,

Jesse Dawson
MD, BSc (Hons), FRCP, FESO
Professor of Stroke Medicine
Consultant Physician

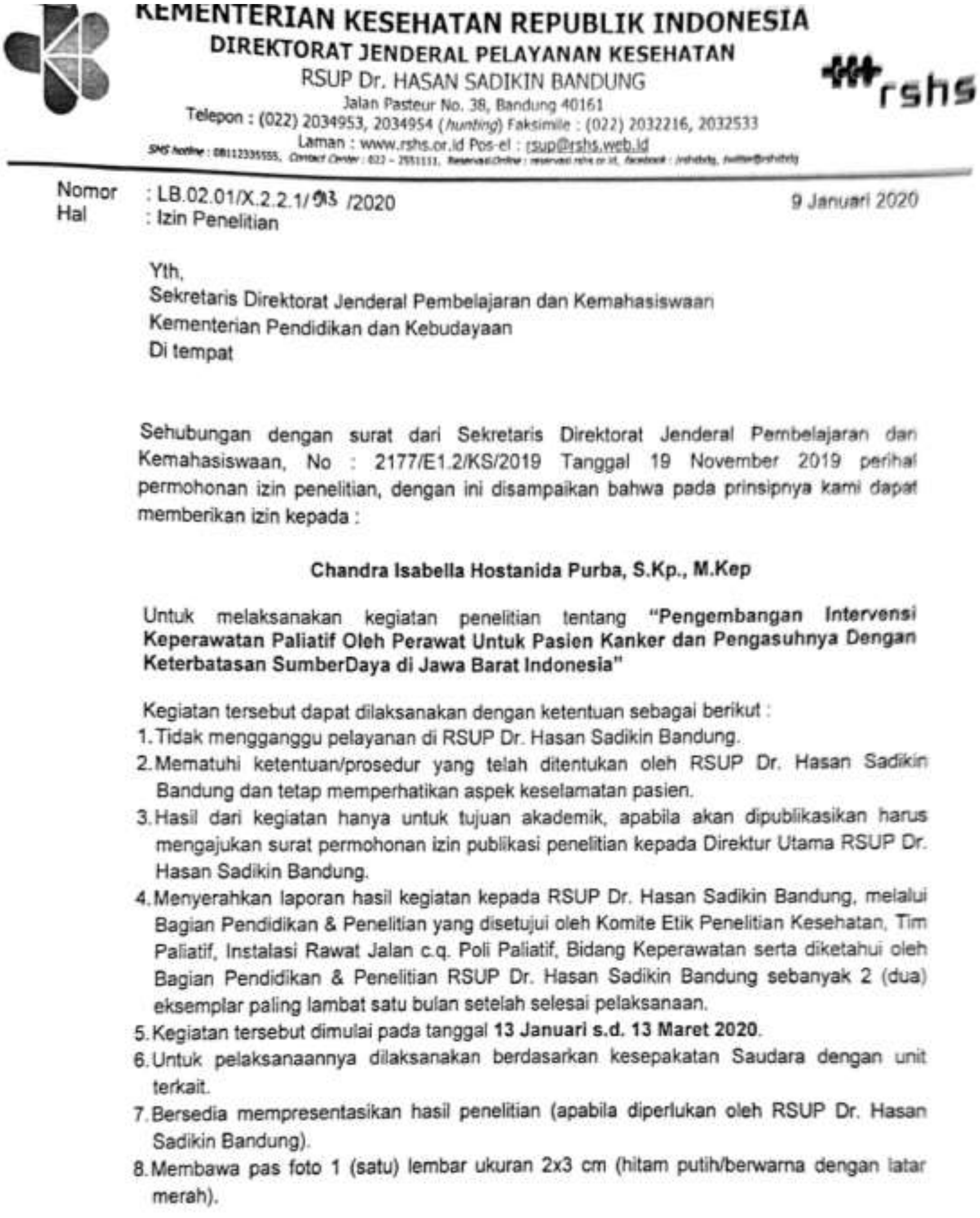
Appendix 7 Research methodology

Details	**STAGES**			
	1	**2**	**3**	**4**
Purpose	Outline/justify the main components of the service and suggest the mode of operation in West Java by synthesising empirical evidence generated in previous stages with a systematic review of evidence on palliative care service development in resource-challenged countries.	Investigate the current service, patient access, and existing palliative care service.	Survey patient reported outcomes, level of need, and burdens of people and families who access the hospital.	Explore the patient's/family's/health care providers' preferences regarding and expectations and views of a refined service and an embedded, nurse-led intervention.
Data collection location	University of Glasgow	Palliative care clinic, Hasan Sadikin Hospita	Hasan Sadikin Hospital Shelters around the hospital	Patient house/ Family house Hospital/shelters
Time	10 months: 01 Sept 2021-02 July 2022	Two weeks in November 2019	12 weeks: 01 Nov 2019-31 Jan 2020	6 weeks: 01 Jan-20 Feb 20
Population	Relevant articles	Organisation's structure and communication between staff and other departments. Documents, clinical pathway, medical records, letters confirming tasks/work orders.	Adults with cancer and their family caregivers in Hasan Sadikin Hospital.	Adults with cancer in Hasan Sadikin Hospital Family caregiver Staff of palliative care
Sample	Relevant articles	Documents, clinical pathway, medical records, letters confirming tasks.	Adults with cancer and family caregivers in Hasan Sadikin hospital meet the criteria. Sample size calculations were made using the Slovin formula.	Adults with cancer in Hasan Sadikin hospital who meet the criteria. Family caregivers Palliative care providers who meet the criteria.

Details	STAGES			
	1	2	3	4
Sample size	All relevant articles	All relevant documents	220 patients and 227 families	10 patients were chosen for their characteristics shown in the stage 2 findings: age, gender, needs, burdens, type of cancer, and others. 10 families were chosen, nominated by the patient
Sampling technique	Purposive sampling	Total sampling	Convenience sampling.	Patients: purposive sampling Family caregivers' members: convenience sampling Staff: convenience sampling.
Inclusion & exclusion criteria	Relevant articles .	All documents about palliative care services	Inclusion criteria for patients: Adult 18 years old and over. Person with cancer who accesses palliative care services in the hospital. Exclusion criteria for patients: Patient who is too weak to answer questions. Patient with high cognitive dysfunction, a diagnosis of delirium or experiencing mental disorders. Inclusion criteria for family members: Adult aged 18 years old and over. Has relation with patient (spouse/children/parents/siblings/other relatives) Acts as the main carer for the patient. Exclusion criteria for family: None.	Inclusion criteria for patients: Adult patient 18 years old and over Person with cancer who accesses palliative care services in the hospital. Exclusion criteria for patients: Patient who is too weak to answer questions. Patient with high cognitive dysfunction, diagnosis of delirium or experiencing mental disorders. Inclusion criteria for the family: Adult patient 18 years old and over. Has relation with patient (spouse/children/parents/siblings/other relatives) Act as the main carer for the patient Exclusion criteria: for family: None. Inclusion criteria for staff: Member of the palliative

Details	**STAGES**			
	1	**2**	**3**	**4**
				care team, as confirmed by their appointment letter representative of the interdisciplinary palliative care team. Exclusion criteria for staff: none.
Data collection instruments	Literature searching	Study list: Organisation's structure exists, and communication. Observation of task performance.	Demographics/clinical characteristics form for patients and families. The Integrated Palliative Outcomes Scale (IPOS), The Supportive Care Needs Survey (SCNS) 34/45 for patient and partner/family. Zarit Caregiver Burden (ZBI).	Demographics/clinical characteristics form for patients. Demographic characteristics form for families. Demographic characteristics form for staff. Semi-structured interviews using interview guides devised for this research
Method	Mixed methods: synthesis	Qualitative: descriptive	Quantitative: surveys	Qualitative: interview
Outcomes	List the main components of the service and suggest the mode of operation in West Java compared to that in other resource-challenged countries.	Description of the current service, patient access and services provided by existing palliative care services.	Statistic description of the outcomes, level of need and burdens of people who access the hospital.	Lists of patient's/family's/health care providers' expectations of a nurse-led intervention service.
Data analysis	Data were analysed using a systematic literature review.	Data were transcribed and analysed using *NVivo* programme	Data were analysed using Statistical *Product and Service Solutions (SPSS).*	Data were transcribed and analysed using *NVivo* programme.

Appendix 8 Research permit from Indonesia Government Indonesia



KEMENTERIAN KESEHATAN REPUBLIK INDONESIA
DIREKTORAT JENDERAL PELAYANAN KESEHATAN
RSUP Dr. HASAN SADIKIN BANDUNG
Jalan Pasteur No. 38, Bandung 40161
Telepon : (022) 2034953, 2034954 (*hunting*) Faksimile : (022) 2032216, 2032533
Laman : www.rshs.or.id Pos-el : rsup@rshs.web.id
SMS hotline : 08112335555, Contact Center : 022 – 2551111, Reservasi Online : reservasi.rshs.or.id, facebook : /rshsbdg, twitter@rshsbdg

rshs

Nomor : LB.02.01/X.2.2.1/93 /2020
Hal : Izin Penelitian

9 Januari 2020

Yth,
Sekretaris Direktorat Jenderal Pembelajaran dan Kemahasiswaan
Kementerian Pendidikan dan Kebudayaan
Di tempat

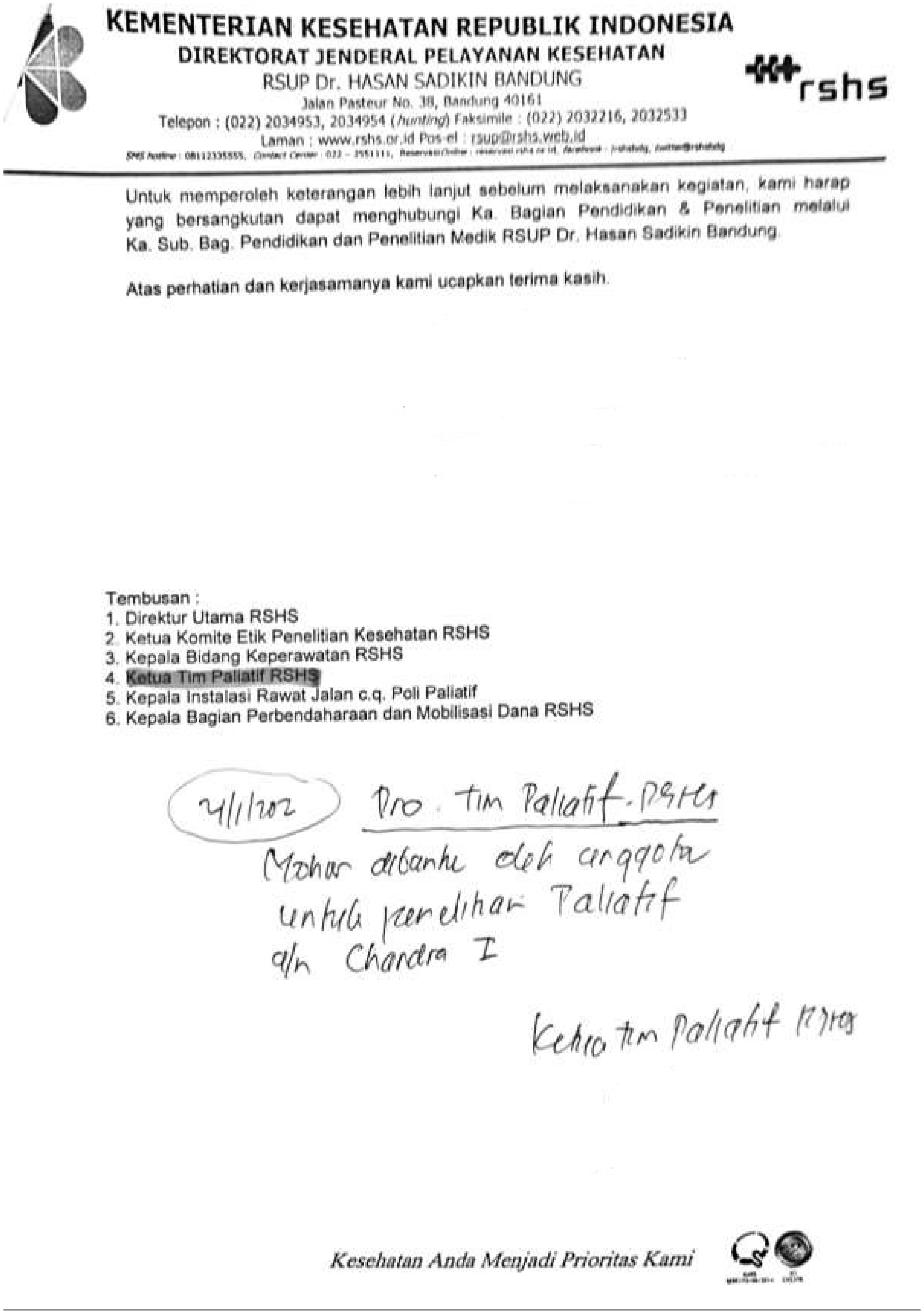
Sehubungan dengan surat dari Sekretaris Direktorat Jenderal Pembelajaran dan Kemahasiswaan, No : 2177/E1.2/KS/2019 Tanggal 19 November 2019 perihal permohonan izin penelitian, dengan ini disampaikan bahwa pada prinsipnya kami dapat memberikan izin kepada :

Chandra Isabella Hostanida Purba, S.Kp., M.Kep

Untuk melaksanakan kegiatan penelitian tentang **"Pengembangan Intervensi Keperawatan Paliatif Oleh Perawat Untuk Pasien Kanker dan Pengasuhnya Dengan Keterbatasan SumberDaya di Jawa Barat Indonesia"**

Kegiatan tersebut dapat dilaksanakan dengan ketentuan sebagai berikut :

1. Tidak mengganggu pelayanan di RSUP Dr. Hasan Sadikin Bandung.
2. Mematuhi ketentuan/prosedur yang telah ditentukan oleh RSUP Dr. Hasan Sadikin Bandung dan tetap memperhatikan aspek keselamatan pasien.
3. Hasil dari kegiatan hanya untuk tujuan akademik, apabila akan dipublikasikan harus mengajukan surat permohonan izin publikasi penelitian kepada Direktur Utama RSUP Dr. Hasan Sadikin Bandung.
4. Menyerahkan laporan hasil kegiatan kepada RSUP Dr. Hasan Sadikin Bandung, melalui Bagian Pendidikan & Penelitian yang disetujui oleh Komite Etik Penelitian Kesehatan, Tim Paliatif, Instalasi Rawat Jalan c.q. Poli Paliatif, Bidang Keperawatan serta diketahui oleh Bagian Pendidikan & Penelitian RSUP Dr. Hasan Sadikin Bandung sebanyak 2 (dua) eksemplar paling lambat satu bulan setelah selesai pelaksanaan.
5. Kegiatan tersebut dimulai pada tanggal **13 Januari s.d. 13 Maret 2020.**
6. Untuk pelaksanaannya dilaksanakan berdasarkan kesepakatan Saudara dengan unit terkait.
7. Bersedia mempresentasikan hasil penelitian (apabila diperlukan oleh RSUP Dr. Hasan Sadikin Bandung).
8. Membawa pas foto 1 (satu) lembar ukuran 2x3 cm (hitam putih/berwarna dengan latar merah).



KEMENTERIAN KESEHATAN REPUBLIK INDONESIA
DIREKTORAT JENDERAL PELAYANAN KESEHATAN
RSUP Dr. HASAN SADIKIN BANDUNG
Jalan Pasteur No. 38, Bandung 40161
Telepon : (022) 2034953, 2034954 (*hunting*) Faksimile : (022) 2032216, 2032533
Laman : www.rshs.or.id Pos-el : rsup@rshs.web.id
SMS hotline : 08112335555, Contact Center : 022 – 2551111, Reservasi Online : reservasi.rshs.or.id, facebook : /rshsbdg, twitter@rshsbdg

Untuk memperoleh keterangan lebih lanjut sebelum melaksanakan kegiatan, kami harap yang bersangkutan dapat menghubungi Ka. Bagian Pendidikan & Penelitian melalui Ka. Sub. Bag. Pendidikan dan Penelitian Medik RSUP Dr. Hasan Sadikin Bandung.

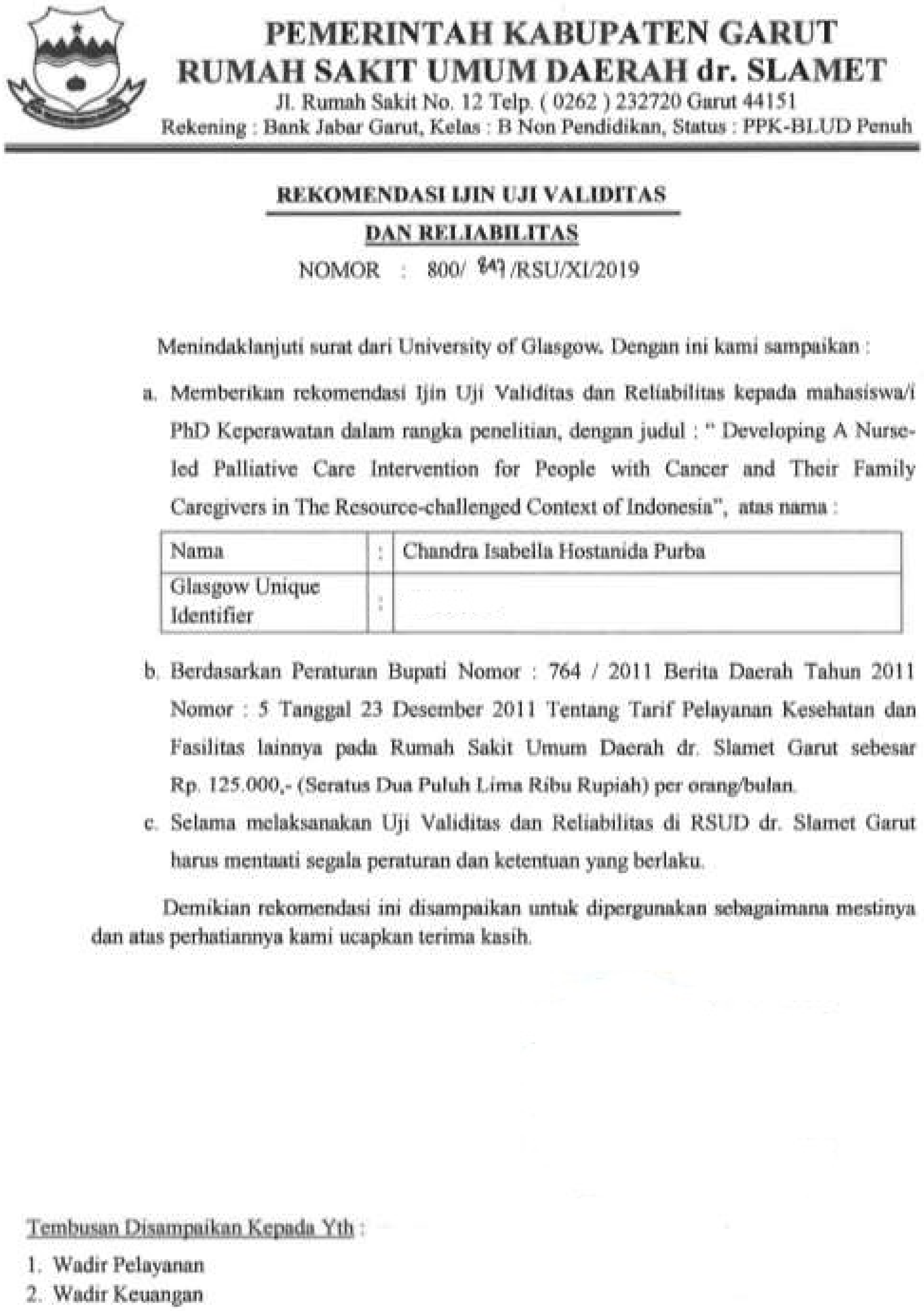
Atas perhatian dan kerjasamanya kami ucapkan terima kasih.

