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A comparison of palliative care needs and palliative care services for community based patients with cancer and non-cancer illnesses in the Greater Glasgow NHS Board area

Vol I

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Submitted to the Departments of Public Health and Palliative Medicine in the Faculty of Medicine of the University of Glasgow, in fulfilment of the requirements for the award of the Degree of Doctor of Philosophy.

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“Palliative Care cannot remove the impact of a tragedy, but it can ensure that the patient’s voice is heard and the needs are addressed”.

I Finlay

J R Soc. Med. 2001; 94: 437-441

Dedicated to my wife Mary and our children, Ciara and Patrick

Abstract

Palliative care is an old approach to patient and family care which is undergoing a process of renewal, resurgence and change. In the 1960's palliative care was mainly for patients with terminal cancer, but the new definition of the World Health Organisation clearly states that palliative care is for all patients with a chronic, progressive and incurable disease regardless of diagnosis. It also states that palliative care should be available from the time of diagnosis and should include the bereavement period. For equality and non-discrimination, palliative care must be available for diseases other than cancer where that condition is chronic, progressive and incurable.

The literature on palliative care mainly relates to cancer with comparatively few references to non-cancer diseases. There are a few studies comparing cancer and non-cancer diseases. These are usually restricted to diseases affecting the same body systems like respiratory or cardiovascular systems.

This current study was conducted in Greater Glasgow NHS Board (GGNHSB) area. Its aims were:

- undertake a comprehensive comparative quantification of the health status and measurement of the outcome of care for patients with cancer and for patients with non-cancer diseases,
- conduct a postal questionnaire survey of health care professionals in the Greater Glasgow NHS Board area to ascertain their views on palliative care both now and for the future,
- compile a directory of current palliative care services available in the Greater Glasgow NHS Board area for cancer and non-cancer diseases.

Both quantitative and qualitative research methods were used. Chronologically the three groups in the study were:

- the voluntary and statutory palliative care service providers,
- all the General Practitioners (GPs) and district nurses practising in GGNHSB area,

- cancer and non-cancer patients living in GGNHSB area.

The voluntary and statutory palliative care service providers, GPs and district nurses were sent postal questionnaires. The patients were visited in their homes and one to one interviews were carried out to collect data along with basic demographic data. In this sample health status and the outcome of care of the patient was measured using the Nottingham Health Profile and Palliative Care Outcome Scale.

There were significant differences between the responses of patients with neurodegenerative diseases and patients with cancer to the Nottingham Health Profile (NHP) and Palliative Care Outcome Scale (POS). Significant correlations were discovered between responses to the two questionnaires particularly for pain and between emotion and anxiety and this helped to further validated the newer POS questionnaire's sensitivity towards pain and anxiety.

There were a number of important findings from this study.

Recognition and education: It is important to ensure the inclusion within palliative care of chronic, progressive incurable diseases and for this additional workload to be adequately staffed and funded. There is a need to promote a clear, simple and friendly definition of *Palliative Care* for health care workers, patients and their carers. Education of the service providers, patients and the public to increase awareness of the palliative care needs of patients with non-cancer diseases will promote recognition and acceptance of this concept.

Patient's choice: There is recognition among the GPs and district nurses for patients to be given the choice of place of care and death, and for patients and their carers to be involved in partnership in care decisions with healthcare professionals from the initial stages. This could be increased and improved if the generalist palliative care providers listened to and understood the needs of patients and their carers and promoted patient centred planning for all future strategies in palliative care.

Co-ordination and communication: There is a need for improved communication and co-ordinated working between primary healthcare, social work community care, specialist palliative care teams, the voluntary sector and the acute setting. Joint working and multi-agency working groups and managed clinical networks could contribute to this.

Services: Finite resources have led to service remodelling and redesign in both voluntary and statutory sectors. There were substantial changes in service provision during the study period. Over the three-year period of the study a greater number of services for patients with non-cancer were discontinued. There is a lack of specialist palliative care services in the acute sector. There is also a need for improved services including availability of hospice beds, palliative care services in care-homes and in particular social work services appear to be under provided.

Health care professionals: The percentage of GPs and district nurses who had used current specialist palliative care services for their patients with cancer was more than double that of those who had used similar services for their patients with non-cancer diseases. GPs and district nurses also placed more importance on future palliative care services for their patients with cancer in comparison to similar services for their non-cancer patients. Compared to the GPs, the nurses had more contact with patients with non-cancer diseases and perhaps because of this had a greater recognition of the need for palliative care services for non-cancer patients.

Service users: Patients with neurodegenerative diseases were younger compared to those with cancer. A higher percentage of patients with neurodegenerative diseases needed help with their daily activities compared to patients with cancer. There was a longer time interval between first appearance of symptoms and confirmation of diagnosis for patients with neurodegenerative diseases compared to patients with cancer. Lack of information was an issue highlighted by both groups of patients. The health status and care of the patients with neurodegenerative diseases was found to be inferior to patients with cancer.