Tembusan :
1. Direktur Utama RSHS
2. Ketua Komite Etik Penelitian Kesehatan RSHS
3. Kepala Bidang Keperawatan RSHS
4. Ketua Tim Paliatif RSHS
5. Kepala Instalasi Rawat Jalan c.q. Poli Paliatif
6. Kepala Bagian Perbendaharaan dan Mobilisasi Dana RSHS

2/1/202 Pro. Tim Paliatif - RSHS
Mohon dibantu oleh anggota
untuk penelitian Paliatif
a/n Chandra I

Ketua tim Paliatif RSHS

Kesehatan Anda Menjadi Prioritas Kami



PEMERINTAH KABUPATEN GARUT
RUMAH SAKIT UMUM DAERAH dr. SLAMET
Jl. Rumah Sakit No. 12 Telp. (0262) 232720 Garut 44151
Rekening : Bank Jabar Garut, Kelas : B Non Pendidikan, Status : PPK-BLUD Penuh

REKOMENDASI IJIN UJI VALIDITAS DAN RELIABILITAS

NOMOR : 800/ 849 /RSU/XI/2019

Menindaklanjuti surat dari University of Glasgow. Dengan ini kami sampaikan :

a. Memberikan rekomendasi Ijin Uji Validitas dan Reliabilitas kepada mahasiswa/i PhD Keperawatan dalam rangka penelitian, dengan judul : " Developing A Nurse-led Palliative Care Intervention for People with Cancer and Their Family Caregivers in The Resource-challenged Context of Indonesia", atas nama :

Nama	:	Chandra Isabella Hostanida Purba
Glasgow Unique Identifier	:	

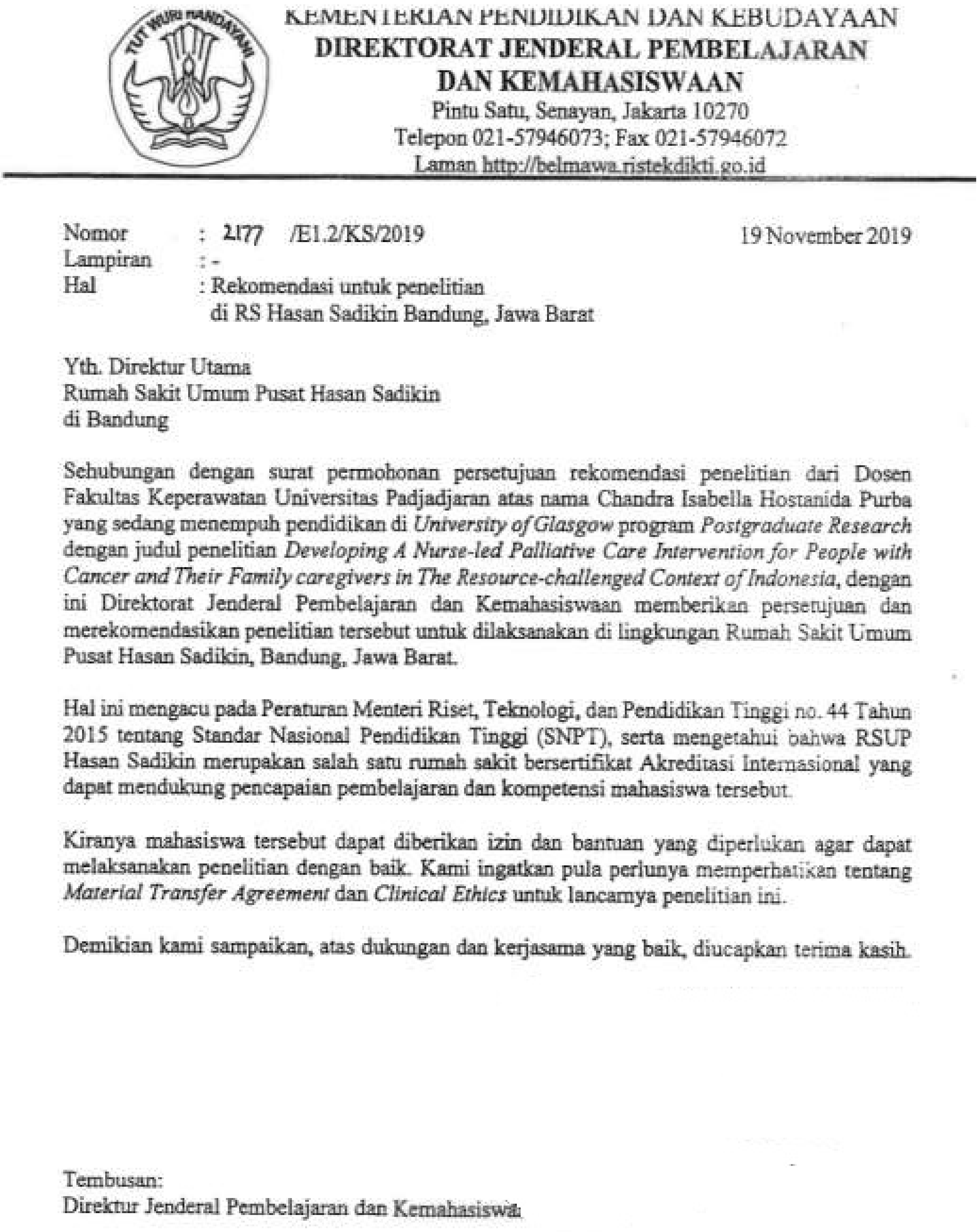
b. Berdasarkan Peraturan Bupati Nomor : 764 / 2011 Berita Daerah Tahun 2011 Nomor : 5 Tanggal 23 Desember 2011 Tentang Tarif Pelayanan Kesehatan dan Fasilitas lainnya pada Rumah Sakit Umum Daerah dr. Slamet Garut sebesar Rp. 125.000,- (Seratus Dua Puluh Lima Ribu Rupiah) per orang/bulan.

c. Selama melaksanakan Uji Validitas dan Reliabilitas di RSUD dr. Slamet Garut harus mentaati segala peraturan dan ketentuan yang berlaku.

Demikian rekomendasi ini disampaikan untuk dipergunakan sebagaimana mestinya dan atas perhatiannya kami ucapkan terima kasih.

Tembusan Disampaikan Kepada Yth :

1. Wadir Pelayanan
2. Wadir Keuangan



KEMENTERIAN PENDIDIKAN DAN KEBUDAYAAN
DIREKTORAT JENDERAL PEMBELAJARAN
DAN KEMAHASISWAAN
Pintu Satu, Senayan, Jakarta 10270
Telepon 021-57946073; Fax 021-57946072
Laman http://belmawa.ristekdikti.go.id

Nomor : 2177 /E1.2/KS/2019 19 November 2019
Lampiran : -
Hal : Rekomendasi untuk penelitian
di RS Hasan Sadikin Bandung, Jawa Barat

Yth. Direktur Utama
Rumah Sakit Umum Pusat Hasan Sadikin
di Bandung

Sehubungan dengan surat permohonan persetujuan rekomendasi penelitian dari Dosen Fakultas Keperawatan Universitas Padjadjaran atas nama Chandra Isabella Hostanida Purba yang sedang menempuh pendidikan di *University of Glasgow* program *Postgraduate Research* dengan judul penelitian *Developing A Nurse-led Palliative Care Intervention for People with Cancer and Their Family caregivers in The Resource-challenged Context of Indonesia*, dengan ini Direktorat Jenderal Pembelajaran dan Kemahasiswaan memberikan persetujuan dan merekomendasikan penelitian tersebut untuk dilaksanakan di lingkungan Rumah Sakit Umum Pusat Hasan Sadikin, Bandung, Jawa Barat.

Hal ini mengacu pada Peraturan Menteri Riset, Teknologi, dan Pendidikan Tinggi no. 44 Tahun 2015 tentang Standar Nasional Pendidikan Tinggi (SNPT), serta mengetahui bahwa RSUP Hasan Sadikin merupakan salah satu rumah sakit bersertifikat Akreditasi Internasional yang dapat mendukung pencapaian pembelajaran dan kompetensi mahasiswa tersebut.

Kiranya mahasiswa tersebut dapat diberikan izin dan bantuan yang diperlukan agar dapat melaksanakan penelitian dengan baik. Kami ingatkan pula perlunya memperhatikan tentang *Material Transfer Agreement* dan *Clinical Ethics* untuk lancarnya penelitian ini.

Demikian kami sampaikan, atas dukungan dan kerjasama yang baik, diucapkan terima kasih.

Tembusan:
Direktur Jenderal Pembelajaran dan Kemahasiswa

PEMERINTAH DAERAH PROVINSI JAWA BARAT
BADAN KESATUAN BANGSA DAN POLITIK
Jalan Supratman No. 44 Tlp. (022) 7206174 - 7205759 Fax. (022) 7106286
Website : bakesbangpol.jabarprov.go.id e-mail : bakesbangpol@jabarprov.go.id
Bandung - 40121

SURAT KETERANGAN PENELITIAN

NOMOR : 070/3047/SKP/XI/2019

Dasar :
1. Peraturan Menteri Dalam Negeri Nomor 41 Tahun 2010 tentang Organisasi dan Tata Kerja Kementerian Dalam Negeri (Berita Negara Republik Indonesia Tahun 2010 Nomor 316), sebagaimana telah diubah Dengan Peraturan Menteri Dalam Negeri Nomor 14 Tahun 2011 tentang Perubahan Atas Peraturan Menteri Dalam Negeri Nomor 41 Tahun 2010 tentang Organisasi dan Tata Kerja Kementerian Dalam Negeri (Berita Negara Republik Indonesia Tahun 2011 Nomor 168);
2. Peraturan Menteri Dalam Negeri Nomor 3 Tahun 2018 tentang Penerbitan Surat Keterangan Penelitian.

Menimbang : Surat Dari : University of Glasgow
Nomor : -
Tanggal : 6 November 2019
Perihal : Penelitian

Nama : **CHANDRA I.H. PURBA, SKp., M.Kep**
Alamat : Jl. Flamboyan Blok F.3 No. 6 RT/RW. 004/012 Jel Sukamaju Baru Kec. Tapos Kota Depok Jabar
Jabatan/Pekerjaan : PNS
No.Tlp : 083856702343
Judul Penelitian : Developing A Nurse-led Palliative Care Intervention For People With Cancer and their Family Caregivers in The Resource-Challenged Context of Indonesia
Bidang Penelitian : Kesehatan
Lokasi Penelitian : Kota Bandung
Lembaga/Instansi Yang Dituju : Badan Kesatuan Bangsa dan Politik Kota Bandung
Waktu Penelitian : November 2019 – April 2020
Status Penelitian : Baru
Anggota Tim Penelitian : Prof. Bridget Johnston & Dr. Grigorios Kotronoulas

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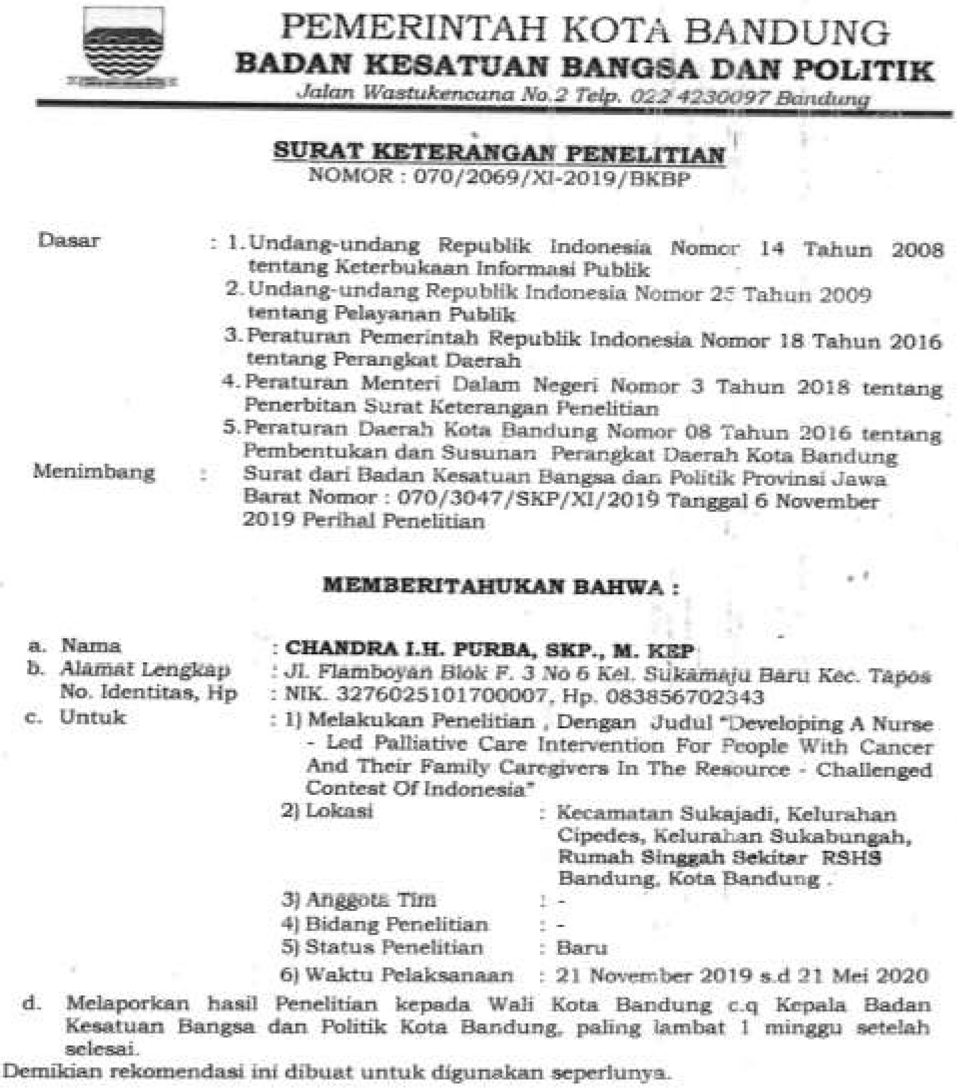
Dikeluarkan : Di Bandung
Pada Tanggal : 21 November 2019

An. KEPALA BADAN KESATUAN BANGSA DAN POLITIK
PROVINSI JAWA BARAT



PEMERINTAH KOTA BANDUNG
BADAN KESATUAN BANGSA DAN POLITIK
Jalan Wastukencana No.2 Telp. 022 4230097 Bandung

SURAT KETERANGAN PENELITIAN
NOMOR : 070/2069/XI-2019/BKBP

Dasar :
1. Undang-undang Republik Indonesia Nomor 14 Tahun 2008 tentang Keterbukaan Informasi Publik
2. Undang-undang Republik Indonesia Nomor 25 Tahun 2009 tentang Pelayanan Publik
3. Peraturan Pemerintah Republik Indonesia Nomor 18 Tahun 2016 tentang Perangkat Daerah
4. Peraturan Menteri Dalam Negeri Nomor 3 Tahun 2018 tentang Penerbitan Surat Keterangan Penelitian
5. Peraturan Daerah Kota Bandung Nomor 08 Tahun 2016 tentang Pembentukan dan Susunan Perangkat Daerah Kota Bandung

Menimbang : Surat dari Badan Kesatuan Bangsa dan Politik Provinsi Jawa Barat Nomor : 070/3047/SKP/XI/2019 Tanggal 6 November 2019 Perihal Penelitian

MEMBERITAHUKAN BAHWA :

a. Nama : **CHANDRA I.H. PURBA, SKP., M. KEP**
b. Alamat Lengkap : *Jl. Flamboyan Blok F. 3 No 6 Kel. Sukamaju Baru Kec. Tapos*
No. Identitas, Hp : NIK. 3276025101700007, Hp. 083856702343
c. Untuk : 1) Melakukan Penelitian , Dengan Judul "Developing A Nurse - Led Palliative Care Intervention For People With Cancer And Their Family Caregivers In The Resource - Challenged Contest Of Indonesia"
2) Lokasi : Kecamatan Sukajadi, Kelurahan Cipedes, Kelurahan Sukabungah, Rumah Singgah Sekitar RSHS Bandung, Kota Bandung .
3) Anggota Tim : -
4) Bidang Penelitian : -
5) Status Penelitian : Baru
6) Waktu Pelaksanaan : 21 November 2019 s.d 21 Mei 2020

d. Melaporkan hasil Penelitian kepada Wali Kota Bandung c.q Kepala Badan Kesatuan Bangsa dan Politik Kota Bandung, paling lambat 1 minggu setelah selesai.

Demikian rekomendasi ini dibuat untuk digunakan seperlunya.

Appendix 9 Participant information sheets, Privacy notice, Informed consent formed

PARTICIPANT INFORMATION SHEET
for patient

1. Title of Project:

Developing Palliative Care Services for Adults with cancer in Poor Resources Country in Indonesia

2. Invitation paragraph

My name is Chandra Isabella Hostanida Purba, an Indonesian nurse and a PhD student at the University of Glasgow. My specific research interest is around developing palliative care service in poor resource country. This study will help improve and spread the palliative care services in Indonesia. We hope the study will also help patients, family members, and health care providers, who are caring for the adults with cancer. I would like to invite you to take part in this study that will form a part of my PhD research project. Taking part in the research is entirely voluntary. You are being invited to take part in a research study because you are meet criteria for potential participants. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. If you decide to take part in this study, you will be given a copy of this Participant Information Sheet and the signed consent form to keep.

2. What is the purpose of the study?

The purpose of this study is to evaluate the existing palliative care service and developing nurse led intervention for adults with cancer in Hasan Sadikin Hospital, West Java Province, Indonesia.

3. **Why have I been invited to participate?**

   You have been invited to take part in this study because you are a patient with cancer in Hasan Sadikin Hospital.

4. **Do I have to take part?**

   No, it is up to you to decide whether you wish to participate in this research. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. You are free to withdraw from the study at any time, without giving a reason.

5. **What will happen to me if I take part?**

   You will be asked to participate in two steps; to complete questionnaires and to be interviewed. In the first step; you will be asked to complete the questioners once and will be contacted only if there is missing data. The questioner will last approximately 15 minutes. Approximately 200 patients will be invited to take part in this study. When we have enough participants, we will not invite any more. You are invited to complete the questionnaire only, not to receive any treatment.

   In step two, we will choose up to 10 Patients from previous step to be interviewed about their expectations in Nurse led intervention either in person or by telephone. This study will be done once; you will be asked to be interviewed if you meet criteria. The interview will last approximately 60 minutes, and your answers will be recorded and transcribed. The study will take place at Hasan Sadikin Hospital, Indonesia, shelters around the hospital or in patient's home depend on participant request. This is a Non-Randomisation study: if you meet the criteria, you may participate. There is no intervention in this study.

6. **What do I have to do?**

   There are no lifestyle restrictions nor interventions in this study.

7. **What are the possible disadvantages and risks of taking part?**

There are no potential disadvantages or harms in taking part in the study”.

8. **What are the possible benefits of taking part?**

   You will not receive any direct benefit from taking part in this study. The information collected during this study will give us a better understanding of palliative care services in Hasan Sadikin Hospital.

9. **Will my taking part in this study be kept confidential?**

   All information which is collected about you, or responses that you provide, during the course of the research will be kept strictly confidential. You will be identified by an ID number, and any information about you will have your name and address removed so that you cannot be recognised from it. Please note that assurances on confidentiality will be strictly adhered to unless evidence of serious harm, or risk of serious harm, is uncovered. In such cases, the University may be obliged to contact relevant statutory bodies/agencies.

   Any data in paper form will be stored in locked cabinets in rooms with restricted access at the University of Glasgow. All data in electronic format will be stored on secure password-protected computers. No one outside of the research team or appropriate governance staff will be able to find out your name, or any other information which could identify you.

10. **What will happen to my data?**

    All study data will be held in accordance with The General Data Protection Regulation (2018). The data will be stored in archiving facilities in line with the University of Glasgow retention policy of up to 10 years. After this period, further retention may be agreed, or your data will be securely destroyed in accordance with the relevant standard procedures.

    Your identifiable information might be shared with people who check that the study is done properly and, if you agree, in coded form with other organisations or universities to carry out research to improve scientific understanding. Your data will form part of the study result that will be published in expert journals, presentations, student dissertations/theses (if applicable) and on the internet for other researchers to use. Your name will not appear in any publication.

11. **What will happen to the results of the research study?**

The results of the study will be published between 2020 and 2023 and will be delivered to the stakeholders as a recommendation to provide bespoke palliative care service in the future. You will be able to obtain a copy of the published report online. You will be participating in health research. If direct quotations are used in any resulting publications or reports, they will be anonymised.

12. **Who is organising and funding the research?**

Universitas Padjadjaran, Indonesia.

13. **Who has reviewed the study?**

The project has been reviewed by the College of Medical, Veterinary & Life Sciences Ethics Committee.

14. **Contact for Further Information**

1. Chandra Isabella Hostanida Purba. PhD Student Nursing School of Medicine, Dentistry and Nursing, College of Medical, Veterinary & Life sciences, Univesity of Glasgow, 57-61 Oakfield Avenue Glasgow, G12 8LL, xxxxxxxx@student.gla.ac.uk. Contact number xxxxxxxxx xxxxxxxx.

2. Dr. Grigorios Kotronoulas, PhD, MSc, BSN, RN, Lecturer - Nursing and Health Care, School of Medicine, Dentistry and Nursing, MVLS, University of Glasgow. Email: grigorious.kotronoulas@glasgow.ac.uk

3. Prof. Bridgette Johnston, Professor of Nursing School of Medicine, Dentistry and Nursing, College of Medical, Veterinary & Life sciences Univesity of Glasgow, 57-61 Oakfield Avenue Glasgow, G12 8LL, email: Bridget.Johnston@glasgow.ac.uk

Thank you for taking the time to read this Participant Information Sheet. Please do not hesitate to contact us if you require any further information.

University of Glasgow | College of Medical, Veterinary & Life Sciences

PARTICIPANT INFORMATION SHEET

For family caregivers

1. Title of Project:

Developing Palliative Care Services for Adults with cancer in Poor Resources Country in Indonesia

2. Invitation paragraph

My name is Chandra Isabella Hostanida Purba, an Indonesian nurse and a PhD student at the University of Glasgow. My specific research interest is around developing palliative care service in poor resource country. This study will help improve and spread the palliative care services in Indonesia. We hope the study will also help patients, family members, and health care providers, who are caring for the adults with cancer. I would like to invite you to take part in this study that will form a part of my PhD research project. Taking part in the research is entirely voluntary. You are being invited to take part in a research study because you are meet criteria for potential participants. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. If you decide to take part in this study, you will be given a copy of this Participant Information Sheet and the signed consent form to keep.

2. What is the purpose of the study?

The purpose of this study is to evaluate the existing palliative care service and developing nurse led intervention for adults with cancer in Hasan Sadikin Hospital, West Java Province, Indonesia.

3. Why have I been invited to participate?

You have been invited to take part in this study because you are the family member caring for patient with cancer in Hasan Sadikin Hospital.

4. **Do I have to take part?**

No, it is up to you to decide whether you wish to participate in this research. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. You are free to withdraw from the study at any time, without giving a reason.

5. **What will happen to me if I take part?**

You will ask to participate in two steps: to complete questionnaires and to be interviewed. In the first step you will be asked to complete the questioners once and will be contacted only if there is missing data. The questioner will last approximately 15 minutes. Up to 200 family caregivers will be invited to take part in this study. When we have enough participants, we will not invite any more. You are invited to complete the questionnaire only, not to receive any treatment.

In the next step we will choose approximately 10 family caregivers to be interviewed about their expectations of nurse-led intervention either in person or by telephone. The interview will last approximately 60 minutes, and your answers will be recorded and transcribed. The study will take place at Hasan Sadikin Hospital, Indonesia, shelters around the hospital or in patient's home depend on participant request. This is a Non-Randomisation study: if you meet the criteria, you may participate. There is no intervention in this study.

6. What do I have to do?

There are no lifestyle restrictions nor interventions in this study.

7. **What are the possible disadvantages and risks of taking part?**

There are no potential disadvantages or harms in taking part in the study".

8. What are the possible benefits of taking part?

You will not receive any direct benefit from taking part in this study. The information collected during this study will give us a better understanding of palliative care services in Hasan Sadikin Hospital.

7. **Will my taking part in this study be kept confidential?**

All information which is collected about you, or responses that you provide, during the course of the research will be kept strictly confidential. You will be identified by an ID number, and any information about you will have your name and address removed so that you cannot be recognised from it. Please note that assurances on confidentiality will be strictly adhered to unless evidence of serious harm, or risk of serious harm, is uncovered. In such cases, the University may be obliged to contact relevant statutory bodies/agencies.

Any data in paper form will be stored in locked cabinets in rooms with restricted access at the University of Glasgow. All data in electronic format will be stored on secure password-protected computers. No one outside of the research team or appropriate governance staff will be able to find out your name, or any other information which could identify you.

8. What will happen to my data?

All study data will be held in accordance with The General Data Protection Regulation (2018).

The data will be stored in archiving facilities in line with the University of Glasgow retention policy of up to 10 years. After this period, further retention may be agreed, or your data will be securely destroyed in accordance with the relevant standard procedures.

Your identifiable information might be shared with people who check that the study is done properly and, if you agree, in coded form with other organisations or universities to carry out research to improve scientific understanding. Your data will form part of the study result that will be published in expert journals, presentations, student dissertations/theses (if applicable) and on the internet for other researchers to use. Your name will not appear in any publication.

10. What will happen to the results of the research study?

The results of the study will be published between 2020 and 2023 and will be delivered to the stakeholders as a recommendation to provide bespoke palliative care service in the future. You will be able to obtain a copy of the published report online. You will be participating in health research. If direct quotations are used in any resulting publications or reports, they will be anonymised.