Resources: Funding was an issue identified by all service providers. Despite the desire to help with non-cancer diseases, providers of specialist palliative care and primary healthcare have their finite resources for palliative care fully utilised with cancer patients at present. The service providers agreed that they would increase their present workload, but were restricted by lack of resources.

Research: There is a lack of evidence on the needs of non-cancer patients, on the best ways of meeting these needs and on the effectiveness and acceptability of services. This is necessary to provide the evidence to justify the resources (human and financial) that need to be allocated to make palliative care services available to all on the *basis of need* and not on *diagnosis*.

Conclusion

This is the first detailed comparative assessment of health needs involving both cancer and non-cancer patients. It is based on data gathered from a range of service providers, both professionals and voluntary groups and covers hospital and community. Views of patients from selected groups are also related to those of professionals. Thus, new insights have been obtained which will not only be of assistance to Greater Glasgow Health Board who have responsibility for providing the service locally, but should contribute to wider policy development.

The use of two health related quality of life measures enabled testing for cross validity and this evidence should assist in future research on the outcome of palliative care.

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The following people made this current study possible and were responsible for its successful completion. The statutory and voluntary sector, palliative care service providers, in GGNHSB area who contributed to identifying palliative care services, the good practices and obstacles that they encountered in their work. The general practitioners and district nurses practising in the GGNHSB area who, despite having a busy workload, took time off to complete the long but comprehensive questionnaire on present and future palliative care services and the obstacles they have to overcome to provide the best possible palliative care service for their patients. Last but not least, the patients who were very friendly and willing to contribute to the improvement of future palliative care services in the GGNHSB area by completing questionnaires about their health status and care and also by voicing views about the care and the obstacles they encounter in accessing palliative care services in GGNHSB area.

I am dedicating this thesis to my wife Mary who has been there every step of the way to listen to my moaning and reading my drafts and supporting me all the time in-spite of my panic attacks when a deadline has to be met. She made sure that our daughter Ciara did not write her own masterpiece in my thesis and always took her out when I needed to get some work done which has been for the past four years. Recently our son Patrick has completed our family. They have all been my inspiration and have given me the strength to keep going whenever I felt lost.

Author's Declaration

This thesis and the research it describes are entirely my own work. During the course of this research, six poster presentations (details are in Appendix 1) were made of the findings as follows:

The following poster was presented in a Poster Session organised by the Health of Communities/Cancer Research Boards. It was held in Glasgow Western Postgraduate Medical Centre in Lancaster Crescent on Tuesday the 13th of January 1998:

1. ***"Palliative Care - A community based health needs assessment in Greater Glasgow NHS Board area"***

The following three posters were presented at the Palliative Care Congress, 27th – 29th March 2000, at the University of Warwick, Warwick:

2. ***General Practitioners' and district nurses' perception of bed availability in hospice and hospitals for palliative care patients.***
3. ***General Practitioners' and district nurses' perception of patients preferred place of death and obstacles preventing this happening.***
4. ***When is referral to a Specialist Palliative Care Team appropriate?***

The following two posters were presented at the 7th Congress of the European Association for palliative care in Palermo, Sicily, April 1st – 5th, 2001:

5. ***Palliative Care needs of patients with Central Nervous System (CNS) diseases.***
6. ***Current and future palliative care services for cancer & non-cancer patients - general practitioners' & community nurses' views.***

The following three articles were published in the Palliative Medicine Journal 2000; 14: 347 – 350. The authors are: Y Velupillai, J Welsh and J McEwen for all the 3 articles

General Practitioners' and district nurses' perception of bed availability in hospice and hospitals for palliative care patients.

General Practitioners' and district nurses' perception of patients preferred place of death and obstacles preventing this happening.

When is referral to a Specialist Palliative Care Team appropriate?

Definitions of terms and glossary

The various terms and definitions used in this current study are mentioned below:

1. ***Palliative Medicine Specialist*** is a Medical Doctor trained in Palliative Medicine and eligible for the Specialist Register.
2. ***Palliative Care Specialist*** is usually a Registered Nurse trained in palliative care to diploma or masters level or a specially trained Allied Health Professional (AHP).
3. ***Specialist Palliative Care Team*** is a multidisciplinary team comprising health care professionals trained in palliative care. The team may be based in a hospice or acute hospital trust.
4. *An interdisciplinary team* is one where all the team members regularly refer to one another and all team members share the decision-making process with care receivers. In this way, a mutual philosophy of care is developed and team members are able to act appropriately and without duplicate or untimely effort.