11. Who is organising and funding the research?

Universitas Padjadjaran, Indonesia.

12. **Who has reviewed the study?**

The project has been reviewed by the College of Medical, Veterinary & Life Sciences Ethics Committee.

13. Contact for Further Information

1. Chandra Isabella Hostanida Purba. PhD Student Nursing School of Medicine, Dentistry and Nursing, College of Medical, Veterinary & Life sciences, Univesity of Glasgow, 57-61 Oakfield Avenue Glasgow, G12 8LL, xxxxxxxxx@student.gla.ac.uk. Contact number xxxxxxxxxx xxxxxxxx.

2. Dr. Grigorios Kotronoulas, PhD, MSc, BSN, RN, Lecturer - Nursing and Health Care, School of Medicine, Dentistry and Nursing, MVLS, University of Glasgow. Email: grigorious.kotronoulas@glasgow.ac.uk
3. Prof. Bridgette Johnston, Professor of Nursing School of Medicine, Dentistry and Nursing, College of Medical, Veterinary & Life sciences Univesity of Glasgow, 57-61 Oakfield Avenue Glasgow, G12 8LL, email: Bridget.Johnston@glasgow.ac.uk

Thank you for taking the time to read this Participant Information Sheet. Please do not hesitate to contact us if you require any further information.

PARTICIPANT INFORMATION SHEET
for staff

1. Title of Project:

Developing Palliative Care Services for Adults with cancer in Poor Resources Country in Indonesia.

2. Invitation paragraph

My name is Chandra Isabella Hostanida Purba, an Indonesian nurse and a PhD student at the University of Glasgow. My specific research interest is around developing palliative care service in poor resource country. This study will help improve and spread the palliative care services in Indonesia. We hope the study will also help patients, family members, and health care providers, who are caring for the adults with cancer. I would like to invite you to take part in this study that will form a part of my PhD research project. Taking part in the research is entirely voluntary. You are being invited to take part in a research study because you are meet criteria for potential participants. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. If you decide to take part in this study, you will be given a copy of this Participant Information Sheet and the signed consent form to keep.

3. What is the purpose of the study?

The purpose of this study is to evaluate the existing palliative care service and developing nurse led intervention for adults with cancer in Hasan Sadikin Hospital, West Java Province, Indonesia.

4. Why have I been invited to participate?

You have been invited to take part in this study because you are staff member of palliative care in Hasan Sadikin Hospital.

5. Do I have to take part?

No, it is up to you to decide whether you wish to participate in this research. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. You are free to withdraw from the study at any time, without giving a reason.

6. What will happen to me if I take part?

This study will be done once; you will be asked to be interviewed either in person or by telephone. The interview will last approximately 60 minutes, and your answers will be recorded and transcribed. Approximately ten (10) palliative care staff members will be interviewed about their expectations of nurse-led intervention. The study will take place at Hasan Sadikin Hospital, Indonesia, or in others place for interview depend on participant request. This is a Non-Randomisation study: if you meet the criteria, you may participate. There is no intervention in this study.

7. What do I have to do?

There are no lifestyle restrictions nor interventions in this study.

8. What are the possible disadvantages and risks of taking part?

There are no potential disadvantages or harms in taking part in the study".

9. What are the possible benefits of taking part?

You will not receive any direct benefit from taking part in this study. The information collected during this study will give us a better understanding of palliative care services in Hasan Sadikin Hospital.

10. Will my taking part in this study be kept confidential?

All information which is collected about you, or responses that you provide, during the course of the research will be kept strictly confidential. You will be identified by an ID number, and any information about you will have your name and address removed so that you cannot be recognised from it. Please note that assurances on confidentiality will be strictly adhered to unless evidence of serious harm, or risk of serious harm, is uncovered. In such cases, the University may be obliged to contact relevant statutory bodies/agencies.

Any data in paper form will be stored in locked cabinets in rooms with restricted access at the University of Glasgow. All data in electronic format will be stored on secure password-protected computers. No one outside of the research team or appropriate governance staff will be able to find out your name, or any other information which could identify you.

11. What will happen to my data?

All study data will be held in accordance with The General Data Protection Regulation (2018). The data will be stored in archiving facilities in line with the University of Glasgow retention policy of up to 10 years. After this period, further retention may be agreed, or your data will be securely destroyed in accordance with the relevant standard procedures.

Your identifiable information might be shared with people who check that the study is done properly and, if you agree, in coded form with other organisations or universities to carry out research to improve scientific understanding. Your data will form part of the study result that will be published in expert journals, presentations, student dissertations/theses (if applicable) and on the internet for other researchers to use. Your name will not appear in any publication.

12. What will happen to the results of the research study?

The results of the study will be published between 2020 and 2023 and will be delivered to the stakeholders as a recommendation to provide bespoke palliative care service in the future. You will be able to obtain a copy of the published report online. You will be participating in health research. If direct quotations are used in any resulting publications or reports, they will be anonymised.

13. Who is organising and funding the research?

Universitas Padjadjaran, Indonesia.

14. Who has reviewed the study?

The project has been reviewed by the College of Medical, Veterinary & Life Sciences Ethics Committee.

15. Contact for Further Information

1. Chandra Isabella Hostanida Purba. PhD Student Nursing School of Medicine, Dentistry and Nursing, College of Medical, Veterinary & Life sciences, Univesity of Glasgow, 57-61 Oakfield Avenue Glasgow, G12 8LL, xxxxxxxxx@student.gla.ac.uk. Contact number xxxxxxxxx xxxxxxxxxx.

2. Dr. Grigorios Kotronoulas, PhD, MSc, BSN, RN, Lecturer - Nursing and Health Care, School of Medicine, Dentistry and Nursing, MVLS, University of Glasgow. Email: grigorious.kotronoulas@glasgow.ac.uk
3. Prof. Bridgette Johnston, Professor of Nursing School of Medicine, Dentistry and Nursing, College of Medical, Veterinary & Life sciences Univesity of Glasgow, 57-61 Oakfield Avenue Glasgow, G12 8LL, email: Bridget.Johnston@glasgow.ac.uk

Thank you for taking the time to read this Participant Information Sheet. Please do not hesitate to contact us if you require any further information.

1. Privacy notice for patient. Project "Developing a Nurse-led palliative care intervention for adults with cancer and their family caregivers in the resource-challenged context of Indonesia"

(Patient, stage 2)

Your Personal Data

The University of Glasgow will be what is known as the 'Data Controller' of your personal data processed in relation in relation to scheduling a survey and any further personal information divulged during our research with you. This privacy notice will explain how The University of Glasgow will process your personal data.

Why we need it.

We are collecting your basic personal data such as name, address, telephone number, in order to send you the project information sheet. We will only collect data that we need in order to contact you for this purpose. Thereafter, through questionnaires we expect to gather some further personal data e.g. gender, age (but not date of birth), marital status, ethnicity, employment status, education level, distance from hospital. The medical data to be gathered are: the type of cancer, comorbidities, performance status, and time since diagnosis. The main data from questionnaires will be about your need and burden in physical, psychological, and emotional symptoms, spiritual and support needs.

Legal basis for processing your data.

We must have a legal basis for processing all personal data. In this instance, the legal basis is Article 6(1)(e) "public task" for personal data and Article 9(2)(j) "research" for the special categories data legal basis.

What we do with it and who we share it with.

All the personal data we collect for/from you (i.e. name, home/work/email address, telephone number) is processed by the staff at the University of Glasgow in the United Kingdom. We will store your personal data in password-protected electronic files on a secure University of Glasgow storage. We will store your personal data separately from data you provide in the questionnaires. Only members of the research team will have access to your personal data. We will not share your personal data with anyone outside the research team.

How long do we keep it for?

Your personal data (i.e. name, home/work/email address, telephone number) will be retained by the University for 3 months after your last contact with the researcher. After this time, data will be securely deleted. Additional personal data (gender, age (but not date of birth), marital status, ethnicity, employment status, education level, distance from hospital, whilst the medical data are: the type of cancer, comorbidities, performance status, and time since been diagnosed) collected during the study that we will treat as research data will be retained for a minimum of 10 years after the end of the study as per University policy.

What are your rights?

You can request access to the information we process about you at any time. If at any point you believe that the information we process relating to you is incorrect, you can request to see this information and may in some instances request to have it corrected or erased. If you wish to exercise any of your rights, please contact dp@gla.ac.uk.

Complaints

If you wish to raise a complaint on how we have handled your personal data, you can contact the University Data Protection Officer who will investigate the matter. Our Data Protection Officer can be contacted at dataprotectionofficer@glasgow.ac.uk

If you are not satisfied with our response or believe we are not processing your personal data in accordance with the law, you can complain to the Information Commissioner's Office (ICO) https://ico.org.uk/.

2. Privacy notice for patient. Project "Developing a Nurse-led palliative care intervention for adults with cancer and their family caregivers in the resource-challenged context of Indonesia"

(Patient, stage 3)

Your Personal Data

The University of Glasgow will be what is known as the 'Data Controller' of your personal data processed in relation to scheduling an interview and any further personal information divulged during our research with you. This privacy notice will explain how The University of Glasgow will process your personal data.

Why we need it.

We are collecting your basic personal data such as name, address, telephone number, in order to send you the project information sheet. We will only collect data that we need in order to contact you for this purpose. Thereafter, through interview, we expect to gather some further personal data e.g. gender, age (but not date of birth), marital status, ethnicity, employment status, education level, distance from hospital. The medical data to be gathered are: the type of cancer, comorbidities, performance status, and time since diagnosis. The main data from one to one interview will be about your views and expectations on Nurse-led intervention.

Legal basis for processing your data.

We must have a legal basis for processing all personal data. In this instance, the legal basis is Article 6(1)(e) "public task" for personal data and Article 9(2)(j) "research" for the special categories data legal basis.

What we do with it and who we share it with.

All the personal data we collect for/from you (i.e. name, home/work/email address, telephone number) is processed by the staff at the University of Glasgow in the United Kingdom. We will store your personal data in password-protected electronic files on a secure University of Glasgow storage. We will store your personal data separately from data you provide during interview. Only members of the research team will have access to your personal data. We will not share your personal data with anyone outside the research team.

How long do we keep it for?

Your personal data (i.e. name, home/work/email address, telephone number) will be retained by the University for 3 months after your last contact with the researcher. After this time, data will be securely deleted. Additional personal data (gender, age (but not date of birth), marital status, ethnicity, employment status, education level, distance from hospital, whilst the medical data are: the type of cancer, comorbidities, performance status, and time since been diagnosed) collected during the study that we will treat as research data will be retained for a minimum of 10 years after the end of the study as per University policy.

What are your rights?

You can request access to the information we process about you at any time. If at any point you believe that the information we process relating to you is incorrect, you can request to see this information and may in some instances request to have it corrected or erased. If you wish to exercise any of your rights, please contact dp@gla.ac.uk.

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If you are not satisfied with our response or believe we are not processing your personal data in accordance with the law, you can complain to the Information Commissioner's Office (ICO) https://ico.org.uk/.

3. Privacy notice family caregiver project “Developing a nurse-led palliative care intervention for adults with cancer and their family caregivers in the Resource-challenged context of Indonesia.”

(Family caregiver, stage 2)

Your Personal Data

The University of Glasgow will be what is known as the ‘Data Controller’ of your personal data processed in relation in relation to scheduling a survey and any further personal information divulged during our research with you. This privacy notice will explain how The University of Glasgow will process your personal data.

Why we need it.

We are collecting your basic personal data such as name, address, telephone number, in order to schedule an interview with you. We will only collect data that we need in order to provide and oversee this service to you. Additionally, we expect to gather some further personal data in the course of our interview with you, gender, age (but not date of birth), marital status, ethnicity, employment status, education level, distance from hospital, duration of caregiving and relationship to the patient. The main data from questionnaires will be about your physical, psychological, and emotional symptoms, spiritual and support needs and burden.

Legal basis for processing your data.

We must have a legal basis for processing all personal data. In this instance, the legal basis is “public task” for personal data and “research” for the special categories data legal basis.

What we do with it and who we share it with.

All the personal data we collect for/from you (i.e. name, home/work/email address, telephone number) is processed by staff at the University of Glasgow in the United Kingdom. We will store your personal data in password-protected electronic files on a secure University of Glasgow storage. We will store your personal data separately from data you provide in questionnaires. Only members of the research team will have access to your personal data. We will not share your personal data with anyone outside the research team.

How long do we keep it for?

Your personal data (i.e. name, home/work/email address, telephone number) will be retained by the University for 3 months after your last contact with the researcher. After this time, data will be securely deleted. Additional personal data (gender, age (but not date of birth), marital status, ethnicity, employment status, education level, distance from hospital, duration of caregiving and relationship to the patient) collected in the questionnaires will treat as research data will be retained for a minimum of 10 years after the end of the study as per University policy.

What are your rights?

You can request access to the information we process about you at any time. If at any point you believe that the information we process relating to you is incorrect, you can request to see this information and may in some instances request to have it corrected or erased. If you wish to exercise any of your rights, please contact dp@gla.ac.uk.

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If you are not satisfied with our response or believe we are not processing your personal data in accordance with the law, you can complain to the Information Commissioner's Office (ICO) https://ico.org.uk/.

4. Privacy notice for family caregiver. Project “Developing a nurse-led palliative care Intervention for adults with cancer and their family caregivers in the resource-challenged context of Indonesia.”

(Family caregiver, stage 3)

Your Personal Data

The University of Glasgow will be what is known as the ‘Data Controller’ of your personal data processed in relation in relation to scheduling an interview and any further personal divulged during our interview with you. This privacy notice will explain how The University of Glasgow will process your personal data.

Why we need it.

We are collecting your basic personal data such as name, address, telephone number, in order to schedule an interview with you. We will only collect data that we need in order to provide and oversee this service to you. Additionally, we expect to gather some further personal data in the course of our interview with you, gender, age (but not date of birth), marital status, ethnicity, employment status, education level, distance from hospital, duration of caregiving and relationship to the patient. The main data from one to one interview will be about your views and expectations on Nurse-led intervention.

Legal basis for processing your data.

We must have a legal basis for processing all personal data. In this instance, the legal basis is “public task” for personal data and “research” for the special categories data legal basis.

What we do with it and who we share it with.

All the personal data we collect for/from you (i.e. name, home/work/email address, telephone number) is processed by staff at the University of Glasgow in the United Kingdom. We will store your personal data in password-protected electronic files on a secure University of Glasgow storage. We will store your personal data separately from data you provide during the interview. Only members of the research team will have access to your personal data. We will not share your personal data with anyone outside the research team.

How long do we keep it for?

Your personal data (i.e. name, home/work/email address, telephone number) will be retained by the University for 3 months after your last contact with the researcher. After this time, data will be securely deleted. Additional personal data (gender, age (but not date of birth), marital status, ethnicity, employment status, education level, distance from hospital, duration of caregiving and relationship to the patient) collected during the interview that we will treat as research data will be retained for a minimum of 10 years after the end of the study as per University policy. Interview content will be de-identified prior to being retained for at least 10 years.

What are your rights?

You can request access to the information we process about you at any time. If at any point you believe that the information we process relating to you is incorrect, you can request to see this information and may in some instances request to have it corrected or erased. If you wish to exercise any of your rights, please contact dp@gla.ac.uk.

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If you are not satisfied with our response or believe we are not processing your personal data in accordance with the law, you can complain to the Information Commissioner’s Office (ICO) https://ico.org.uk/.

5. Privacy notice for patient project "Developing a Nurse-led palliative care intervention for adults with cancer and their family caregivers in the resource-challenged context of Indonesia."

(Staff, stage 3)

Your Personal Data

The University of Glasgow will be what is known as the 'Data Controller' of your personal data processed in relation to your views and expectation on Nurse-led intervention during your role as palliative care team and any further personal divulged during our research with you. This privacy notice will explain how The University of Glasgow will process your personal data.

Why we need it.

We are collecting your basic personal data such as name, address, telephone number, in order to send you the project information sheet. We will only collect data that we need in order to provide and oversee this service to you. Additionally, we expect to gather some further personal from you, e.g. gender, age (but not date of birth), role and how long have been working in the team. The main data from interview will be about your views and expectations on Nurse-led intervention. We will retain such additional personal data for the purposes of the research but treat them as "research data".

Legal basis for processing your data.

We must have a legal basis for processing all personal data. In this instance, the legal basis is "public task" for personal data and "research" for the special categories data legal basis.

What we do with it and who we share it with.

All the personal data we collect for/from you (i.e. name, home/work/email address, telephone number) is processed by staff at the University of Glasgow in the United Kingdom. We will store your personal data in password-protected electronic files on a secure University of Glasgow storage. We will store your personal data separately from data you provide in the questioners. Only members of the research team will have access to your personal data. We will not share your personal data with anyone outside the research team.

How long do we keep it for?

Your personal data (i.e. name, home/work/email address, telephone number) will be retained by the University for 3 months after your last contact with the researcher. After this time, data will be securely deleted. Additional personal data (gender, age (but not date of birth), role and how long have been working in the team) collected during the interview that we will treat as research data will be retained for a minimum of 10 years after the end of the study as per University policy.

What are your rights?

You can request access to the information we process about you at any time. If at any point you believe that the information we process relating to you is incorrect, you can request to see this information and may in some instances request to have it corrected or erased. If you wish to exercise any of your rights, please contact dp@gla.ac.uk.

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If you are not satisfied with our response or believe we are not processing your personal data in accordance with the law, you can complain to the Information Commissioner's Office (ICO) https://ico.org.uk/.

Consent form

University of Glasgow | College of Medical, Veterinary & Life Sciences

Title of Project:

Developing a Nurse-led Palliative Care Interventions for Adults with cancer and their Family caregivers in the Resource-challenged Context of Indonesia.

Stage 2/3

Name of Researcher(s):

1. Chandra Isabella Hostanida Purba
2. Professor Bridget Johnston
3. Dr. Grigorios Kotronoulas

CONSENT FORM

Please initial box

I confirm that I have read and understood the Participant Information Sheet version 4 dated 18/03/2019. ☐

I confirm that I have read and understood the Privacy Notice version 2 dated 04/03/2019.

I have had the opportunity to think about the information and ask questions, and understand the answers I have been given. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. ☐

I confirm that I agree to the way my data will be collected and processed and that data will be stored for up to 10 years in University archiving facilities in accordance with relevant Data Protection policies and regulations. ☐

I understand that all data and information I provide will be kept confidential and will be seen only by study researchers. ☐

I agree to take part in the study ☐

I agree to my interview being audio-recorded. ☐

I understand that the recorded interview will be transcribed word by word and the transcription stored for up to 10 years in University archiving facilities in accordance with Data Protection policies and regulations. ☐

I understand that my information and things that I say in an interview or focus group discussion may be quoted in reports and articles that are published about the study, but my name or anything else that could tell people who I am will not be revealed. ☐

Name of participant ____________ Date ______________________

Signature

____

______________________ ____________ ______________________

Researcher Date Signature

(1 copy for participant; 1 copy for researcher)

Appendix 10 Questionnaires Indonesian version (IPOS, ZBI, SCNS 34 patient & SCNS 45 P&CG).

a. Integrated Palliative Outcomes Scale (IPOS) Indonesian version

IPOS Versi Pasien.

Nama pasien : ....
Tanggal (dd/mm/yyyy) : ....
Nomor pasien : ....
(untuk digunakan staf)

www.pos-pal.org

Q1. Apa yang telah menjadi masalah atau gangguan utama dalam seminggu terakhir?

1.
....
2.
....
3.
....

Q2. Di bawah ini adalah daftar gejala-gejala, yang mungkin atau tidak pernah anda alami. Untuk setiap gejala, mohon centang <u>satu kotak</u> yang paling menggambarkan bagaimana p<u>engaruhnya selama seminggu terakhir</u>.

	Tidak sama sekali	Sedikit	Sedang	Sangat	Sangat sekali
Nyeri	0	1	2	3	4
Nafas tersengal-sengal	0	1	2	3	4
Lemah atau kekurangan tenaga	0	1	2	3	4
Mual (merasa seperti akan sakit)	0	1	2	3	4
Muntah	0	1	2	3	4
Kehilangan Nafsu makan	0	1	2	3	4

Sembelit	0	1	2	3	4
Mulut sakit atau kering	0	1	2	3	4
Mengantuk	0	1	2	3	4
Sulit bergerak	0	1	2	3	4
Bila ada gejala lain yang anda rasakan, harap tuliskan di kolom di bawah ini dan centang kotak yang sesuai dengan apa yang anda rasakan satu minggu yang lalu					
1.	0	1	2	3	4
2.	0	1	2	3	4
3.	0	1	2	3	4

Bila anda memiliki kekhawatiran meyangkut kuisoner ini, harap menanyakan langsung kepada peneliti

Selama seminggu terakhir:

	Tidak sama sekali	*Jarang*	*Kadang-kadang*	*Kebanyakan waktu*	*Selalu*
Q3. Pernahkah anda merasa gelisah atau cemas terhadap penyakit atau pengobatan anda?	0	1	2	3	4
Q4. Pernahkah keluarga atau teman anda merasakan cemas terhadap anda?	0	1	2	3	4
Q5. Pernahkah anda pernah merasa tertekan/ depresi?	0	1	2	3	4
	Selalu	*Kebanyakan waktu*	*Kadang-kadang*	*Jarang*	*Tidak sama sekali*
Q6. Pernahkah anda merasa damai?	0	1	2	3	4
Q7. Apakah anda bisa membagikan perasaan pada keluarga atau teman sebanyak yang anda inginkan?	0	1	2	3	4
Q8. Apakah anda mendapatkan informasi yang anda inginkan?	0	1	2	3	4
	Tidak masalah / masalah selesai	*Sebagian besar masalah sudah selesai*	*Sebagian masalah telah selesai*	*Masalah susah untuk diselesaikan*	*Masalah belum selesai*
Q9. Apakah beberapa masalah praktis akibat penyakit anda pernah ditangani? (seperti finansial atau personal)	0	1	2	3	4
	Oleh saya sendiri	*Dengan bantuan teman atau saudara*			*Dibantu staf*

Q10. Apakah masalah yang timbul dari penyakit anda telah terselesaikan? (misal: masalah keuangan atau masalah personal)			

b. SCNS 34 (Patient) Indonesian version

KUESIONER PELAYANAN SUPORTIF

Petunjuk pengisian: Untuk membantu kami dalam merencanakan pelayanan kesehatan yang lebih baik bagi pasien kanker, kami tertarik untuk melihat apakah kebutuhan Anda terpenuhi atau tidak selama terdiagnosis dan terapi kanker. Mohon beri tanda (√) pada angka jawaban yang menggambarkan kebutuhan yang paling anda butuhkan selama satu bulan terakhir.