Abbreviations

- AIDS = Acquired Immune Deficiency Syndrome
- ASR = Age standardised rates
- COPD = Chronic Obstructive Pulmonary Disease
- ECOG = Eastern Co-operative Oncology Group
- EORTC QLQ-C30 = European Organisation for Research on Cancer Treatment
- Quality of Life Questionnaire
- GGNHSB = Greater Glasgow NHS Board
- GPs = General Practitioners
- HIV = Human Immunodeficiency Virus
- KPS = Karnofsky performance score
- NHP = Nottingham Health Profile
- NHS = National Health Service
- AHP = Allied Health Professional
- PhD = Doctor of Philosophy
- POS = Palliative Care Outcome Scale
- QALYs = Quality adjusted life years
- SMR = Standardised Mortality Ratio
- SNAP = Scottish Needs Assessment Programme
- UK = United Kingdom
- USA = United States of America
- WHO = World Health Organisation

The following abbreviations were used in the tables:

- ASR = Age standardised rates
- CNS = Central Nervous System
- CVS = Cardiovascular system
- DNs = District Nurses
- HD = Huntington's disease
- MND = motor neurone disease
- MS = multiple sclerosis

Chapter 1

Introduction

Palliate = to relieve without curing

(Latin *palliatus* = to cloak, mask or shield)

> *"Palliative Care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain and other symptoms, the psychological, social and spiritual needs of the patient are paramount".*[1]

> *"The goal of palliative care is the achievement of optimal symptom control, the best possible quality of life, as well as appropriate rehabilitation for the patients, their family, friends and carers".*[2]

The term *Palliative Care*, connotes treatment measures directed at disease related symptoms rather than at the disease itself. Palliative care is intended to provide comfort and to enhance the quality as opposed to the quantity of life.[3] World Health Organisation's (WHO) definition of palliative care suggests that both disease-orientated and palliative treatments should be available over the spectrum of disease stages, and that the availability of palliative care services should be based on *need* and not on *life expectancy.*[3] Palliative care should not be associated exclusively with terminal care or with cancer care. Many patients need it early in the course of their disease, sometimes from the moment of diagnosis.

At present, many patients do not receive specialist palliative care for recurrent or advanced disease although this has been shown to be effective.[4] One of the reasons is that patients present late, especially those of low socio-economic status.[4,5] The Scottish Executive (2001) published a report on cancer scenarios as an aid to planning cancer services in Scotland in the next decade.[5] In this document they stated that *with the increasing prevalence of cancer in an ageing population, it is likely that many more will require the input of primary care services.*[5] Hence the demand for palliative care will increase with resultant resource implications. Palliative care is clearly an important and sensitive issue for patients with cancer and other progressive, incurable non-cancer diseases.

Home support services and specialist palliative care accommodation (hospices and hospital wards) are frequently required and a more co-ordinated approach is needed.[5]

Studies have shown that symptom control can be sub-optimal,[6] that physical symptoms are inadequately controlled and that psychological and spiritual issues are neglected or scantily understood.[7] In many cases patients, their relatives and carers are unaware of the sources of support available to them.[8] There is evidence to support the case that most patients would prefer to die at home.[9] However, the statistical evidence on actual place of death does not reflect this preference.[10]

When considering the current level of need for palliative care, one must define the patient groups in whom palliative care may be appropriate. In the past, palliative care services have often been restricted to patients suffering from advanced cancer, with hospice services dealing almost exclusively with these patients. However there is growing recognition that other diseases require periods of palliation.[11] The present priority of the Labour government is to ensure access to treatment according to *need and need alone* and to tackle *inequalities at all levels*.[12;13] In 1998 it was shown that admission to hospice appeared to be by chance rather than by the need of the patients.[14] The patients with non-cancer diseases need palliative care to have a better quality of life and if they are denied this due to lack of access then it is a form of *inequality in health care* and needs to be addressed.

1. History of palliative care and hospice movement

The term *hospice* (from the same linguistic root as *hospitality*) can be traced back to medieval times when it referred to a place of shelter and rest for weary or ill travellers on a long journey. The modern hospice movement began in the 1950s and in 1967 Dame Cicely Saunders founded St Christopher's Hospice in Sydenham, London.[15] Cicely Saunders first put forward her ideas and concerns about the neglect of the dying in 1958, and campaigned for better medical care for such patients, introducing sometimes controversial measures in pain relief. Her innovative approach to the use of analgesics emphasised the anticipation of, rather than the response to, pain.[16]

Saunders introduced the idea of specialised care for the dying to the United States during a 1963 visit to Yale University. Her lecture, given to medical students, nurses, social workers, and chaplains about the concept of holistic hospice care, included photos of terminally ill cancer patients and their families, showing the dramatic differences before and after the symptom control care. This lecture launched a chain of events, which resulted in the development of the modern hospice movement hospice care.[16]

Initially hospices provided palliative care beds. This service was funded by voluntary or charity groups and was mainly for cancer patients. This system of palliative care has evolved to provide community care by support teams, derived from a recommendation by the working group on terminal care who produced the National Terminal Care Policy.[17] Palliative Care aims to improve the quality of life and quality of death. Therefore it offers health gain by offering to patients, family members and carers a better quality of life, not an extend life expectancy only.[18] By providing high quality care and a comfortable and peaceful death, grief may be relieved and hence decrease subsequent demands on health care services.

The following short history of palliative care and hospice is from a world wide web search[19]:

> *"Each society throughout history has evolved special ways of caring for the dying and the bereaved. In olden day China the "death houses" offered a place for the destitute dying to stay and in New Zealand, Maori customs give practical support for the family at the time of death, and encourage the community to participate in the mourning rituals while in East Africa, wise elders give both practical and spiritual support to the dying and bereaved. In the eastern parts of the Roman Empire, there were houses that offered a place of refuge for the needy; not only to the sick and dying, but also to the hungry wayfarer, the woman in labour, orphans and the poor. These sanctuaries became known as* hospitium, *from which the modern terms hospital, hospice, hostel and hotel are derived. Soon hospices were to be found along pilgrim routes, at mountain passes and river crossings where travellers met great hazards. Gradually local people also came to rely on these houses. This tradition of hospice care continued into medieval times under religious orders such as the Benedictines, who were charged with care for the needy. In Western Europe and North America until the 19th Century, caring for the dying and the bereaved was seen primarily as the job of the family and the church. In the last 100 years, dying has increasingly been seen as a medical event, not as a milestone in the life and history of a family".*[19]

Other important milestones in the history of palliative care/hospice[19]

1800s: Madame Garnier of Lyon, France opened a *calvaire* to care for the dying. In 1879 Mother Mary Aikenhead of the Irish Sisters of Charity opened Our Lady's Hospice in Dublin, caring only for the dying. By the late 19th Century, the increase in municipal or charitably financed infirmaries, almshouses and hospitals, and the expansion of medical knowledge, began the process of *medicalising* dying. (By the mid-20th Century, almost 80% of people in the U.S.A. died in a hospital or nursing home.)

1905: The Irish Sisters of Charity opened St. Joseph's Hospice in East London, to care for the sick and the dying and Dame Cicely Saunders worked here.

Early 1900s: In London, St. Luke's Hospice and the Hospice of God opened to serve the dying destitute.

1950s: The Marie Curie Memorial Foundation, a cancer charity, supplemented existing homes for the dying by opening a number of nursing homes for dying cancer patients, and developed a basic nursing service for people at home.[20]

1967-75: Many hospice and palliative care programs started in Great Britain in the years following Cicely Saunders founding of the St Christopher's hospice in London and they adapted the St. Christopher's model to local needs, offering in-patient and home care. The St Christopher's model consists of in-patient beds, day services, home care, research and education and nearly all hospices provide these and now many have input to acute hospitals.

1990-2000: There is well-established hospice and palliative care services in Canada, Australia, New Zealand, and much of Asia and Western Europe. Hospice and palliative care is now available in over 40 countries world-wide, including many less-developed nations.

2. Palliative Care in Scotland

The latest cancer plan for Scotland was published by the Scottish Executive (2001) and was called "*Cancer in Scotland – Action for Change*".[13] The health minister quoted that:

> *"over the last 10 years more than 150,000 Scots have lost their lives to cancer. Many more will have faced the fear, worry, and uncertainty of illness, diagnosis, and treatment. Many too will have benefited from the advances in prevention, screening, and treatment that in the past two decades have helped prolong life".*

Chapter six of the document[13] is about palliative care and the opening statement recites "*as defined by the World Health Organisation, palliative care is NOT synonymous with Terminal care and is NOT restricted to cancer*". It continues by saying that "*Palliative* *care is an integral part of all clinical practice which takes as its starting point the quality rather than the quantity of life remaining*". Palliative care needs can arise at any stage of a patient's care, and embrace psychosocial, emotional and spiritual issues surrounding life threatening illness as well as the management of pain and other distressing symptoms. Everyone, patients and carers, should be aware of services from which they might benefit but we know that palliative care is not well understood by all patients and their carers, who too often equate it with end-stage disease and terminal care. As a result, many patients may be denied optimal and timely symptom control and support. The cancer plan highlighted integration of planning and delivery of services, monitoring and maintaining standards for palliative care. They suggest that information required to support continuous quality improvement will be provided from existing sources such as the Hospice Activity Data System (HADS).