No	**Selama sebulan terakhir, bagaimana tingkat kebutuhan akan bantuan terhadap :**	**Tidak Membutuhkan**		**Membutuhkan**		
		Tidak ada kebutuhan	**Kebutuhan cukup Terpenuhi**	**Kebutuhan Rendah**	**Kebutuhan Sedang**	**Kebutuhan Tinggi**
1	Nyeri	1	2	3	4	5
2	Kekurangan energi/ Kelelahan	1	2	3	4	5
3	Merasa tidak sehat sepanjang waktu	1	2	3	4	5
4	Beraktivitas disekitar rumah	1	2	3	4	5
5	Tidak mampu melakukan hal-hal yang biasa dilakukan	1	2	3	4	5
6	Cemas	1	2	3	4	5
7	Merasa murung dan tertekan	1	2	3	4	5
8	Merasa sedih	1	2	3	4	5
9	Cemas akan penyebaran kanker	1	2	3	4	5
10	Kekhawatir jika hasil pengobatan tidak sesuai yang diinginkan	1	2	3	4	5
11	Merasa tidak pasti akan masa depan	1	2	3	4	5
12	Belajar untuk mengendalikan kondisi anda	1	2	3	4	5
13	Memandang situasi yang ada secara positif	1	2	3	4	5
14	Berpikir mengenai kematian	1	2	3	4	5
15	Perubahan hasrat seksual	1	2	3	4	5
16	Perubahan dalam hubungan seksual anda	1	2	3	4	5
17	Merasa prihatin atas kekhawatiran orang terdekat Anda	1	2	3	4	5
18	Mempunyai banyak pilihan dokter spesialis yang bisa dikonsultasi	1	2	3	4	5
19	Mempunyai lebih banyak pilihan rumah sakit untuk berobat	1	2	3	4	5
20	Staf medis menyakinkan Anda bahwa anda rasakan adalah normal	1	2	3	4	5

21	Staf rumah sakit cepat menangani kebutuhan fisik anda	1	2	3	4	5
22	Staf rumas sakit mengerti dan menunjukkan kepekaan terhadap perasaan dan kebutuhan emosional anda.	1	2	3	4	5
23	Mendapat informasi tertulis mengenai aspek penting dari perawatan anda	1	2	3	4	5
24	Diberikan informasi (dalam bentuk tertulis, gambar, diagram) mengenai cara penanganan efek samping dan penyakit selama di rumah	1	2	3	4	5
25	Mendapatkan penjelasan mengenai pemeriksaan yang Anda butuhkan	1	2	3	4	5
26	Mendapatkan cukup informasi tentang manfaat dan efek samping dari pengobatan sebelum anda menentukan pilihan pengobatan	1	2	3	4	5
27	Mendapatkan informasi tentang hasil pemeriksaan secepat mungkin	1	2	3	4	5
28	Mendapatkan informasi bahwa kanker terkendali dan mengecil/berkurang	1	2	3	4	5
29	Mendapatkan informasi tentang hal yang anda lakukan untuk membantu proses penyembuhan anda	1	2	3	4	5
30	Memilki akses terhadap konseling profesional (misalnya psikolog, pekerja sosial, konselor, perawat spesialis) jika anda, keluarga atau teman membutuhkannya.	1	2	3	4	5
31	Mendapat informasi tentang hubungan seksual	1	2	3	4	5
32	Diperlakukan secara manusiawi, bukan hanya sekedar sebuah kasus	1	2	3	4	5
33	Mendapatkan perawatan di rumah sakit atau klinik senyaman mungkin secara fisik	1	2	3	4	5
34	Memiliki seorang anggota staf medis yang dapat diajak berbicara mengenai semua aspek dari kondisi anda, pengobatan dan tindak lanjut pengobatan.	1	2	3	4	5

c. *ZARIT BURDEN INTERVIEW* (ZBI)

PETUNJUK PENGISIAN :
SILAHKAN LINGKARI NOMOR PADA KOLOM YANG TERSEDIA PADA SETIAP PERTANYAAN, SESUAI YANG SAUDARA RASAKAN SEBAGAI PENGASUH INSAN PASCA STROKE, DENGAN KETERANGAN PILIHAN JAWABAN.

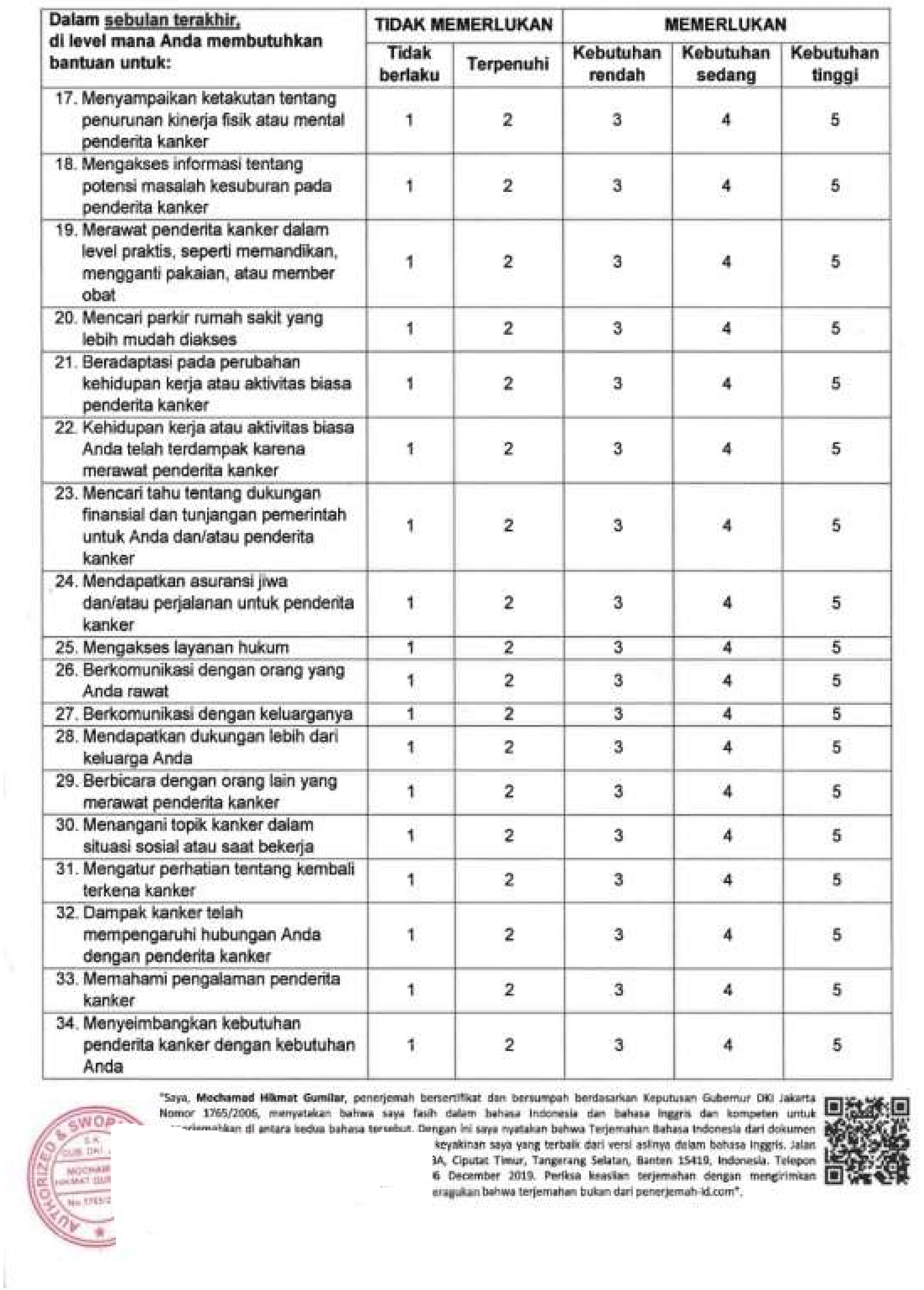
Lingkari jawaban yang paling menggambarkan perasaan Anda.	**Tdk Pernah**	**Jarang**	**Kadangkadang**	**Cukup Sering**	**Hampir Selalu**
1. Apakah Anda merasa bahwa insan pasca stoke meminta bantuan lebih dari yang ia butuhkan?	0	1	2	3	4
2.Apakah Anda merasa tidak mempunyai waktu untuk mengurus diri sendiri karena merawat insan pasca stroke?	0	1	2	3	4
3. Apakah Anda merasa stres antara merawat insan pasca stroke atau mencoba melakukan kewajiban lain untuk keluarga atau pekerjaan Anda?	0	1	2	3	4
4. Apakah Anda merasa malu karena kelemahan insan pasca stroke?	0	1	2	3	4
5. Apakah Anda merasa marah saat bersama insan pasca stroke?	0	1	2	3	4
6. Apakah Anda merasa bahwa kondisi insan pasca stroke mempengaruhi hubungan Anda dengan anggota keluarga lain atau teman menjadi kurang baik?	0	1	2	3	4
7. Apakah Anda merasa khawatir dengan masa depan insan pasca stroke?	0	1	2	3	4
8. Apakah Anda merasa insan pasca stroke bergantung pada diri Anda?	0	1	2	3	4
9. Apakah Anda merasa tegang saat bersama insan pasca stroke?	0	1	2	3	4
10. Apakah Anda merasa kesehatan Anda dikorbankan karena keterlibatan Anda dengan insan pasca stroke?	0	1	2	3	4
11. Apakah Anda merasa tidak mempunyai privasi seperti yang Anda inginkan karena insan pasca stroke?	0	1	2	3	4
12. Apakah Anda merasa kehidupan sosial Anda dikorbankan karena merawat insan pasca stroke?	0	1	2	3	4
13. Apakah Anda merasa tidak nyaman mengajak teman Anda ke rumah karena keberadaan insan pasca stroke?	0	1	2	3	4
14. Apakah Anda merasa bahwa insan pasca stroke mengharapkan Anda merawatnya seolah-olah Anda adalah satu-satunya orang tempat ia bergantung?	0	1	2	3	4

15. Apakah Anda merasa tidak mempunyai cukup uang untuk merawat insan pasca stroke, selain untuk pengeluaran pribadi Anda?	0	1	2	3	4
16. Apakah Anda merasa bahwa Anda tidak mampu lagi merawat insan pasca stroke lebih lama lagi?	0	1	2	3	4
17. Apakah Anda merasa kehilangan kendali atas hidup Anda semenjak keberadaan insan pasca stroke?	0	1	2	3	4
18. Apakah Anda berharap untuk bisa menyerahkan perawatan insan pasca stroke pada orang lain?	0	1	2	3	4
19. Apakah Anda merasa tidak yakin dengan apa yang harus dilakukan pada insan pasca stroke?	0	1	2	3	4
20. Apakah Anda merasa bahwa Anda harus melakukan sesuatu yang lebih untuk insan pasca stroke?	0	1	2	3	4
21. Apakah Anda merasa bahwa Anda dapat melakukan hal yang lebih baik lagi dalam merawat insan pasca stroke?	0	1	2	3	4
22. Secara umum, apakah Anda merasa beban dalam merawat insan pasca stroke?	0	1	2	3	4

d. SCNS 45 P& CG Indonesian version

Dalam sebulan terakhir, di level mana Anda membutuhkan bantuan untuk:	**TIDAK MEMERLUKAN**		**MEMERLUKAN**		
	Tidak berlaku	**Terpenuhi**	**Kebutuhan rendah**	**Kebutuhan sedang**	**Kebutuhan tinggi**
1. Mengakses informasi terkait kebutuhan Anda sebagai perawat/pendamping	1	2	3	4	5
2. Mengakses informasi mengenai orang dengan prognosis atau kemungkinan hasil kanker	1	2	3	4	5
3. Mengakses informasi tentang layanan dukungan untuk perawat/pendamping penderita kanker	1	2	3	4	5
4. Mengakses informasi tentang terapi alternatif	1	2	3	4	5
5. Mengakses informasi tentang kemungkinan kebutuhan fisik penderita kanker	1	2	3	4	5
6. Mengakses informasi tentang manfaat dan efek samping perawatan	1	2	3	4	5
7. Mendapatkan perawatan medis terbaik untuk penderita kanker	1	2	3	4	5
8. Mengakses layanan perawatan kesehatan lokal saat dibutuhkan	1	2	3	4	5
9. Terlibat langsung dengan perawatan kanker bersama dengan tim medis	1	2	3	4	5
10. Memiliki kesempatan untuk mendiskusikan perhatian Anda dengan dokter	1	2	3	4	5
11. Percaya diri bahwa semua dokter saling berbicara untuk mengoordinasikan perawatan penderita kanker	1	2	3	4	5
12. Memastikan ada manajer kasus untuk mengoordinasikan layanan untuk penderita kanker	1	2	3	4	5
13. Memastikan keluhan terkait perawatan penderita kanker tersampaikan dengan baik	1	2	3	4	5
14. Mengurangi stress dalam kehidupan penderita kanker	1	2	3	4	5
15. Menjaga kesehatan diri sendiri, termasuk tidur dan makan yang benar	1	2	3	4	5
16. Mendapatkan kontrol nyeri yang memadai untuk penderita kanker	1	2	3	4	5

"Saya, **Mochamad Hikmat Gumilar**, penerjemah bersertifikat dan bersumpah berdasarkan Keputusan Gubernur DKI Jakarta Nomor 1765/2006, menyatakan bahwa saya fasih dalam bahasa Indonesia dan bahasa Inggris dan kompeten untuk menerjemahkan di antara kedua bahasa tersebut. Dengan ini saya nyatakan bahwa Terjemahan Bahasa Indonesia dari dokumen [redacted] dan akurat sejauh kemampuan dan keyakinan saya yang terbaik dari versi aslinya dalam bahasa Inggris. Jalan C3A, Ciputat Timur, Tangerang Selatan, Banten 15419, Indonesia. Telepon 06 December 2019. Periksa keaslian terjemahan dengan mengirimkan meragukan bahwa terjemahan bukan dari penerjemah-id.com".



Dalam **sebulan terakhir,** di level mana Anda membutuhkan bantuan untuk:	TIDAK MEMERLUKAN		MEMERLUKAN		
	Tidak berlaku	Terpenuhi	Kebutuhan rendah	Kebutuhan sedang	Kebutuhan tinggi
17. Menyampaikan ketakutan tentang penurunan kinerja fisik atau mental penderita kanker	1	2	3	4	5
18. Mengakses informasi tentang potensi masalah kesuburan pada penderita kanker	1	2	3	4	5
19. Merawat penderita kanker dalam level praktis, seperti memandikan, mengganti pakaian, atau member obat	1	2	3	4	5
20. Mencari parkir rumah sakit yang lebih mudah diakses	1	2	3	4	5
21. Beradaptasi pada perubahan kehidupan kerja atau aktivitas biasa penderita kanker	1	2	3	4	5
22. Kehidupan kerja atau aktivitas biasa Anda telah terdampak karena merawat penderita kanker	1	2	3	4	5
23. Mencari tahu tentang dukungan finansial dan tunjangan pemerintah untuk Anda dan/atau penderita kanker	1	2	3	4	5
24. Mendapatkan asuransi jiwa dan/atau perjalanan untuk penderita kanker	1	2	3	4	5
25. Mengakses layanan hukum	1	2	3	4	5
26. Berkomunikasi dengan orang yang Anda rawat	1	2	3	4	5
27. Berkomunikasi dengan keluarganya	1	2	3	4	5
28. Mendapatkan dukungan lebih dari keluarga Anda	1	2	3	4	5
29. Berbicara dengan orang lain yang merawat penderita kanker	1	2	3	4	5
30. Menangani topik kanker dalam situasi sosial atau saat bekerja	1	2	3	4	5
31. Mengatur perhatian tentang kembali terkena kanker	1	2	3	4	5
32. Dampak kanker telah mempengaruhi hubungan Anda dengan penderita kanker	1	2	3	4	5
33. Memahami pengalaman penderita kanker	1	2	3	4	5
34. Menyeimbangkan kebutuhan penderita kanker dengan kebutuhan Anda	1	2	3	4	5

"Saya, **Mochamad Hikmat Gumilar**, penerjemah bersertifikat dan bersumpah berdasarkan Keputusan Gubernur DKI Jakarta Nomor 1765/2006, menyatakan bahwa saya fasih dalam bahasa Indonesia dan bahasa Inggris dan kompeten untuk menerjemahkan di antara kedua bahasa tersebut. Dengan ini saya nyatakan bahwa Terjemahan Bahasa Indonesia dari dokumen [redacted] keyakinan saya yang terbaik dari versi aslinya dalam bahasa Inggris. Jalan 3A, Ciputat Timur, Tangerang Selatan, Banten 15419, Indonesia. Telepon 6 December 2019. Periksa keaslian terjemahan dengan mengirimkan eragukan bahwa terjemahan bukan dari penerjemah-id.com".

Dalam sebulan terakhir, di level mana Anda membutuhkan bantuan untuk:	TIDAK MEMERLUKAN		MEMERLUKAN		
	Tidak berlaku	Terpenuhi	Kebutuhan rendah	Kebutuhan sedang	Kebutuhan tinggi
35. Menyesuaikan dengan perubahan tubuh penderita kanker	1	2	3	4	5
36. Menyampaikan masalah pada kehidupan seks Anda	1	2	3	4	5
37. Mendapatkan dukungan emosional untuk diri Anda sendiri	1	2	3	4	5
38. Mendapatkan dukungan emosional untuk orang tercinta	1	2	3	4	5
39. Menangani perasaan Anda tentang kematian dan sekarat	1	2	3	4	5
40. Menghadapi orang lain yang tidak mengetahui dampak merawat penderita kanker terhadap hidup Anda	1	2	3	4	5
41. Mengatasi pemulihan penderita kanker yang tidak seperti yang Anda harapkan	1	2	3	4	5
42. Membuat keputusan tentang hidup Anda dalam konteks ketidakpastian	1	2	3	4	5
43. Mendalami kepercayaan spiritual Anda	1	2	3	4	5
44. Menemukan arti dalam penyakit penderita kanker	1	2	3	4	5
45. Memiliki kesempatan untuk berpartisipasi dalam mengambil keputusan tentang perawatan penderita kanker					

Terima kasih telah mengisi survei ini

Survei Kebutuhan Perawatan Dukungan – Pendamping & Perawat

Pusat Riset Kesehatan & Psiko-onkologi (CHeRP) & Pusat Psikologi Medis dan Pengambilan Keputusan Berbasis Bukti (CeMPED) 2009)

SCNS–P&C45 tidak boleh disalin atau digunakan tanpa izin. Untuk meminta izin, harap kirim email ke: afaf.girgis@unsw.edu.au

Cancer Council
New South Wales

"Saya, **Mochamad Hikmat Gumilar**, penerjemah bersertifikat dan bersumpah berdasarkan Keputusan Gubernur DKI Jakarta Nomor 1765/2006, menyatakan bahwa saya fasih dalam bahasa Indonesia dan bahasa Inggris dan kompeten untuk
[redacted] ...ita bahasa tersebut. Dengan ini saya nyatakan bahwa Terjemahan Bahasa Indonesia dari dokumen
...eyakinan saya yang terbaik dari versi aslinya dalam bahasa Inggris. Jalan
..., Ciputat Timur, Tangerang Selatan, Banten 15419, Indonesia. Telepon
... December 2019. Periksa keaslian terjemahan dengan mengirimkan
...ragukan bahwa terjemahan bukan dari penerjemah-id.com".

Appendix 11 Questionnaires English version (IPOS, ZBI, SCNS 34 patient & SCNS 45 P&CG)

a. IPOS Patient English Version

Patient name : ....
Date (dd/mm/yyyy) : ....
Patient number : .... *(for staff use)*

Q1. What have been your main problems or concerns over the past week?

1.
....

2.
....

	Not at all	Slightly	Moderately	Severely	Over-whelmingly
Pain	☐	☐	☐	☐	
Shortness of breath	☐	☐	☐	☐	
Weakness or lack of energy	☐	☐	☐	☐	
Nausea (feeling like you are going to be sick)	☐	☐	☐	☐	
Vomiting (being sick)	☐	☐	☐	☐	
Poor appetite	☐	☐	☐	☐	
Constipation	☐	☐	☐	☐	
Sore or dry mouth	☐	☐	☐	☐	
Drowsiness	☐	☐	☐	☐	
Poor mobility	☐	☐	☐	☐	
Please list any other symptoms not mentioned above, and tick one box to show how they have affected you over the past week.					

1.	☐	☐	☐	☐	
2.	☐	☐	☐	☐	
3.	☐	☐	☐	☐	

3.

……………………………………………………………………………………………………
……………

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick one box that best describes how it has affected you over the past week.

Over the past week:

	Not at all	Occasionally	Sometimes	Most of the time	Always
Q3. Have you been feeling anxious or worried about your illness or treatment?	0☐	1☐	2☐	3☐	4☐
Q4. Have any of your family or friends been anxious or worried about you?	0☐	1☐	2☐	3☐	4☐
Q5. Have you been feeling depressed?	0☐	1☐	2☐	3☐	4☐
	Always	Most of the time	Sometimes	Occasionally	Not at all
Q6. Have you felt at peace?	0☐	1☐	2☐	3☐	4☐
Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	0☐	1☐	2☐	3☐	4☐
Q8. Have you had as much information as you wanted?	0☐	1☐	2☐	3☐	4☐
	Problems addressed/	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed

	No problems				
Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)	0☐	1☐	2☐	3☐	4☐
	On my own	With help from a friend or relative			With help from a member of staff
Q10. How did you complete this questionnaire?	☐	☐			☐

If you are worried about any of the issues raised on this questionnaire then please speak to your doctor or nurse

b. Zarit Burden Interview Assessing Caregiver Burden

Gerontologic health scientific literature identifies a number of scales to measure caregiver burden. The Zarit Scale of Caregiver Burden or the Zarit Burden Interview is the most widely used instrument. Originally designed and tested in 1980 containing 29 items, it was reduced to 22 questions. Subsequent adaptation of the scale made it particularly attractive. The research reported in The Gerontologist (2001, Vol 41, No. 5, 652-657) that a short 12-item version and 4-item screening version were found to correlate well with the full 22-item version. The short and simple 4-item screen, proven to be valid and reliable for its designated use, is self-administered by the caregiver. The screen has proven to be a helpful resource tool for caregivers and their families.

Zarit Caregiver Burden Assessment (Revised, 22-items)

Name:____________________________ Date: ____

The following is a list of statements that reflect how people sometimes feel when taking care of another person. After reading each statement, indicate how often you experience the feelings listed by circling the number that best corresponds to the frequency of these feelings.