Our National Health indicated that we are committed to ensuring that effective palliative care services are available to all who need them.[12] The section on palliative care states that palliative care deals with the total care needs of people. The Scottish Executive has pledged that they will ensure that effective palliative care services are supported. They also said that the Clinical Standards Board for Scotland (now NHS Quality Improvement Scotland) will develop standards for both palliative care and specialist palliative care. The Clinical Standards Board for Scotland was established in April 1999 and has developed generic standards and these are *patient focused* and designed to provide *safe and effective clinical care.*[21]

3. Palliative care in the GGNHSB area

At the time of this current study (1997-2000) there were few specialist palliative care services even for cancer diseases in any of the hospitals in GGNHSB area. The only acute Trust in Scotland with a multidisciplinary team, was based in Edinburgh (at the Western General Hospital) in the Regional Cancer Unit. This team supported patients (and their families) suffering from cancer as well as non-cancer disease,[22] and advised on complex aspects of advancing disease.

The Beatson Oncology Centre, the Regional Cancer Centre, which sees 60 percent of Scotland's cancer cases is based in the Western Infirmary in Glasgow, and caters for 7000 referred new patients per annum. The Centre provided oncological sessional input to 4 hospitals in the GGNHSB area (Southern General, Victoria Infirmary, Stobhill, Glasgow Royal Infirmary and to five other Health Boards in the West of Scotland). In 1997 there was no comprehensive list of the individual palliative care services for cancer and non-cancer diseases in GGNHSB area.

3.1. The estimated need for palliative care

GGNHSB issued the document "*Palliative Care Services in Greater Glasgow - A Framework for the Future*" in May 1997 for public consultation.[23]This document estimated that for the population of the GGNHSB area (894,301 – 1991 census) there were:[18]

- approximately 3,200 cancer deaths each year,
- approximately 6,300 deaths due to potentially progressive, incurable non-cancer disease.

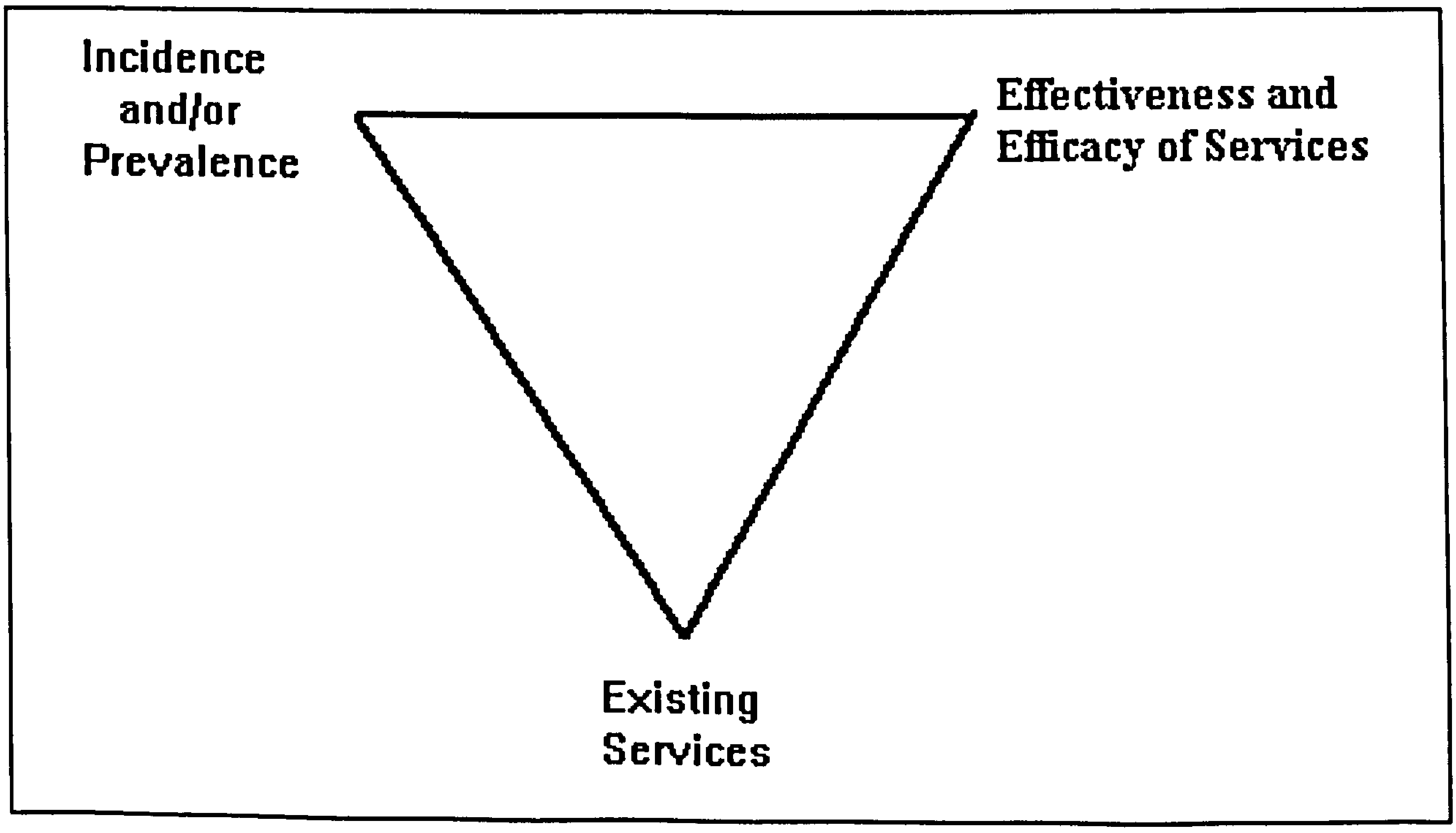
Within the 9,500 deaths mentioned above, there were three main groups[18]:

- those who had a palliative period of advancing progressive disease,
- those for whom there was a period where the disease was stable and where they had relatively few symptoms, followed by sudden death,

- those for whom there was a chronic disease, where the disease was not clearly progressing, but who might have periods of progression and symptoms where they would benefit from palliative care, and then periods of remission.

To compare the needs of cancer and non-cancer patients and views of health care providers on palliative care a health needs assessment process was chosen to consider need and demand and match with supply. Health needs assessment is a continuous process of profiling and determining priorities for any given population or subgroup in a defined area or locality. It is an essential and integral part of delivering high quality health care to that population or targeted group.[24] Needs assessment in health care has been identified as the population's ability to benefit from health care (epidemiological approach to needs assessment).[25] This depends on the number of individuals affected (incidence and prevalence) and the effectiveness of the services to meet the need.[26] In order to do population health care needs assessment, the three main ingredients as illustrated in Figure 1 must be examined.

Figure 1 The three pillars of need assessment



Clark's assessment of Health Authorities (1997) who had conducted palliative care needs assessment showed that needs assessment has considerable potential to influence future purchasing and service provision.[27] It was found that only 49 percent of the respondents had conducted a needs assessment (and the comprehensive nature of these needs assessments was questionable) for palliative care in the last five years[27]. For a successful community health needs assessment to be possible and effective, it needs collaboration between primary care and public health departments.[28] Projects were found to be effective when led by local public health departments where time and resources was not a problem.[28]

In 2001 Addington wrote that changes early in the 1990s in the NHS separating the purchaser and provider led to the district health authorities determining local need for health care, purchasing it and monitoring its quality.[20] This change led to a focus on needs assessment which helped to introduce the concept of on need and not the diagnosis for palliative care service provision. This was re-enforced by Higginson's book (1997) *Epidemiologically based needs assessment on palliative and terminal care.*[18]

Higginson (1997) in the chapter on *"Palliative and Terminal Care"* [18] based the population needs assessment on a population of 1,000,000 and the methodology used for this was as follows. The estimated incidence and prevalence rates of the symptoms and other problems in cancer and in patients with progressive non-cancer diseases were calculated. From these data key issues for health commissioners were formulated. The Glasgow population in the 1991 census was 894,301 and the following assumptions were made for Glasgow, similar to those by Higginson's in the chapter on *"Palliative and Terminal Care"*.[18]

For cancer patients in a population of 894,301 per year

- 1,967 would experience pain,
- 1,163 would have trouble with breathing,
- 1,140 would have symptoms of vomiting or feeling sick,
- 1,073 would require a hospital or home palliative care team,

- 447 would require inpatient hospice or specialist unit care.

For patients with progressive non-cancer diseases in a population of 894,301 per year

- 3,756 would experience pain,
- 2,772 would have trouble with breathing,
- 1,547 would have symptoms of vomiting or feeling sick,
- 2,119 would have mental confusion
- 894 may require a support team for their palliative care
- 447 may require inpatient palliative care

3.2. Palliative Care Strategy 2003 for GGNHSB

The major issues addressed by the strategy are building expertise in primary care; developing specialist palliative care services from bases in each of the three hospices; developing expertise in palliative care in the five main hospitals; improving communication between professionals in the various settings and with patients, including immediate access to information; improving access to information for patients and their families; addressing *quality of life* issues and establishing systems for the ongoing education and training of professionals. Over the past three years the main focus has been on primary care and hospice-based services. Resources have recently been acquired from the New Opportunities Fund (NOF) and have been used to develop systems to meet communication, training and information needs, and also to employ additional *paramedical* staff to train professional colleagues in techniques and interventions to help improve quality of life. Further resources from NOF have just been granted to develop palliative care services for people with conditions other than cancer. Emphasis now will be on building up expertise and commitment amongst hospital staff.[29]