	Never	**Rarely**	**Sometimes**	**Frequently**	**Nearly Always**
1) Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
2) Do you feel embarrassed you're your relative's behavior?	0	1	2	3	4
3) Do you feel angry when you are around your relative?	0	1	2	3	4
4) Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	0	1	2	3	4
5) Are you afraid what the future holds for your relative?	0	1	2	3	4
6) Do you feel strained when you are around your relative?	0	1	2	3	4

7) Do you feel that you do not have as much privacy as you would like because of your relative?	0	1	2	3	4
8) Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
9) Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
10) Do you feel that you have lost control of your life since your relative's illness?	0	1	2	3	4
11) Do you wish you could just leave the care of your relative to someone else?	0	1	2	3	4
12) Do you feel uncertain about what to do about your relative?	0	1	2	3	4
13) Do you feel that you should be doing more for your relative?	0	1	2	3	4
14) Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
15) Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4
16) Do you feel that your relative asks for more help than (s)he needs?	0	1	2	3	4
17) Do you feel that because of the time you spend with your relative that you do not have enough time for yourself?	0	1	2	3	4
18) Do you feel your relative is dependent upon you?	0	1	2	3	4
19) Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
19) Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
20) Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
21) Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
22) Do you feel that you do not have enough money to care for your relative in addition to the rest of your expenses?	0	1	2	3	4

Scoring Instructions: A
dd Items 1-12 Total 1-12 (maximum score = 48)
Add Items 13-21 Total 13-21 (maximum score = 36)
Score #22 (maximum score = 4)

Total Score (88) ___

A courtesy of L'Orech Yomim/Centre for Healthy Living, Inc. 2011
Suggested Scoring: **Zarit Burden Interview: Revised (22-items)**
Total score range: 0 to 8 0-21: no to mild burden
21-40: mild to moderate burden

41-60: moderate to severe burden
≥ 61: severe burden

Original: Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. The Gerontologist 1980; 20:649

c. SUPPORTIVE CARE NEEDS SURVEYSHORT FORM 34 Patient

(SCNS-SF34)

The Cancer Council
New South Wales
Centre for Health Research
& Psycho-oncology (CHeRP)

INSTRUCTIONS

To help us plan better services for people diagnosed with cancer, we are interested in whetheror not needs which you may have faced as a result of having cancer have been met. For everyitem on the following pages, indicate whether you have needed help with this issue within the last month as a result of having cancer. Put a circle around the number which best describes whether you have needed help with this in the last month. There are 5 possible answers to choose from:

NO NEED	**Not applicable** – This was not a problem for me as a result ofhaving cancer.
	Satisfied - I did need help with this, but my need for help was satisfied at the time.
SOME NEED	**Low need** - This item caused me concern or discomfort. I had littleneed for additional help.
	Moderate need - This item caused me concern or discomfort. I had some need for additional help.
	High need - This item caused me concern or discomfort. I had a strong need for additional help.

For example

In the last month, what was your level of need for help with:	No need		Some need		
	Not applicable	Satisfied	Low need	Moderate need ○	High d
Being informed about things you can do to help yourself to get well	1	2	3	4	5

If you put the circle where we have, it means that you did not receive as much information as you wanted about things you could do to help yourself get well, and therefore needed some more information.

Now please complete the survey on the next 2 pages.

In the last month, what was your level of need for help with:	No need				Some need
	Not applicable	Satisfied	Low need	Moderate need	High need
1. Pain	1	2	3	4	5
2. Lack of energy/tiredness	1	2	3	4	5
3. Feeling unwell a lot of the time	1	2	3	4	5
4. Work around the home	1	2	3	4	5
5. Not being able to do the things you used to do	1	2	3	4	5
6. Anxiety	1	2	3	4	5
7. Feeling down or depressed	1	2	3	4	5
8. Feelings of sadness	1	2	3	4	5
9. Fears about the cancer spreading	1	2	3	4	5
10. Worry that the results of treatment are beyond your control	1	2	3	4	5
11. Uncertainty about the future	1	2	3	4	5
12. Learning to feel in control of your situation	1	2	3	4	5
13. Keeping a positive outlook	1	2	3	4	5
14. Feelings about death and dying	1	2	3	4	5
15. Changes in sexual feelings	1	2	3	4	5
16. Changes in your sexual relationships	1	2	3	4	5
17. Concerns about the worries of those close to you	1	2	3	4	5
18. More choice about which cancer specialists you see	1	2	3	4	5
19. More choice about which hospital you attend	1	2	3	4	5
20. Reassurance by medical staff that the way you feel is normal	1	2	3	4	5

21. Hospital staff attending promptly to your physical needs	1	2	3	4	5
22. Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	1	2	3	4	5
23. Being given written information about the important aspects of your care	1	2	3	4	5
24. Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	1	2	3	4	5
25. Being given explanations of those tests for which you would like explanations	1	2	3	4	5
26. Being adequately informed about the benefits and side-effects of treatments before you choose to have them	1	2	3	4	5
27. Being informed about your test results as soon as feasible	1	2	3	4	5
28. Being informed about cancer which is under control or diminishing (that is, remission)	1	2	3	4	5
29. Being informed about things you can do to help yourself to get well	1	2	3	4	5
30. Having access to professional counselling (eg, psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it	1	2	3	4	5
31. Being given information about sexual relationships	1	2	3	4	5
32. Being treated like a person not just another case	1	2	3	4	5
33. Being treated in a hospital or clinic that is as physically pleasant as possible	1	2	3	4	5
34. Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	1	2	3	4	5

Thank you for completing this survey. *Centre for Health Research & Psycho-oncology (2003) Supportive Care Needs Survey - Short Form 34. The Supportive Care Needs Survey - Short Form 34 may not be copied or used without permission.To request permission, please email: CHeRP@newcastle.edu.au*

The Cancer Council
New South Wales
Centre for Health Research
& Psycho-oncology (CHeRP)

d. SCNS 45 partner & family caregivers' English version

SUPPORTIVE CARE NEEDS SURVEY PARTNERS & CARE
(SCNS-P&C45)

INSTRUCTIONS

Caring for or living with someone with cancer may raise issues for you that are distinct from the needs of the person with cancer. We are interested in finding out more about your needs as a support person, or carer for someone with cancer.

For every item on the following pages, indicate whether you have needed help with this issue within the last month as a result of caring for or living with a person with cancer. Please always ensure that you answer the questions in regard to YOUR OWN EXPERIENCE AS A CARER OR PARTNER of a person with cancer, not in regard to what the person with cancer may be experiencing.

Put a circle around the number which best describes whether you have needed help with this in the last month. If you feel the question is not relevant to your situation please make sure to circle option 1 'Not applicable'. There are 5 possible answers to choose from:

NO NEED	1	**Not applicable** - This was not a problem for me as a result of supporting someone with cancer.
	2	**Satisfied** - I did need help with this, but my need for help was satisfied at the time.
	3	**Low need** - This item caused me concern or difficulty. I had little need for additional help.
SOME NEED	4	**Moderate need** - This item caused me concern or difficulty. I had some need for additional help.
	5	**High need** - This item caused me concern or difficulty. I had a strong need for additional help.

For example

In the last month, what was your level of need for help with:		No		Some		
		Not	High applicable	Low	Moderate Satisfied	
1	Accessing information that is easy to understand	1	2	3	[✓ 4]	5

If you put the circle where we have, it means that you did not receive as much easy to understand information as you wanted and therefore had a moderate need for more

Now please complete the survey on the next 3 pages.

In the last month, what was your level of need for help with:		No need		Some need		
		Not applicable	Satisfied need	Low need	Moderate need	High need
1.	Accessing information relevant to your needs as a carer/partner	1	2	3	4	5
2.	Accessing information about the person with cancer's prognosis, or likely outcome	1	2	3	4	5
3.	Accessing information about support services for carers/partners of adults with cancer	1	2	3	4	5
4.	Accessing information about alternative therapies	1	2	3	4	5
5.	Accessing information on what the person with cancer's physical needs are likely to be	1	2	3	4	5
6.	Accessing information about the benefits and side-effects of treatments	1	2	3	4	5
7.	Obtaining the best medical care for the person with cancer	1	2	3	4	5
8.	Accessing local health care services when needed	1	2	3	4	5
9.	Being involved in the person with cancer's care, together with the medical team	1	2	3	4	5
10.	Having opportunities to discuss your concerns with the doctors	1	2	3	4	5
11.	Feeling confident that all the doctors are talking to each other to coordinate the person with cancer's care	1	2	3	4	5
12.	Ensuring there is an ongoing case manager to coordinate services for the person with cancer	1	2	3	4	5
13.	Making sure complaints regarding the person with cancer's care are properly addressed	1	2	3	4	5
14.	Reducing stress in the person with cancer's life	1	2	3	4	5

15.	Looking after your own health, including eating and sleeping properly	1	2	3	4	5
16.	Obtaining adequate pain control for the person with cancer	1	2	3	4	5
17.	Addressing fears about the person with cancer’s physical or mental deterioration	1	2	3	4	5
18.	Accessing information about the potential fertility problems in the person with cancer	1	2	3	4	5
19.	Caring for the person with cancer on a practical level, such as with bathing, changing dressings, or giving medications	1	2	3	4	5
20.	Finding more accessible hospital parking	1	2	3	4	5
21.	Adapting to changes to the person with cancer’s working life, or usual activities	1	2	3	4	5
22.	The impact that caring for the person with cancer has had on your working life, or usual activities	1	2	3	4	5
23.	Finding out about financial support and government benefits for you and/or the person with cancer	1	2	3	4	5
24.	Obtaining life and/or travel insurance for the person with cancer	1	2	3	4	5
25.	Accessing legal services	1	2	3	4	5
26.	Communicating with the person you are caring for	1	2	3	4	5
27.	Communicating with the family	1	2	3	4	5
28.	Getting more support from your family	1	2	3	4	5
29.	Talking to other people who have cared for someone with cancer	1	2	3	4	5
30.	Handling the topic of cancer in social situations or at work	1	2	3	4	5
31.	Managing concerns about the cancer coming back	1	2	3	4	5
32.	The impact that cancer has had on your relationship with the person with cancer	1	2	3	4	5
33.	Understanding the experience of the person with cancer	1	2	3	4	5
34.	Balancing the needs of the person with cancer	1	2	3	4	5

	and your own needs					
35.	Adjusting to changes in the person with cancer's body	1	2	3	4	5
36.	Addressing problems with your sex life	1	2	3	4	5
37.	Getting emotional support for yourself	1	2	3	4	5
38.	Getting emotional support for your loved ones	1	2	3	4	5
39.	Working through your feelings about death and dying	1	2	3	4	5
40.	Dealing with others not acknowledging the impact on your life of caring for a person with cancer	1	2	3	4	5
41.	Coping with the person with cancer's recovery not turning out the way you expected	1	2	3	4	5
42.	Making decisions about your life in the context of uncertainty	1	2	3	4	5
43.	Exploring your spiritual beliefs	1	2	3	4	5
44.	Finding meaning in the person with cancer's illness	1	2	3	4	5
45.	Having opportunities to participate in decision making about the person withcancer's treatment	1	2	3	4	5

Thank you very much for completing this survey

Supportive Care Needs Survey -Partners & Care
Centre for Health Research & Psycho-oncology (CHeRP) & Centre for Medical Psychology and Evidence-based Decision-making (CeMPED) (2009)

Cancer Council New South Wales
Centre for Health Research & Psycho-oncology (CHeRP)

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Appendix 12 IPOS & SCNS caregiver & partner Validity and reliability test

a. IPOS Validity test

Correlations			
		Total Score	
1	Pearson Correlation	.643**	Valid
	Sig. (2-tailed)	0	
	N	27	
2	Pearson Correlation	.596**	Valid
	Sig. (2-tailed)	0.001	
	N	27	
3	Pearson Correlation	.863**	Valid
	Sig. (2-tailed)	0	
	N	27	
4	Pearson Correlation	.566**	Valid
	Sig. (2-tailed)	0.002	
	N	27	
5	Pearson Correlation	.466*	Valid
	Sig. (2-tailed)	0.014	
	N	27	
6	Pearson Correlation	.813**	Valid
	Sig. (2-tailed)	0	
	N	27	
7	Pearson Correlation	.678**	Valid
	Sig. (2-tailed)	0	
	N	27	
8	Pearson Correlation	.436*	Valid
	Sig. (2-tailed)	0.023	
	N	27	
9	Pearson Correlation	.495**	Valid
	Sig. (2-tailed)	0.009	
	N	27	
10	Pearson Correlation	.598**	Valid
	Sig. (2-tailed)	0.001	
	N	27	
q3	Pearson Correlation	0.287	
	Sig. (2-tailed)	0.147	
	N	27	
q4	Pearson Correlation	.459*	Valid
	Sig. (2-tailed)	0.016	
	N	27	
q5	Pearson Correlation	.542**	Valid
	Sig. (2-tailed)	0.003	
	N	27	
q6	Pearson Correlation	.689**	Valid
	Sig. (2-tailed)	0	

	N	27	
q7	Pearson Correlation	.532**	Valid
	Sig. (2-tailed)	0.004	
	N	27	
q8	Pearson Correlation	0.059	
	Sig. (2-tailed)	0.771	
	N	27	
q9	Pearson Correlation	0.2	
	Sig. (2-tailed)	0.317	
	N	27	
q10	Pearson Correlation	.c	
	Sig. (2-tailed)	.	
	N	27	
total	Pearson Correlation	1	
	Sig. (2-tailed)		
	N	27	
** Correlation is significant at the 0.01 level (2-tailed).			
* Correlation is significant at the 0.05 level (2-tailed).			
c Cannot be computed because at least one of the variables is constant.			

IPOS Reliability test

Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.838	.836	17

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
1	26.04	133.114	.567	.905	.822
2	27.22	137.103	.524	.928	.826
3	26.30	125.217	.828	.941	.807
4	26.78	135.872	.479	.993	.827
5	27.04	140.422	.376	.993	.833
6	26.48	125.182	.764	.906	.810
7	26.33	128.077	.592	.832	.820
8	26.78	141.410	.343	.795	.834
9	26.37	137.781	.394	.871	.832
10	27.11	136.410	.524	.924	.825
q3	26.07	146.533	.188	.550	.842
q4	25.48	142.567	.384	.842	.832
q5	26.30	136.140	.449	.903	.829
q6	26.04	137.960	.643	.740	.823
q7	26.78	136.026	.434	.939	.830
q8	26.81	153.849	-.048	.890	.853
q9	25.85	149.285	.098	.832	.846

b. SCNS caregiver & partner validity and reliability test

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
score	370.70	3788.040	.647	.735
VAR00002	370.87	3824.937	.253	.738
VAR00003	370.65	3821.692	.531	.737
VAR00004	371.43	3761.075	.484	.733
VAR00005	370.74	3770.292	.758	.733
VAR00006	370.78	3810.451	.468	.736
VAR00007	370.43	3852.439	.395	.739
VAR00008	370.91	3811.810	.388	.737
VAR00009	370.74	3835.292	.337	.738
VAR00010	370.74	3825.111	.386	.737
VAR00011	371.39	3746.431	.778	.732
VAR00012	371.35	3746.237	.723	.732
VAR00013	370.78	3816.814	.409	.737
VAR00014	370.87	3783.300	.641	.734
VAR00015	370.83	3821.787	.311	.737
VAR00016	370.91	3769.719	.721	.733
VAR00017	370.78	3800.178	.598	.736
VAR00018	371.35	3762.874	.585	.733
VAR00019	371.09	3797.992	.449	.736
VAR00020	371.70	3817.767	.213	.737
VAR00021	371.74	3712.747	.764	.729
VAR00022	371.09	3776.447	.626	.734
VAR00023	370.65	3794.874	.630	.735
VAR00024	370.65	3795.783	.621	.735
VAR00025	371.35	3781.783	.429	.735
VAR00026	371.74	3770.111	.569	.734
VAR00027	371.43	3765.075	.661	.733
VAR00028	370.96	3817.771	.399	.737
VAR00029	371.43	3754.257	.692	.732
VAR00030	371.70	3718.040	.784	.730
VAR00031	372.26	3727.565	.632	.731
VAR00032	371.30	3764.676	.568	.733
VAR00033	371.30	3754.040	.617	.732
VAR00034	371.00	3779.727	.554	.734
VAR00035	371.91	3752.719	.597	.732
VAR00036	372.22	3775.178	.370	.734
VAR00037	371.91	3763.265	.516	.733
VAR00038	371.74	3747.111	.633	.732
VAR00039	371.30	3815.130	.234	.737
VAR00040	371.91	3722.174	.652	.730
VAR00041	371.65	3782.237	.420	.735
VAR00042	372.09	3740.083	.599	.732
VAR00043	371.43	3749.530	.607	.732
VAR00044	371.48	3802.352	.373	.736
VAR00045	371.48	3752.625	.640	.732
VAR00046	185.83	946.877	.989	.944

SCNS caregiver & partner reliability test

Reliability Statistics

Cronbach's Alpha	N of Items
.740	46

Appendix 13 PPI flyer

University of Glasgow

'Via, Veritas, Vita'

PATIENT AND
PUBLIC INVOLVEMENT

Chandra Isabella Purba
[redacted]@student.gla.ac.uk
[redacted]

University of Glasgow

Are you an adult with experience of cancer?
Have you had experience of living with cancer?
Have you cared for someone with cancer?
Do you want to influence research in palliative care for people with cancer in a resource-challenged country?
Do you have experience of palliative care in hospital?
Could you be and advisor to a project on developing palliative care in Indonesia

My name is Chandra Isabella Purba. I am a full time PhD student in nursing at University of Glasgow.
For my PhD I hope to evaluate an existing palliative care service and develop a nurse-led intervention for people with cancer and families in resource-challenged context in Indonesia

You will involve in:

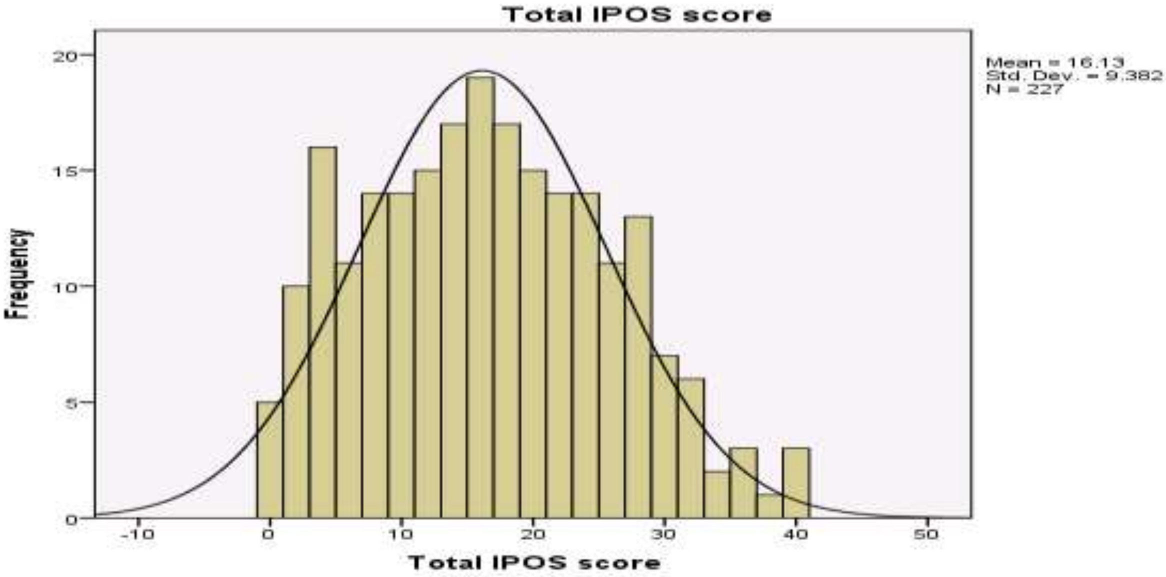
- Helping create recruitment strategy
- Assist with developing themes from data
- Review writing styles
- Help with writing a lay summary
- Helping develop patient information leaflets for the new services
- How much or how little your contribute depends on you.
- Anything will be helpful to me and will make my PhD better and the research more meaningful

Appendix 14 Complete score all questionnaires (IPOS, ZBI, SCNS 34 patient & SCNS 45 P&CG)

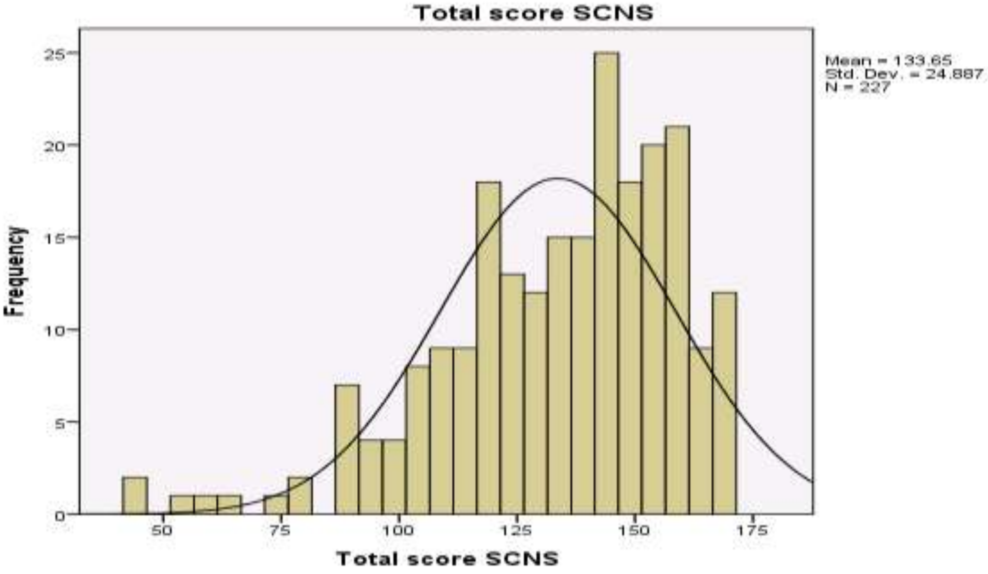
Complete IPOS score

No	Item	Not at all		Slightly		Moderately		Severely		Over-whelmingly	
		f	%	*f*	%	*f*	%	*f*	%	*f*	%
1	Pain	31	13.7	32	14.1	35	15.4	81	35.7	114	50.2
2	Shortness of breath	112	49.3	22	9.	39	17.2	22	9.7	32	14.1
3	Weakness	49	21.6	34	15	45	19.8	36	15.9	63	27.8
4	Nausea	93	41	38	16.7	47	20.7	20	8.8	29	12.8
5	Vomiting	120	52.9	34	15	34	15	13	5.7	26	11.5
6	Poor appetite	67	29.5	2	11.9	54	23.8	40	1.6	39	1.2
7	Constipation	129	56.8	23	10.1	29	12.8	17	7.5	29	12.8
8	Sore mouth	5	33	40	17.6	41	18.1	29	12.8	42	18.5
9	Drowsiness	83	36.6	24	10.6	46	20.3	37	16.3	37	16.3
10	Poor mobility	93	41	34	15	39	17.2	21	9.3	40	17.6
12	Feeling anxious about your illness or treatment.	20	8.8	10	4.4	61	26.9	47	20.7	89	39.2
13	Have any of your family or friends been anxious or worried about you?	8	3.5	9	4	30	13.2	77	33.9	103	45.4
14	Have you been feeling depressed.	63	27.8	29	12.8	52	22.9	34	15	49	21.6
15	Have you felt at peace?	30	13.2	30	13.2	70	30.8	44	19.4	53	23.3
16	Have you been able to share how you are feeling with your family or friends as much as you wanted?	51	22.5	27	11.9	52	22.9	48	21.1	49	21.6
17	Have you had as much information as you wanted?	34	15	31	13.7	102	44.9	25	11	35	15.4
18	Have any practical	17	7.5	16	7	31	13.7	6	33.5	87	38.3

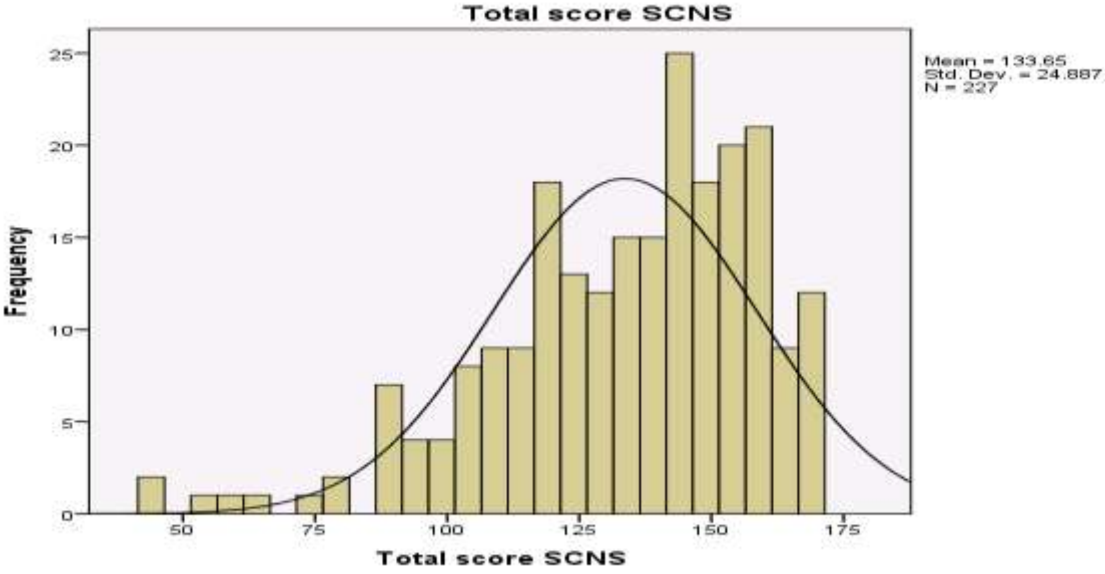
	problems resulting from your illness been addressed?										
11	Number of other symptoms.	None		One		Two		Three		Four	
		f	%	f	%	f	%	f	%	f	%
		167	13.6	41	18.1	14	6.2	5	2.2	0	0
19	How did you complete this questionnaire?	Myself		Family		Staff		Mixed			
		f	%	f	%	f	%	f	%		
		1	0.4	164	72.2	6	2.7	56	25.4		



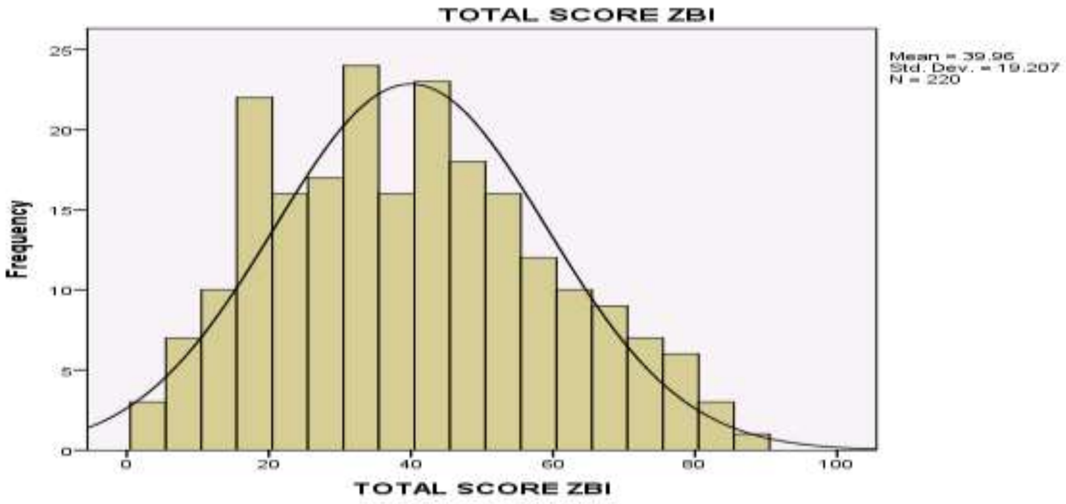
b. **Complete score SCNS patients.**



c. **Complete score SCNS 45 P& CG**



d. ZBI complete score



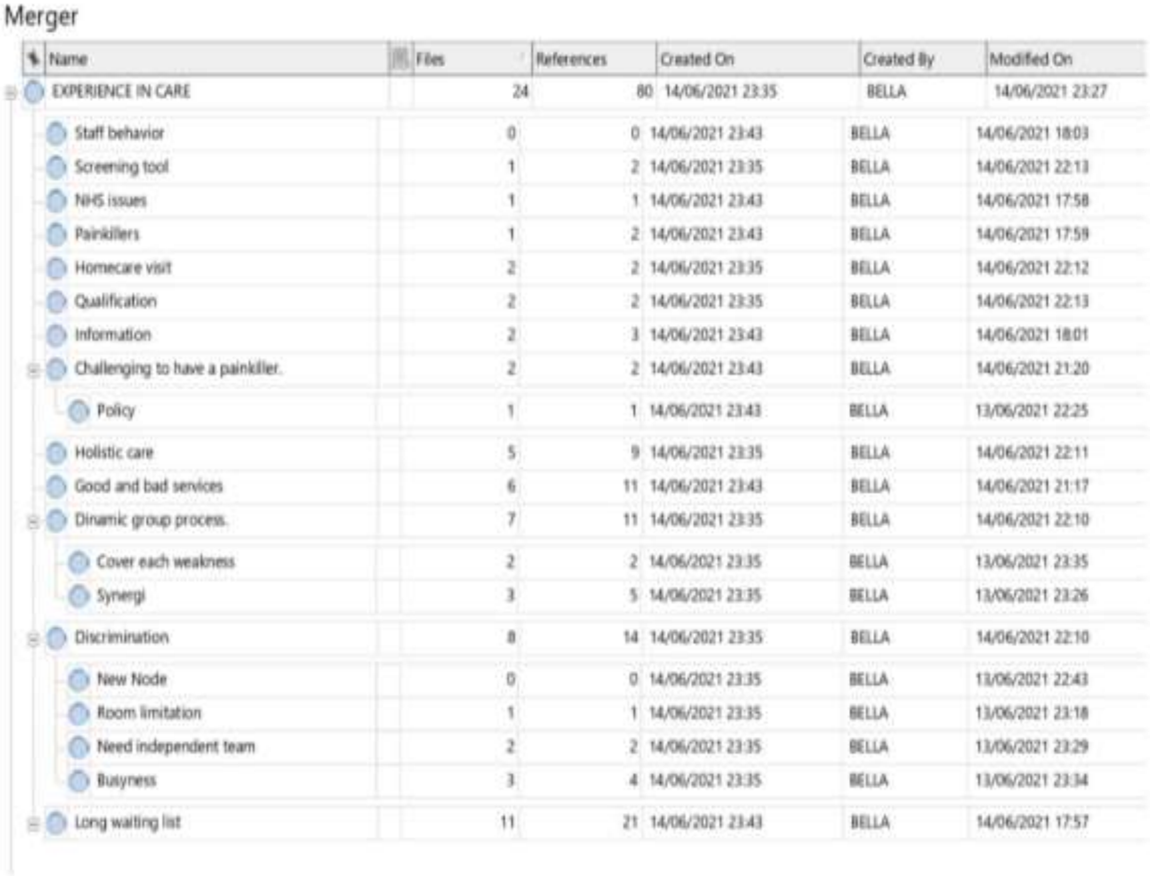
ZBI levels of burdens & high-risk level

No.	ZBI Burden Level	Frequency	Percent (%)
1	No Burden	43	19.1
2	Medium Burden	73	33.2
3	High Burden	69	31.4
4	Severe burden	36	16.4

ZBI Risk of depression

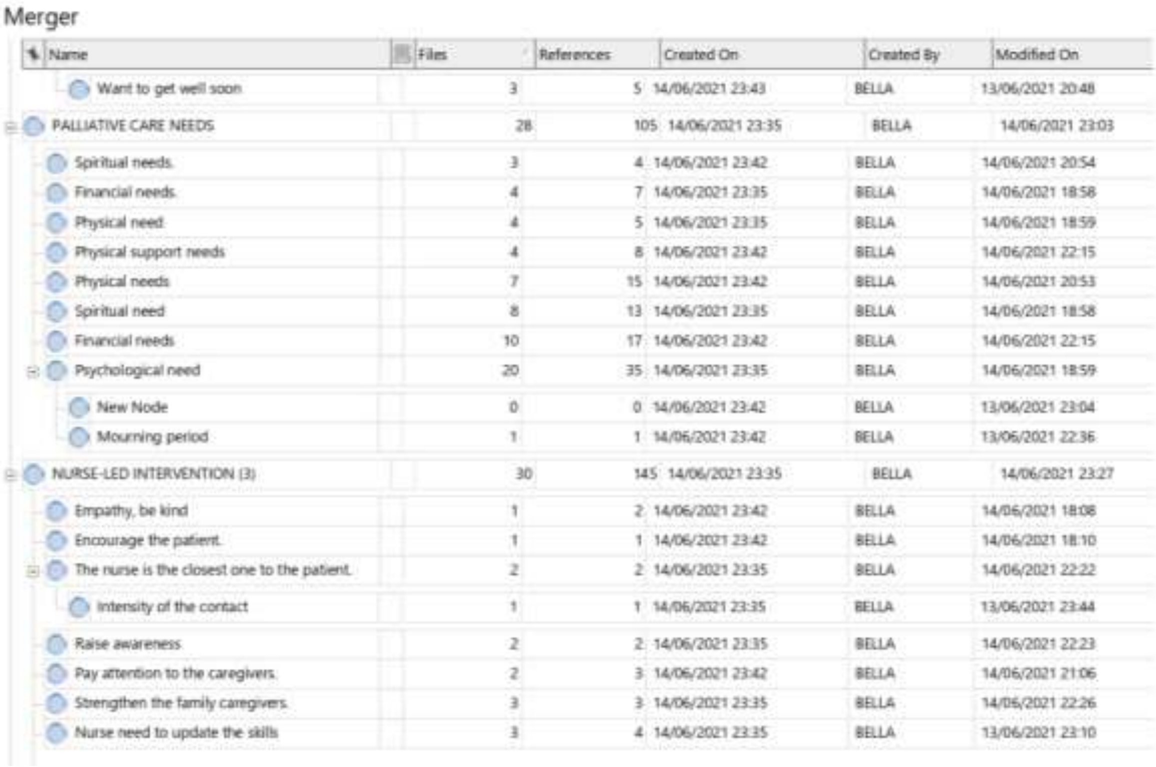
No.	ZBI Burden Level	Frequency	Percent (%)
1	No risk	55	25
2	High risk	165	75

Appendix 15 The codes, subthemes and themes of interview study.



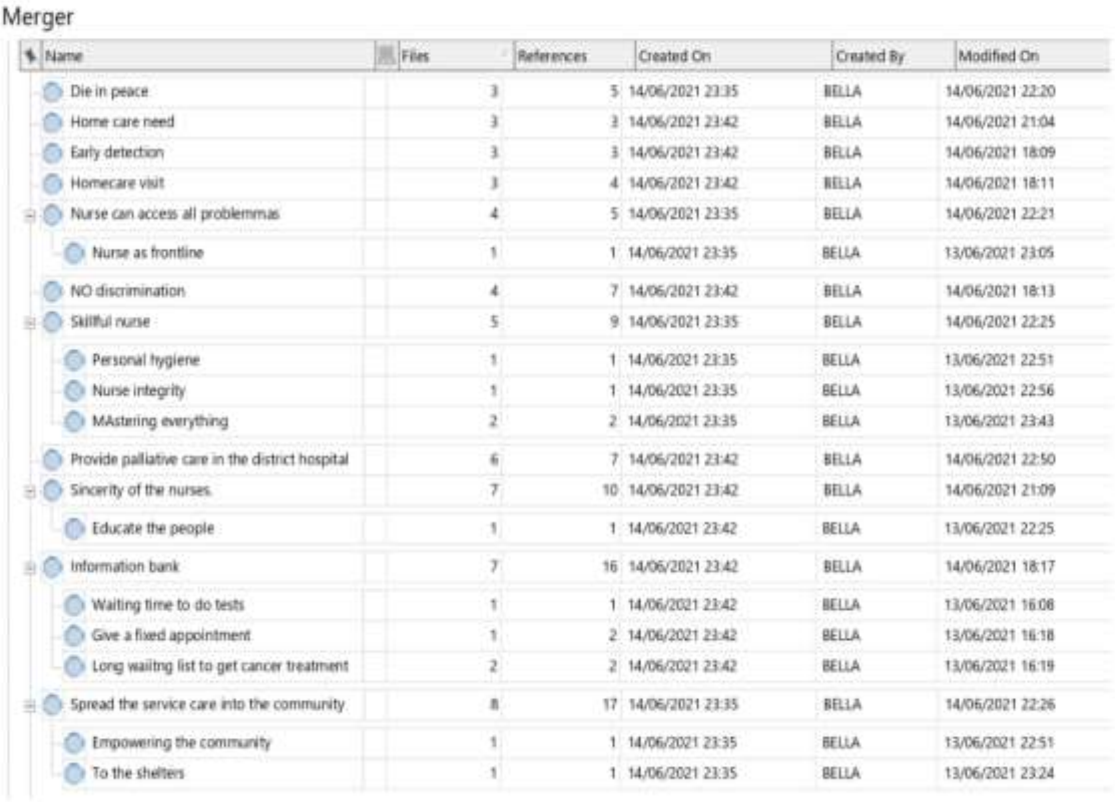
Merger

Name	Files	References	Created On	Created By	Modified On
EXPERIENCE IN CARE	24	80	14/06/2021 23:35	BELLA	14/06/2021 23:27
Staff behavior	0	0	14/06/2021 23:43	BELLA	14/06/2021 18:03
Screening tool	1	2	14/06/2021 23:35	BELLA	14/06/2021 22:13
NHS issues	1	1	14/06/2021 23:43	BELLA	14/06/2021 17:58
Painkillers	1	2	14/06/2021 23:43	BELLA	14/06/2021 17:59
Homecare visit	2	2	14/06/2021 23:35	BELLA	14/06/2021 22:12
Qualification	2	2	14/06/2021 23:35	BELLA	14/06/2021 22:13
Information	2	3	14/06/2021 23:43	BELLA	14/06/2021 18:01
Challenging to have a painkiller.	2	2	14/06/2021 23:43	BELLA	14/06/2021 21:20
Policy	1	1	14/06/2021 23:43	BELLA	13/06/2021 22:25
Holistic care	5	9	14/06/2021 23:35	BELLA	14/06/2021 22:11
Good and bad services	6	11	14/06/2021 23:43	BELLA	14/06/2021 21:17
Dinamic group process.	7	11	14/06/2021 23:35	BELLA	14/06/2021 22:10
Cover each weakness	2	2	14/06/2021 23:35	BELLA	13/06/2021 23:35
Synergi	3	5	14/06/2021 23:35	BELLA	13/06/2021 23:26
Discrimination	8	14	14/06/2021 23:35	BELLA	14/06/2021 22:10
New Node	0	0	14/06/2021 23:35	BELLA	13/06/2021 22:43
Room limitation	1	1	14/06/2021 23:35	BELLA	13/06/2021 23:18
Need independent team	2	2	14/06/2021 23:35	BELLA	13/06/2021 23:29
Busyness	3	4	14/06/2021 23:35	BELLA	13/06/2021 23:34
Long waiting list	11	21	14/06/2021 23:43	BELLA	14/06/2021 17:57



Merger

Name	Files	References	Created On	Created By	Modified On
Want to get well soon	3	5	14/06/2021 23:43	BELLA	13/06/2021 20:48
PALLIATIVE CARE NEEDS	28	105	14/06/2021 23:35	BELLA	14/06/2021 23:03
Spiritual needs.	3	4	14/06/2021 23:42	BELLA	14/06/2021 20:54
Financial needs.	4	7	14/06/2021 23:35	BELLA	14/06/2021 18:58
Physical need	4	5	14/06/2021 23:35	BELLA	14/06/2021 18:59
Physical support needs	4	8	14/06/2021 23:42	BELLA	14/06/2021 22:15
Physical needs	7	15	14/06/2021 23:42	BELLA	14/06/2021 20:53
Spiritual need	8	13	14/06/2021 23:35	BELLA	14/06/2021 18:58
Financial needs	10	17	14/06/2021 23:42	BELLA	14/06/2021 22:15
Psychological need	20	35	14/06/2021 23:35	BELLA	14/06/2021 18:59
New Node	0	0	14/06/2021 23:42	BELLA	13/06/2021 23:04
Mourning period	1	1	14/06/2021 23:42	BELLA	13/06/2021 22:36
NURSE-LED INTERVENTION (3)	30	145	14/06/2021 23:35	BELLA	14/06/2021 23:27
Empathy, be kind	1	2	14/06/2021 23:42	BELLA	14/06/2021 18:08
Encourage the patient.	1	1	14/06/2021 23:42	BELLA	14/06/2021 18:10
The nurse is the closest one to the patient.	2	2	14/06/2021 23:35	BELLA	14/06/2021 22:22
Intensity of the contact	1	1	14/06/2021 23:35	BELLA	13/06/2021 23:44
Raise awareness	2	2	14/06/2021 23:35	BELLA	14/06/2021 22:23
Pay attention to the caregivers.	2	3	14/06/2021 23:42	BELLA	14/06/2021 21:06
Strengthen the family caregivers.	3	3	14/06/2021 23:35	BELLA	14/06/2021 22:26
Nurse need to update the skills	3	4	14/06/2021 23:35	BELLA	13/06/2021 23:10



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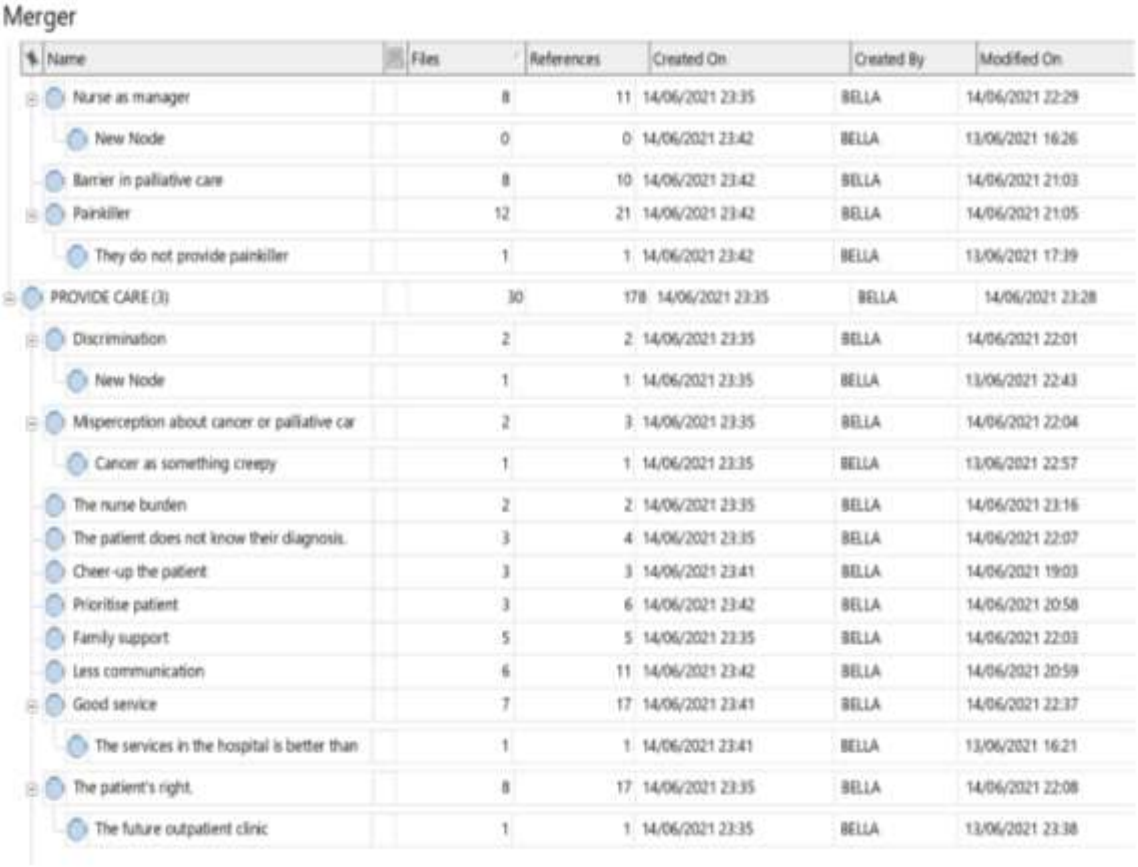
Name	Files	References	Created On	Created By	Modified On
Die in peace	3	5	14/06/2021 23:35	BELLA	14/06/2021 22:20
Home care need	3	3	14/06/2021 23:42	BELLA	14/06/2021 21:04
Early detection	3	3	14/06/2021 23:42	BELLA	14/06/2021 18:09
Homecare visit	3	4	14/06/2021 23:42	BELLA	14/06/2021 18:11
Nurse can access all problemmas	4	5	14/06/2021 23:35	BELLA	14/06/2021 22:21
Nurse as frontline	1	1	14/06/2021 23:35	BELLA	13/06/2021 23:05
NO discrimination	4	7	14/06/2021 23:42	BELLA	14/06/2021 18:13
Skillful nurse	5	9	14/06/2021 23:35	BELLA	14/06/2021 22:25
Personal hygiene	1	1	14/06/2021 23:35	BELLA	13/06/2021 22:51
Nurse integrity	1	1	14/06/2021 23:35	BELLA	13/06/2021 22:56
MAstering everything	2	2	14/06/2021 23:35	BELLA	13/06/2021 23:43
Provide palliative care in the district hospital	6	7	14/06/2021 23:42	BELLA	14/06/2021 22:50
Sincerity of the nurses.	7	10	14/06/2021 23:42	BELLA	14/06/2021 21:09
Educate the people	1	1	14/06/2021 23:42	BELLA	13/06/2021 22:25
Information bank	7	16	14/06/2021 23:42	BELLA	14/06/2021 18:17
Waiting time to do tests	1	1	14/06/2021 23:42	BELLA	13/06/2021 16:08
Give a fixed appointment	1	2	14/06/2021 23:42	BELLA	13/06/2021 16:18
Long wailtng list to get cancer treatment	2	2	14/06/2021 23:42	BELLA	13/06/2021 16:19
Spread the service care into the community	8	17	14/06/2021 23:35	BELLA	14/06/2021 22:26
Empowering the community	1	1	14/06/2021 23:35	BELLA	13/06/2021 22:51
To the shelters	1	1	14/06/2021 23:35	BELLA	13/06/2021 23:24