4. Conclusion

Need assessment in palliative care has generally looked at the needs of various groups of cancer and non-cancer diseases, but there have been no *comparisons* of the *needs* of patients with cancer or non-cancer diseases. In recent years there has been a shift in the thinking that *palliative care was exclusively for cancer diseases.* This has initiated recognition that patients with non-cancer diseases should have access to palliative care services based on their need not diagnosis. Community health care professionals, namely General Practitioners and district nurses have always provided general palliative care in the community. Community care could be service-led or needs-led and the difference between these is that "*instead of having to conform to service eligibility criteria, the assessed needs of service users must conform to the agency's definition of eligible need if services are to be provided*"[30]. So if services are to be truly needs-led the assessor must be separate from the agency setting the definition of need, eligibility and priorities.[31] This current study provided an opportunity for an impartial researcher to present evidence to develop palliative care services that are needs-led in Greater Glasgow for the future. This was the secondary end point. The primary end point of this research was to assess the services available for cancer and non-cancer patients, to obtain the views of GPs and district nurses and to compare these. The methodology was one of needs assessment. A further secondary end point was an evaluation of need of cancer and non-cancer patients the results of which would be useful to GGNHSB.

GGNHSB commissioned a community based needs assessment in palliative care to inform the Board's strategy for providing an efficient and effective palliative care service for the residents in the GGNHSB area. This Doctor of Philosophy (PhD) study was part of the GGNHSB enhanced review process. As part of the "*Framework for the future*" process an assessment of palliative care needs, including those identified by patients, was to be undertaken to enable future development of the service.[23] The Public Health and Palliative Medicine Departments in Glasgow University jointly agreed to undertake this project and a research proposal was submitted to the University and the Health Board. It has been reported that 90 percent of the last year of a cancer patient's life is spent in the community.[32] Based on this statistic the community was targeted for this health needs assessment in palliative care in the GGNHSB area.

Part of a comprehensive system of needs assessment should include identification of services available, interviews with patients and a questionnaire survey of GPs and District nurses.[33] The purpose of this current study was to compare the two groups of patients (cancer and non-cancer) and their health care service providers (GPs and district nurses) and to investigate the need and care of patients, both cancer and non-cancer, requiring palliative care in the community. There was a gap in the evidence as to which group of patients had greater palliative care needs and also as to the perceptions and views of GPs and District nurses on providing palliative care for these two groups of patients. Certain cancer and non-cancer diseases were selected for this current study and the background for this will be discussed after the literature on palliative care needs assessment is reviewed.

The next chapter (2) of the current study consists of the literature review that was carried out from the beginning (1997) to date (2003). Chapter three states the aims and objectives of the current study and the null hypothesis is defined. Chapter four of this study is the synopsis and background section that was included to provide concise data of the GGNHSB area. There is a brief outline of the various stages of the current study. It also comprises brief summaries of the cancers (only those included in this current study) and non-cancer diseases (only those included in this current study) requiring palliative care. Chapter five through seven details the methodology, results and the discussion for the three groups: i) statutory and voluntary sectors, ii) GPs and district nurses and the iii) selected cancer and non-cancer patients in the GGNHSB area respectively. These three chapters start with an outline of the objectives for the group investigated in that chapter and conclude by summarising if these have been met. Chapter eight provides conclusions and recommendations from the findings of the current study.

Chapter 2

Literature review

1. Introduction

The materials used for this review were books and chapters from books; on-line Internet databases and various websites; reviewing unpublished reports and other PhD theses by hand searching. In-depth hand searching was not feasible as published studies in palliative care were identified in 122 different journals in 1996 and is increasing yearly.[34] The electronic databases used were:

- Index Medicus online (MEDLINE),
- Bath Information and Data Services (BIDS) and Excerpta Medica (EMBASE),
- System for Information on Grey Literature (SIGLE),
- NHS Centre for Reviews and Dissemination[35] (CRD) and their Database of Abstracts of Reviews of Effectiveness (DARE),
- National Research Register[36] (NRR),
- Cochrane Database of Systematic Reviews[37](CDSR)
- Cancerlit,
- PsycLIT,
- Cumulative Index to Nursing and Allied Health Literature (CINAHL).

The key words used in these searches were needs assessment; palliative care; history of palliative care; malignant and cancer; lung, breast and colo-rectal; non-malignant and non-cancer; motor neurone disease, multiple sclerosis and Huntington's disease; community; patients; health professionals; GPs and district nurses; terminally ill; Nottingham health profile; palliative care outcome scale; questionnaires; quality of life;

Reference Manager (Bibliographic software package) was used to manage the references.[38]

The following literature review will have an introduction on palliative care, assess the various definitions of palliative care and look at the services and the providers of these services in the community. There will be an assessment of needs in general and the various approaches to *needs assessment* before focusing on *needs assessment in palliative care.*

The review of the literature will examine two aspects of palliative care, namely cancer and non-cancer patients and their needs and conclude by examining the obstacles to recognition of research evidence in palliative care.