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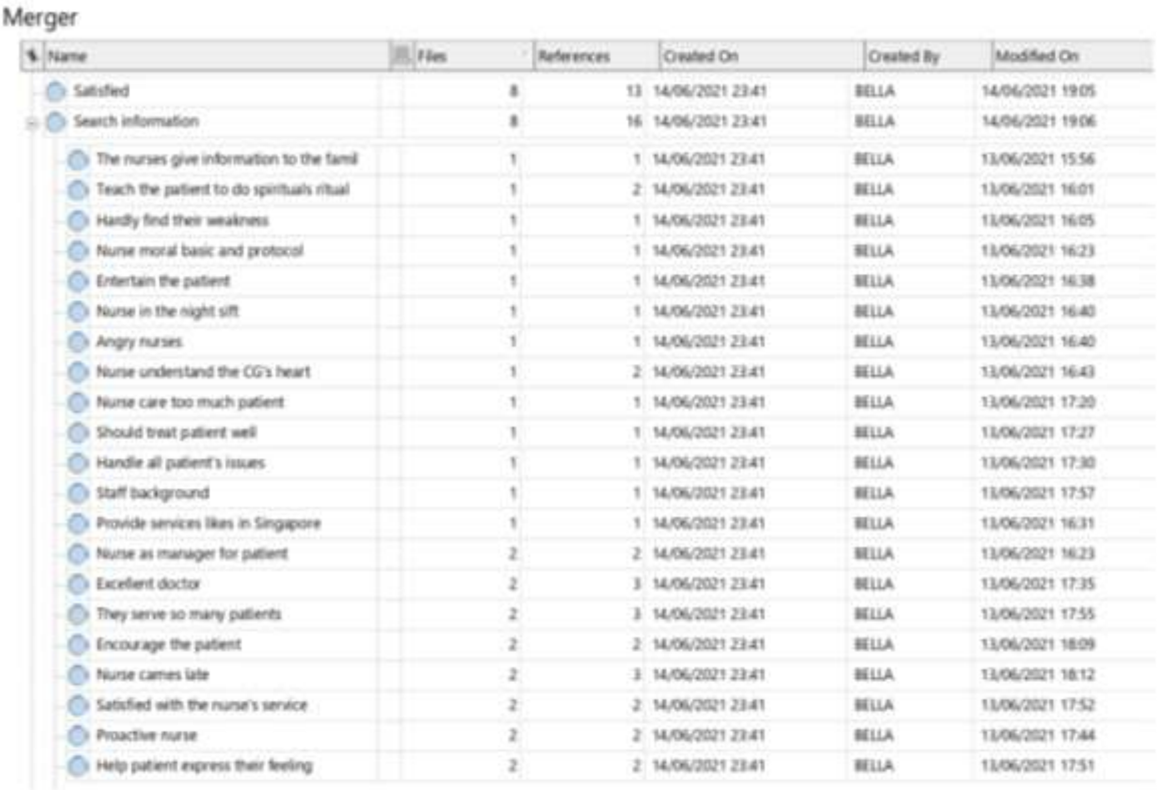
Name	Files	References	Created On	Created By	Modified On
Nurse as manager	8	11	14/06/2021 23:35	BELLA	14/06/2021 22:29
New Node	0	0	14/06/2021 23:42	BELLA	13/06/2021 16:26
Barrier in palliative care	8	10	14/06/2021 23:42	BELLA	14/06/2021 21:03
Painkiller	12	21	14/06/2021 23:42	BELLA	14/06/2021 21:05
They do not provide painkiller	1	1	14/06/2021 23:42	BELLA	13/06/2021 17:39
PROVIDE CARE (3)	30	178	14/06/2021 23:35	BELLA	14/06/2021 23:28
Discrimination	2	2	14/06/2021 23:35	BELLA	14/06/2021 22:01
New Node	1	1	14/06/2021 23:35	BELLA	13/06/2021 22:43
Misperception about cancer or palliative car	2	3	14/06/2021 23:35	BELLA	14/06/2021 22:04
Cancer as something creepy	1	1	14/06/2021 23:35	BELLA	13/06/2021 22:57
The nurse burden	2	2	14/06/2021 23:35	BELLA	14/06/2021 23:16
The patient does not know their diagnosis.	3	4	14/06/2021 23:35	BELLA	14/06/2021 22:07
Cheer-up the patient	3	3	14/06/2021 23:41	BELLA	14/06/2021 19:03
Prioritise patient	3	6	14/06/2021 23:42	BELLA	14/06/2021 20:58
Family support	5	5	14/06/2021 23:35	BELLA	14/06/2021 22:03
Less communication	6	11	14/06/2021 23:42	BELLA	14/06/2021 20:59
Good service	7	17	14/06/2021 23:41	BELLA	14/06/2021 22:37
The services in the hospital is better than	1	1	14/06/2021 23:41	BELLA	13/06/2021 16:21
The patient's right.	8	17	14/06/2021 23:35	BELLA	14/06/2021 22:08
The future outpatient clinic	1	1	14/06/2021 23:35	BELLA	13/06/2021 23:38



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Name	Files	References	Created On	Created By	Modified On
Satisfied	8	13	14/06/2021 23:41	BELLA	14/06/2021 19:05
Search information	8	16	14/06/2021 23:41	BELLA	14/06/2021 19:06
The nurses give information to the famil	1	1	14/06/2021 23:41	BELLA	13/06/2021 15:56
Teach the patient to do spirituals ritual	1	2	14/06/2021 23:41	BELLA	13/06/2021 16:01
Hardly find their weakness	1	1	14/06/2021 23:41	BELLA	13/06/2021 16:05
Nurse moral basic and protocol	1	1	14/06/2021 23:41	BELLA	13/06/2021 16:23
Entertain the patient	1	1	14/06/2021 23:41	BELLA	13/06/2021 16:38
Nurse in the night sift	1	1	14/06/2021 23:41	BELLA	13/06/2021 16:40
Angry nurses	1	1	14/06/2021 23:41	BELLA	13/06/2021 16:40
Nurse understand the CG's heart	1	2	14/06/2021 23:41	BELLA	13/06/2021 16:43
Nurse care too much patient	1	1	14/06/2021 23:41	BELLA	13/06/2021 17:20
Should treat patient well	1	1	14/06/2021 23:41	BELLA	13/06/2021 17:27
Handle all patient's issues	1	1	14/06/2021 23:41	BELLA	13/06/2021 17:30
Staff background	1	1	14/06/2021 23:41	BELLA	13/06/2021 17:57
Provide services likes in Singapore	1	1	14/06/2021 23:41	BELLA	13/06/2021 16:31
Nurse as manager for patient	2	2	14/06/2021 23:41	BELLA	13/06/2021 16:23
Excellent doctor	2	3	14/06/2021 23:41	BELLA	13/06/2021 17:35
They serve so many patients	2	3	14/06/2021 23:41	BELLA	13/06/2021 17:55
Encourage the patient	2	2	14/06/2021 23:41	BELLA	13/06/2021 18:09
Nurse cames late	2	3	14/06/2021 23:41	BELLA	13/06/2021 18:12
Satisfied with the nurse's service	2	2	14/06/2021 23:41	BELLA	13/06/2021 17:52
Proactive nurse	2	2	14/06/2021 23:41	BELLA	13/06/2021 17:44
Help patient express their feeling	2	2	14/06/2021 23:41	BELLA	13/06/2021 17:51

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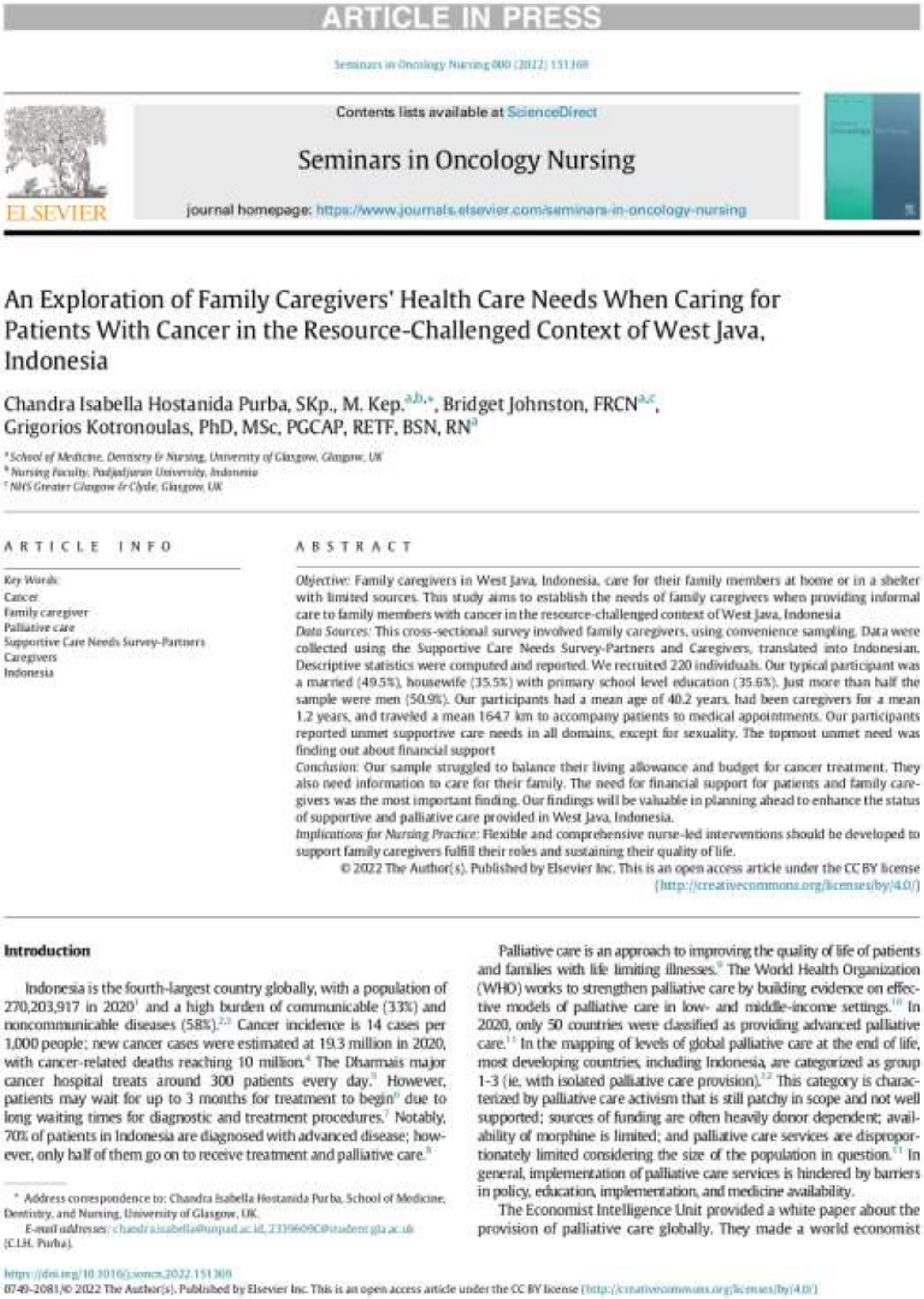
Name	Files	References	Created On	Created By	Modified On
Provide emotion support to the patient	3	4	14/06/2021 23:41	BELLA	13/06/2021 18:12
Give written information	4	4	14/06/2021 23:41	BELLA	13/06/2021 18:08
The work of the team	9	30	14/06/2021 23:35	BELLA	14/06/2021 23:26
New Node	0	0	14/06/2021 23:35	BELLA	13/06/2021 21:17
Caring	9	18	14/06/2021 23:42	BELLA	14/06/2021 20:57
Caring is the nature of the nurse	1	1	14/06/2021 23:42	BELLA	13/06/2021 22:24
Serve with your heart	1	1	14/06/2021 23:42	BELLA	13/06/2021 22:24
Be patient	14	30	14/06/2021 23:41	BELLA	14/06/2021 19:02

Appendix 16 Article published from this study



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An Exploration of Family Caregivers' Health Care Needs When Caring for Patients With Cancer in the Resource-Challenged Context of West Java, Indonesia

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ABSTRACT

Objective: Family caregivers in West Java, Indonesia, care for their family members at home or in a shelter with limited sources. This study aims to establish the needs of family caregivers when providing informal care to family members with cancer in the resource-challenged context of West Java, Indonesia

Data Sources: This cross-sectional survey involved family caregivers, using convenience sampling. Data were collected using the Supportive Care Needs Survey-Partners and Caregivers, translated into Indonesian. Descriptive statistics were computed and reported. We recruited 220 individuals. Our typical participant was a married (49.5%), housewife (35.5%) with primary school level education (35.6%). Just more than half the sample were men (50.9%). Our participants had a mean age of 40.2 years, had been caregivers for a mean 1.2 years, and traveled a mean 164.7 km to accompany patients to medical appointments. Our participants reported unmet supportive care needs in all domains, except for sexuality. The topmost unmet need was finding out about financial support

Conclusion: Our sample struggled to balance their living allowance and budget for cancer treatment. They also need information to care for their family. The need for financial support for patients and family caregivers was the most important finding. Our findings will be valuable in planning ahead to enhance the status of supportive and palliative care provided in West Java, Indonesia.

Implications for Nursing Practice: Flexible and comprehensive nurse-led interventions should be developed to support family caregivers fulfill their roles and sustaining their quality of life.

Introduction

Indonesia is the fourth-largest country globally, with a population of 270,203,917 in 2020[1] and a high burden of communicable (33%) and noncommunicable diseases (58%).[2,3] Cancer incidence is 14 cases per 1,000 people; new cancer cases were estimated at 19.3 million in 2020, with cancer-related deaths reaching 10 million.[4] The Dharmais major cancer hospital treats around 300 patients every day.[5] However, patients may wait for up to 3 months for treatment to begin[6] due to long waiting times for diagnostic and treatment procedures.[7] Notably, 70% of patients in Indonesia are diagnosed with advanced disease; however, only half of them go on to receive treatment and palliative care.[8]

Palliative care is an approach to improving the quality of life of patients and families with life limiting illnesses.[9] The World Health Organization (WHO) works to strengthen palliative care by building evidence on effective models of palliative care in low- and middle-income settings.[10] In 2020, only 50 countries were classified as providing advanced palliative care.[11] In the mapping of levels of global palliative care at the end of life, most developing countries, including Indonesia, are categorized as group 1-3 (ie, with isolated palliative care provision).[12] This category is characterized by palliative care activism that is still patchy in scope and not well supported; sources of funding are often heavily donor dependent; availability of morphine is limited; and palliative care services are disproportionately limited considering the size of the population in question.[11] In general, implementation of palliative care services is hindered by barriers in policy, education, implementation, and medicine availability.

The Economist Intelligence Unit provided a white paper about the provision of palliative care globally. They made a world economist

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quality ranking of death in 40 countries based on 20 indicators.[13] In 2015, 80 countries were included with 20 quantitative and qualitative indicators across five categories. Indonesia was placed 53rd in the rankings with a score of 33.6/100.[14] Although Indonesia marks significant improvements in palliative care, implementation is still challenging. An important step was integration of palliative care into the national cancer control program between 2014 and 2019. However, a recent study declared that Indonesia still lacks formal institutions to support people with long-term illnesses, as shown in the absence of hospice care and the lack of policy related to palliative care.[15] Specialist palliative services are mainly available on the Java Island, and specialized staff is available only in two cities.

Furthermore, legal restrictions hinder access to opioids, and difficulty in medication transportation across 17,000 islands together with isolated communities with limited facilities and low public awareness further aggravates the situation.[14] Several facilitators and barriers to addressing the significant demand for palliative care in Indonesia have been identified.[16] Facilitators include government and volunteering organization policies and cultural beliefs about the role of the family in caring for the patient. Recommendations have been made for specialist training on palliative care to nurses and doctors, advances in academic curricula, and provision of education to families and communities.[16] Nevertheless, Indonesia still suffers from a lack of cancer awareness, unhelpful cultural beliefs, financial burden, a paternalistic style of communication, and unmet information needs.[17]

Due to the limited access to palliative care and hospice care, it is the family who primarily cares for patients with (advanced) cancer in Indonesia. Indonesia has a communal culture, whereby family members belong to one another,[18] with the family generally providing care on a 24/7 basis.[19] This task is perceived as an obligation deeply rooted in cultural belief.[20] Even though the Indonesian government established a National Health System in 2014,[21] the patient and family are responsible for meeting expenses related to managing advanced cancer. Furthermore, Indonesia does not have a national pension scheme. As such, the caring capabilities of the family may be affected by their finances, and subsequently, the quality of care provided to patients depends on the caregiving capabilities of the family.

Family caregivers in Indonesia need support with diverse and demanding tasks. These include organizing and providing hands-on care, monitoring and managing symptoms, offering emotional support, looking after and communicating with the broader family, accessing resources and managing finances, being the patient's advocate, negotiating the health care system, taking action and making decisions, taking navigating the health care system, and preparing for an uncertain future.[22] No formal training or home-visit programs are available to empower family caregivers to care for the patient at home. Living in the same house with the patient adds to the task list for family caregivers, who may also have to support other family members.[15] Unavoidably, advanced cancer exacerbates the challenge for family caregivers. The evidence suggests that family caregivers in Indonesia experience a moderate burden in their role.[23] Despite these known challenges, little is known about family caregivers' own needs for supportive care in the Indonesian context. Therefore, this study aimed to comprehensively investigate the supportive care needs of family caregivers in West Java, Indonesia.

Material and Methods

Study Design, Setting, Sample, and Sampling

A quantitative, cross-sectional survey was conducted as part of a larger, four-stage mixed-methods project to develop a nurse-led palliative care intervention for the resource-challenged context of Indonesia. The survey was conducted in Hasan Sadikin Hospital and 13 shelters around the hospital in West Java Province, Indonesia.

Our sample included family caregivers who provided voluntary (unpaid) care to ill family members with advanced cancer. We used convenience sampling based on the following inclusion criteria: Adults 18 years old or older; has a relationship with the patient by blood or marriage; primary family caregiver for a patient with advanced cancer. Family caregivers providing care to patients without advanced cancer and paid caregivers were excluded.

We used the Krejcie and Morgan formula[24] to calculate our target sample size. For a survey with population 700 people, 95% confidence level, 0.5 standard deviation, and 5% confidence interval, the required sample is 248-254 people. Thus, we planned to approach 250 individuals.

Ethics

We obtained ethics approval for the whole project from the University of Glasgow College of Medicine, Veterinary and Life Sciences ethics committee (200180198) and ethics clearance from Hasan Sadikin Hospital (LB.02.01/X.6.5/344/2019). We as researchers and authors are also certified in Good Clinical Practice for Research and the General Data Protection Regulation.

Data Collection

Family caregivers were identified from patient lists at Hasan Sadikin Hospital and 13 shelters. All shelters were managed by nongovernmental organizations that raised money from the public. All shelters provided free shared bedrooms. Some of them provide free laundry, water drinking and staple food (rice), ambulance as well as buying medicine prescribed for the patient. Two different recruitment approaches were used to enhance the potential participants by posters and went directly to the potential participant. At the hospital, the nurse lead introduced the researcher to the patients with cancer and family caregivers. The researcher also approached the shelter's manager to request to meet the patient with cancer and their families who stayed at the shelter. Patients nominated their primary family caregiver, then eligibility was checked and an invitation to participate was offered. Eligible family caregivers received a privacy notice and information sheet. They had the opportunity to ask further questions and 24-48 hours to decide whether they wanted to take part or not before signing the informed consent. Participants were free to withdraw without a requirement to justify their decision. Those participants who wanted to complete the questionnaires at home were supplied with an envelope and stamp. The researcher attended the shelters daily to collect questionnaires from participants who chose to return questionnaires in person. The first author double-checked all questionnaires for completeness and verified with participants where missing data were identified. This led to an almost complete data set.

Measures

We used the Supportive Care Needs Survey-Partners and Caregivers (SCNS-P&C)[25] to measure the unmet needs of partner/family caregivers across the illness trajectory. The SCNS-P&C has 45 questions across four domains: information and communication practical needs, health care and service needs, work and social needs, and psychological and emotional needs. Total scores range from 0 to 225. Participants chose one answer for each question on five-point Likert scales, ranging from no needs (0) to high needs (4). The higher the score, the more needed item.[25] The original SCNS-P&C was translated into Indonesian and tested for validity and reliability. Three nursing experts in Indonesia were invited to review the Indonesian translation for content validity. All of them are bilingual, finished their postgraduate studies overseas, and work as a nurse in the hospital and as lecturers in the nursing faculty. They gave a score to each item. The scale was scored as follows: 1 = irrelevant; 2 = slight relevant; 3 = quite relevant and 4 = highly relevant.[26] A content validity index is the total score of the three divided by three. It had a final score of 3.67. Grades 3 and 4 were considered relevant. They agreed that the content of all items in the adapted Indonesian version was valid. Then the questionnaire was distributed to 23 participants to see the reliability test. Cronbach's alpha was computed as 0.94. In terms of internal consistency, values above 0.70 indicate good internal consistency.[27]

Demographic Data

A demographic data form was used to collect the following data: family caregiver's age, gender, marital status, occupation, education level, ethnicity, distance home-hospital, relationship to the patient, and duration functioning as a caregiver.

Data Analysis

Data were inspected visually by the first author upon data entry. Data quality was verified by running an outliers analysis; no odd entries or missing data were identified in the data set. Total and subscale scores were calculated by summing up individual item ratings. Data were analyzed using SPSS version 26.0 (IBM Corp.) and displayed as frequencies, rates (%), mean, standard deviation (SD), and range.

Results

Sample Characteristics

Between December 2019 and February 2020, we recruited 220 family caregivers. The overall response rate to the survey was excellent (88%). Reasons for not returning the questionnaires were as follows: Not able to fill the questionnaires (7), going home temporarily and not coming back until we finished the data collection (15), not understanding how to complete (3) it, and accidentally losing the questionnaire (5). Most caregivers were Sundanese (86.8%) and male (50.9%). Participants mean age was 40.2 years (SD 12). Complete demographic data are shown in Table 1.

Overview of Reported Supportive Care Needs

TABLE 1
Demographic Data of the Participant's Family Caregivers (n = 220).

Variable/ Category	Family caregivers M (SD); Range
Age	40.16 (13.6) 16-72
Distance home to the hospital (km)	164.7 km (1-3,000 km)
Duration as a family caregiver	1.17 years
	n/%
Gender	
Male	112 (50.9)
Age in years	
<36	81 (36.7)
≥36	139 (62.9)
Ethnicity	
Sundanese	191 (86.8)
Javanese	22 (10)
Others	7 (3.2)
Work status	
Housewives	78 (35.5)
Worker general	39 (17.6)
Entrepreneur	35 (16)
Jobless	28 (12.7)
Others	40 (18.2)
Education level	
No school	1 (0.5)
Primary	99 (45)
Junior	46 (20.9)
High	61 (27.7)
Bachelor	13 (5.9)
Duration as a family caregiver	
<1 year	165 (75)
1-2 years	28 (12.7)
>2 years	27 (12.3)

km, kilometer; SD, standard deviation (it measures the dispersion of a dataset relative to its mean).

A mean total SCNS-P&C score of 170.6 (SD 29.8; min-max 57-225) was found (Table 2). Thirty four out of 45 items were scored as high need by minimum 60% of the sample. Most participants reported unmet supportive care needs in all SCNS-P&C domains (Table 3). The greatest unmet need was finding out about financial support and travel insurance for a person with cancer (81.4%) (Table 4). Additional unmet needs included discussing concerns with physicians (80%), identifying best medical care and information on treatment's side effects (78.2%) and accessing support services for carers/partners (76.4%). The top met needs were problems with sex life (69.1%), dealing with others not acknowledging the impact of caring for a person with cancer (61%), getting emotional support (50.9%), cancer's impact on the partner (41.8%); and feelings about death and dying (39.1%).

Health Care and Service Needs Domain

Unmet needs in this domain were reported by 30.9%-74% participants or on average 60.3% of participants. Addressing problems with sex life was the least reported unmet need (30.9% of participants), while getting more support from family was the greatest unmet need (74.1% of participants).

Psychological and Emotional Needs Domain

Unmet psycho-emotional needs were reported by 49%-70% of our sample or on average 60.9% of participants. Getting emotional support for themselves was reported as an unmet need by only 49% of participants. Conversely, accessing information and looking after their own health was reported as an unmet need by 70% of participants.

TABLE 2
Total and Domain-Specific SCNS-P&C Scores.

DOMAIN	Number of items	Min-Max		Mean/SD	Median/IQR
		questionnaire	participant		
Information and communication/practical needs	18	18-90	8-76	37.7 (9.3)	38.9 (13)
Psychological and emotional	14	14-70	1-50	29.6 (9.1)	30.3 (13)
Work and social and security needs	8	8-40	0-50	33.43 (10.7)	34.3 (17)
Health care and service	5	5-25	0-50	33.1 (11.4)	35 (18)
Total score all domains	45	57-225	220	170.8 (29.8)	176.5 (193.0)

IQR, interquartile range; SCNS-P&C, Supportive Care Needs Survey-Partners and Caregivers; SD, standard deviation.

TABLE 3
Breakdown of Supportive Care Needs of Family Caregivers per Individual SCNS-P&C Item (n = 220).

Item	(n) answering this item	No need-Low need		Moderate-high need	
		n	%	*n*	%
Domain Information/communication and practical needs/(2-10, 11-14, 16-19,45)					
2. Accessing information about the person with cancer's prognosis, or likely outcome	220	56	25.5	164	74.5
3. Accessing information about support services for careers/partners of people with cancer.	220	52	23.6	168	76.4
4. Accessing information about alternative therapies?	220	84	38.2	136	61.8
5. Accessing information on what the person with cancer's physical needs is likely to be.	220	55	25	165	75
6. Accessing information about the benefits and side effects of treatments?	220	52	23.6	168	76.4
7. Obtaining the best medical care for the person with cancer?	220	48	21.8	172	78.2
8. Accessing local health care services when needed?	220	60	27.3	160	72.7
9. Being involved in the person with cancer's care, together with the medical team?	220	68	30.9	152	69.1
10. Having opportunities to discuss your concerns with the doctors?	220	44	20	176	80
11. Feeling confident that all the doctors are talking to each other to coordinate the person with cancer care?	220	61	27.7	159	72.3
12. Ensuring there is an ongoing case manager to coordinate services for the person with cancer?	220	66	30	154	70
13. Making sure complaints regarding the person with cancer's care are properly addressed?	220	55	25	165	75
14. Reducing stress in the person with cancer's life?	220	60	27.3	160	72.7
16. Obtaining adequate pain control for the person with cancer?	220	57	25.9	163	74.1
17. Addressing fears about the person with cancer's physical or mental deterioration?	220	64	29.1	156	70.9
18. Accessing information about the potential fertility problems in a person with cancer?	220	92	41.81	128	58.2
19. Caring for the person with cancer on a practical level, such as bathing, changing dressings, or giving medications?	220	88	40	132	60
45.Having opportunities to participate in decision-making about the person with cancer's treatment?	220	53	24.1	167	75.8
Health care service (26,27,28,30,33),					
26. Communicating with the person you are caring for?	220	74	33.6	146	66.4
27. Communicating with the family?	220	71	32.2	147	66.8
28. Getting more support from your family?	220	57	25.9	163	74.1
30. Handling the topic of cancer in social situations or at work?	220	77	35	143	65
33. Understanding the experience of the person with cancer?	220	91	41.3	129	58.7
36. Addressing problems with your sex life?	220	152	69.1	68	30.9
Work and social/security needs (20-25,29,40),					
20. Finding more accessible hospital parking?	220	129	58.61	91	41.4
21. Adapting to changes to the person with cancer's working life, or usual activities?	220	84	38.2	136	61.8
22. The impact that caring for the person with cancer has had on your working life or usual activities?	220	92	41.8	128	58.2
23. Finding out about financial support and government benefits for you and/or the person with cancer?	220	41	18.6	179	81.4
24. Obtaining life and/or travel insurance for the person with cancer?	220	41	18.6	179	81.4
25. Accessing legal services?	220	85	38.6	135	61.4
29. Talking to other people who have cared for someone with cancer?	220	67	30.5	153	69.5
40. Dealing with others not acknowledging the impact on your life of caring for a person with cancer?	220	134	60.9	86	39.1
Psychological and emotional needs (1, 15, 31, 32, 33, 34, 35,37,38,39,41,42,43,44).					
1. Accessing information relevant to your needs as a career/partner.	220	66	30	154	70
15. Looking after your own health, including eating and sleeping properly?	220	65	30	154	70
31. Managing concerns about cancer coming back?	220	83	37.8	137	62.2
32. The impact that cancer has had on your relationship with the person with cancer?	220	92	41.81	148	67.3
33. Understanding the experience of the person with cancer?	220	91	41.3	129	58.7
34. Balancing the needs of the person with cancer and your own needs?	220	70	31.8	150	68.2
35. Adjusting to changes in the person with cancer's body?	220	107	48.6	113	51.4
37. Getting emotional support for yourself?	220	112	50.9	108	49.1
38. Getting emotional support for your loved ones?	220	103	46.8	117	53.2
39. Working through your feelings about death and dying?	220	86	39.1	134	60.9
41. Coping with the person with cancer's recovery not turning out the way you expected?	220	76	34.6	144	65.4
42. Making decisions about your life in the context of uncertainty?	220	104	47.2	116	52.8
43. Exploring your spiritual beliefs?	220	79	35.9	141	64.1
44. Finding meaning in the person with cancer's illness.	220	89	40.5	211	59.5

SCNS-P&C, Supportive Care Needs Survey-Partners and Caregivers.

Work and Social Needs Domain

Reporting of unmet needs in this domain varied from 39% to 81% (average 61.7% of participants). Financial support and travel insurance was chosen as an unmet need by 81.4% of participants, whereas dealing with others not acknowledging the impact of caregiving on their lives was reported as an unmet need by only 39.1% of participants.

Information and Practical Needs Domain

Information and practical needs were reported as unmet by 58%-80% of participants or on average by 71.8% of participants. Accessing information about potential fertility problems was the least reported unmet need (58.2%). Having opportunities to discuss concerns with the doctors was chosen by the vast majority (80%).

Discussion

Unmet Needs of Family Caregivers in Indonesia

We aimed to comprehensively map supportive care needs of family caregivers in the resource-challenged context of West Java, Indonesia. The greatest unmet need was finding out about financial support and travel insurance for a person with cancer (81.4%). Additional important unmet needs included discussing concerns with physicians (80%), accessing best medical care and information on treatment's side effects (78.2%), and accessing support services for carers/partners (76.4%). On average, most participants reported unmet information and practical needs (71.8%), followed by work and social life needs (61.7%).

TABLE 4
Top Met and Unmet Needs in the Sample (n = 220).

Item	Questions	n*	No-low need		Moderate-high need	
			n	%	n	%
23	Finding out about financial support and government benefits for you and/or the person with cancer?	220	41	18.6	179	81.4
24	Obtaining life and/or travel insurance for the person with cancer?	220	41	18.6	179	81.4
10	Having opportunities to discuss your concerns with the doctors?	220	44	20	176	80
7	Obtaining the best medical care for the person with cancer?	220	48	21.8	172	78.2
6	Accessing information about the benefits and side-effects of treatments?	220	48	21.8	168	76.4
3	Accessing information about support services for careers/partners of people with cancer.	220	52	23.6	168	76.4
36	Addressing problem with your sex life?	220	152	69.1	68	30.9
40	Dealing with others not acknowledging the impact on your life of caring for a person with cancer?	220	134	61	86	39.1
37	Getting emotional support for yourself?	220	112	50.9	108	49.1
39	Working through your feelings about death and dying?	220	86	39.1	134	60.9
32	The impact that cancer has had on your relationship with the person with cancer.	220	92	41.8	128	58.2

* Total participants answering. The first five items are the highest need; then the second five items are the less need.

Uncertainty around finances was a logical concern in our sample; 83.7% of Indonesia's health insurance users struggle financially,[21] particularly around balancing living costs and cancer-related costs. Indonesia has a culture in which family members care for their relatives, irrespective of core or extended family.[28] One important obligation includes budgeting to care for the family; this is because Indonesia does not have a retirement wage system. The descendants will care for and be borne by the parents and vice versa when the ascendants get older.[18] Before the government covered health insurance, low-income families rarely took sick family members to the hospitals. However, even now, free treatment at the hospital does not always cover all expenses; wealthier families still have greater access to health care options for their family members.[14]

We found that our sample struggled to fund travel costs for the patient. Even people from the same province may struggle to reach the hospital because they reside in remote areas. Communities are isolated with limited facilities and difficult transportation. Usually, patients use public transportation, such as small buses, which is slow. If they want to arrive at the hospital faster and more comfortably, they have to pay extra to hire a private car. A recent report also stated that Indonesian palliative care is only available in two cities on Java Island, leaving the rest of the country without access to specialist care.[14] Treatment centers for cancer are still limited in Indonesia, which practically leaves family caregivers with little choice in finding the best medical care for patients.

The most challenging roles for family caregivers seem to be dealing with patients' suffering and financial and emotional swings while still requiring time for social activities.[29] Such challenges also exist in other developing countries in Asia.[30-32] Additional support and guidance are crucial for family caregivers during care transitions.[18] Health care staff and family caregivers have interdependent roles in providing palliative care.[16] In a resource-poor country like Indonesia, nurses could emerge as leaders in developing palliative care because of their strong relationships with patients and families.[15,33] In comparison, in developed countries such as the UK, the government provides health care support workers with an adequate skill set to care for the patient at home.[34]

Our participants experienced widespread lack of information. This result is hardly surprising. In Indonesia, waiting times to be transferred to a clinic are approximately 60 minutes.[35] Waiting to see the physician in the clinic requires another 60 minutes.[36] In the pharmacy, it takes 90 minutes to have medications prescribed.[37] However, the consultation with the physician may only be 2-8 minutes.[36] Patients and families may find it overly challenging to discuss the patient's condition during this very tight time.[38] Relying on more open communication with nurses could be a solution to the lack of information. A previous study in Indonesia found that more than 85% of survey respondents had a good experience communicating with their nurse and received adequate, responsive information to their expressed needs.[39] Nurses have a strategic role in how the health care system functions and delivers best quality care.[40,41]

Met Needs of Family Caregivers in Indonesia

The top met needs in our study were resolving problems with sex life (69.1%), dealing with others not acknowledging the impact of caring for a person with cancer (61%), getting emotional support (50.9%), cancer's impact on the partner (41.8%); and feelings about death and dying (39.1%)

Although assuming a caregiving role might lead family caregivers to sacrifice their own needs,[42] our sample overall did not report significant impact on their sex life. A previous study in Indonesia found that sexuality is considered taboo, and people feel ashamed to talk about it.[43] Health care professionals recognize that sexual activity is a private issue.[44] However, palliative care ethos still requires careful assessment of potential issues affecting the patient and the family to provide holistic care.[45] A lack of confidence among health professionals to discuss sexuality issues with the patient and the family is still present.[46] Health professionals should be aware of social norms about sex before initiating the discussion about this matter[47] but also understand that sexual expression continues until the end of life.[48]

The Indonesian culture is communal, which places a strong responsibility on family members to care for and protect each other and demands loyalty throughout life, particularly on Java Island. There is a proverb: *mangan ora mangan waton kumpul* (even if there is no food to eat, being together is the most important thing).[49] As such, the ill will always belongs to the family. Compared to European patients, patients in Indonesia may report fewer psychological and autonomy issues.[50] The family may play a crucial role in this. However, this responsibility could well overburden the family,[23] and hence, the need for continuing support for family caregivers.[51] Community services could provide support by helping the family clean up the house, prepare for the funeral, and facilitate the existential and emotional pain during grieving. Community nurses can directly support the patient at home[52] and the family to address their needs.[53] External support and community participation can also be solutions for families involved in palliative and end-of-life care.[54]

Witnessing their loved one die can be a life-altering experience for many family caregivers. Only 39% of our sample required support with death and dying. This result might be either because our sample was long-term caregivers (25% were providing care for more than a quality ranking of death in 40 countries based on 20 indicators.[13] In 2015, 80 countries were included with 20 quantitative and qualitative indicators across five categories. Indonesia was placed 53rd in the rankings with a score of 33.6/100.[14] Although Indonesia marks significant improvements in palliative care, implementation is still challenging. An important step was integration of palliative care into the national cancer control program between 2014 and 2019. However, a recent study declared that Indonesia still lacks formal institutions to support people with long-term illnesses, as shown in the absence of hospice care and the lack of policy related to palliative care.[15] Specialist palliative services are mainly available on the Java Island, and specialized staff is available only in two cities.

Furthermore, legal restrictions hinder access to opioids, and difficulty in medication transportation across 17,000 islands together with isolated communities with limited facilities and low public awareness further aggravates the situation.[14] Several facilitators and barriers to addressing the significant demand for palliative care in Indonesia have been identified.[16] Facilitators include government and volunteering organization policies and cultural beliefs about the role of the family in caring for the patient. Recommendations have been made for specialist training on palliative care to nurses and doctors, advances in academic curricula, and provision of education to families and communities.[16] Nevertheless, Indonesia still suffers from a lack of cancer awareness, unhelpful cultural beliefs, financial burden, a paternalistic style of communication, and unmet information needs.[17]

Due to the limited access to palliative care and hospice care, it is the family who primarily cares for patients with (advanced) cancer in Indonesia. Indonesia has a communal culture, whereby family members belong to one another,[18] with the family generally providing care on a 24/7 basis.[19] This task is perceived as an obligation deeply rooted in cultural belief.[20] Even though the Indonesian government established a National Health System in 2014,[21] the patient and family are responsible for meeting expenses related to managing advanced cancer. Furthermore, Indonesia does not have a national pension scheme. As such, the caring capabilities of the family may be affected by their finances, and subsequently, the quality of care provided to patients depends on the caregiving capabilities of the family.

Family caregivers in Indonesia need support with diverse and demanding tasks. These include organizing and providing hands-on care, monitoring and managing symptoms, offering emotional support, looking after and communicating with the broader family, accessing resources and managing finances, being the patient's advocate, negotiating the health care system, taking action and making decisions, taking navigating the health care system, and preparing for an uncertain future.[22] No formal training or home-visit programs are available to empower family caregivers to care for the patient at home. Living in the same house with the patient adds to the task list for family caregivers, who may also have to support other family members.[15] Unavoidably, advanced cancer exacerbates the challenge for family caregivers. The evidence suggests that family caregivers in Indonesia experience a moderate burden in their role.[23] Despite these known challenges, little is known about family caregivers' own needs for supportive care in the Indonesian context. Therefore, this study aimed to comprehensively investigate the supportive care needs of family caregivers in West Java, Indonesia.

Material and Methods

Study Design, Setting, Sample, and Sampling

A quantitative, cross-sectional survey was conducted as part of a larger, four-stage mixed-methods project to develop a nurse-led palliative care intervention for the resource-challenged context of Indonesia. The survey was conducted in Hasan Sadikin Hospital and 13 shelters around the hospital in West Java Province, Indonesia.

Our sample included family caregivers who provided voluntary (unpaid) care to ill family members with advanced cancer. We used convenience sampling based on the following inclusion criteria: Adults 18 years old or older; has a relationship with the patient by blood or marriage; primary family caregiver for a patient with advanced cancer. Family caregivers providing care to patients without advanced cancer and paid caregivers were excluded.

We used the Krejcie and Morgan formula[24] to calculate our target sample size. For a survey with population 700 people, 95% confidence level, 0.5 standard deviation, and 5% confidence interval, the required sample is 248-254 people. Thus, we planned to approach 250 individuals.

Ethics

We obtained ethics approval for the whole project from the University of Glasgow College of Medicine, Veterinary and Life Sciences ethics committee (200180198) and ethics clearance from Hasan Sadikin Hospital (LB.02.01/X.6.5/344/2019). We as researchers and authors are also certified in Good Clinical Practice for Research and the General Data Protection Regulation.

Data Collection

Family caregivers were identified from patient lists at Hasan Sadikin Hospital and 13 shelters. All shelters were managed by nongovernmental organizations that raised money from the public. All shelters provided free shared bedrooms. Some of them provide free laundry, water drinking and staple food (rice), ambulance as well as buying medicine prescribed for the patient. Two different recruitment approaches were used to enhance the potential participants by posters and went directly to the potential participant. At the hospital, the nurse lead introduced the researcher to the patients with cancer and family caregivers. The researcher also approached the shelter's manager to request to meet the patient with cancer and their families who stayed at the shelter. Patients nominated their primary family caregiver, then eligibility was checked and an invitation to participate was offered. Eligible family caregivers received a privacy notice and information sheet. They had the opportunity to ask further questions and 24-48 hours to decide whether they wanted to take part or not before signing the informed consent. Participants were free to withdraw without a requirement to justify their decision. Those participants who wanted to complete the questionnaires at home were supplied with an envelope and stamp. The researcher attended the shelters daily to collect questionnaires from participants who chose to return questionnaires in person. The first author double-checked all questionnaires for completeness and verified with participants where missing data were identified. This led to an almost complete data set.

Measures

We used the Supportive Care Needs Survey-Partners and Caregivers (SCNS-P&C)[25] to measure the unmet needs of partner/family caregivers across the illness trajectory. The SCNS-P&C has 45 questions across four domains: information and communication practical needs, health care and service needs, work and social needs, and psychological and emotional needs. Total scores range from 0 to 225. Participants chose one answer for each question on five-point Likert scales, ranging from no needs (0) to high needs (4). The higher the score, the more needed item.[25] The original SCNS-P&C was translated into Indonesian and tested for validity and reliability. Three nursing experts in Indonesia were invited to review the Indonesian translation for content validity. All of them are bilingual, finished their postgraduate studies overseas, and work as a nurse in the hospital and as lecturers in the nursing faculty. They gave a score to each item. The year) who had enough time to come to terms with the dying process, or conversely, they were still hoping their loved one might be cured. Although the presence of the family is vital, most patients in Indonesia would rather die in the hospital due to the limited organized home-based services.[55] As such, it is not uncommon for Indonesian family caregivers to express guilt for letting the patient die at home, which can augment the family's suffering. Guilt may be experienced because to care at home means no access to supportive and palliative care. There is no access to health care support workers in palliative care services in Indonesia,[15] which forces most patients in Indonesia to want to die in the hospital in hope for better care.[30] This is in stark contrast with patients in many developed countries, who may prefer to die at home because of being able to access advanced care and support provided at home.[38]

Study Strengths and Limitations

This study was the first to use a validated questionnaire translated into Indonesian to measure family caregivers' needs in the context of advanced cancer. Although a convenience sample was recruited from one single region in Indonesia, wide diversity in their demographics reflects the wider Indonesian family caregiving population. We followed current guidance to translate and linguistically validate the SCNS-P&C. However, full validation was beyond the scope of this project. Additional research is warranted to test the psychometric properties of the Indonesian SCNS-P&C thoroughly. Nonresponse bias is thought to be minimal,[24] given our very high response rate (88%). Since 86% of participants were of a Sundanese ethnic background, it is possible that our findings are skewed toward cultural practices and needs of this ethnic group. However, approximately 34 million Sundanese people live in 27 districts of West Java Province, with varied demographics and geographic areas. Our sample came from all districts because the hospital is the only referral center for West Java Province; therefore, we believe it accurately represents the target population in West Java.

Implications for Practice for Oncology Nurses

Oncology nurses in developing palliative care services in Indonesia will have a crucial role to bridge problems with their vital functions to support patients and families with daily practical needs, spiritual needs, and symptom management.[15] Previous studies advocate for better education for families who look after ill loved ones.[56] Oncology nurses can open the outpatient clinic for consultation, train the family to provide basic care and self-care at home, and monitor progress and emerging needs via remote or home visits.

Implications for Future Research

Additional research is required to replicate and expand our findings in the wider Indonesian context. Our findings pinpoint areas for the development and testing of interventions to support and empower families in Indonesia to care for their ill loved ones. Attending to needs emerging from inequalities in accessing health care services will require comprehensive consultation with all relevant stakeholders to enable provision of truly accessible palliative care that is person-centered and respectful of all parties' (patients and families) needs and capabilities.

Conclusion

We provided a broad perspective of family caregivers' support needs in Indonesia, revealing that family caregivers require support to fulfill multiple roles at home, particularly as they struggle with finding financial support for the patient and for themselves. The requirement for structured services to support family caregivers of patients with advanced cancer in Indonesia is evident. Nurses can play a crucial role in this area by providing specific training[15] and education.[16] We propose investment in developing flexible nurse-led interventions for resource-challenged countries that rely on comprehensive assessments and person-centered care. Such nurse-led interventions have the potential to enhance the quality of life of both patients and families by providing tailored, holistic services both in the hospital and at home.[57,58]

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