2. Palliative care

2.1. Definitions of Palliative care and terminal care

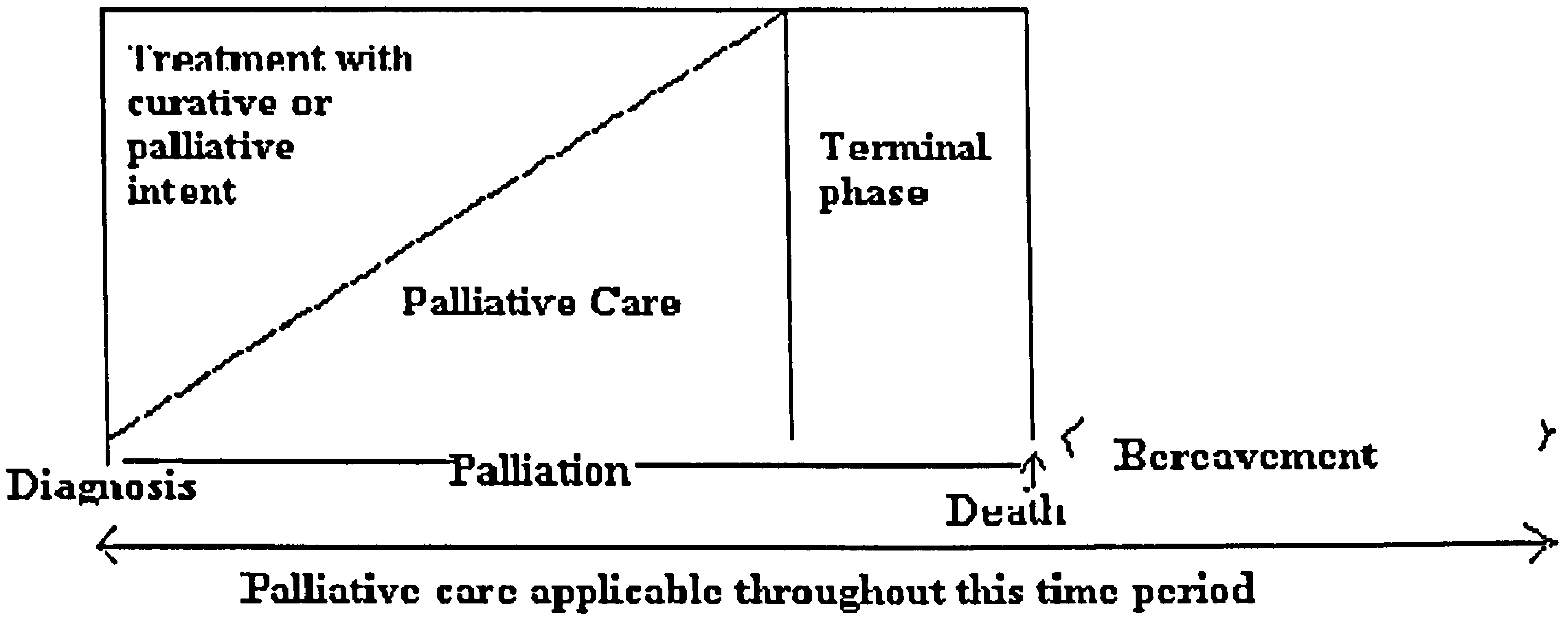
"Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual".[1]

Palliative care[1]:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of an illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications'

Figure 2 illustrates WHO's concept of palliative care in a broad way and encompasses all aspects from diagnosis to death, and beyond to the bereavement period for the relatives and loved ones.[1] This includes both cancer and non-cancer diseases. The WHO's definition of *palliative care* is difficult in practice especially in service provision because if fully implemented it entails significant amount of resources both human and financial.

Figure 2 WHO's perception of palliative care



The UK Standing Medical Advisory Committee and Standing Nursing and Midwifery Advisory Committee defined palliative care[15] (1992) as:

> *"the active total care offered to a patient with a progressive illness and their family when it is recognised that the illness is no longer curable, in order to concentrate on the quality of life and the alleviation of distressing symptoms within the framework of a co-ordinated service. Palliative care neither hastens nor postpones death; it provides a relief from pain and other distressing symptoms and integrates the psychological and spiritual aspects of care. In addition it offers a support system to help during the patient's illness and in bereavement. 'Family' is used as a general term to cover closely attached individuals, whatever their legal status".*

The Standing Medical Advisory Committee and Standing Nursing and Midwifery Advisory Committee[15] also recommended that:

- all appropriate patients should have access to palliative care services
- similar services should be developed for patients dying from diseases other than cancer
- services should be provided individually for patients wherever they are rather than be centred in units
- palliative care should be developed as part of normal NHS provision and integrated with general practice
- purchasing authorities should provide a comprehensive service
- palliative care specialists of all disciplines should be available as a source of advice and a clinical resource
- there should be an expansion of education programmes in palliative care.

Needs assessment for hospice and specialist palliative care services - from philosophy to contracts was published in 1993 and Doyle in the chapter *Specialist Palliative Care services defined* argued that it can be difficult to recognise patients with advanced disease especially in those patients with non-cancer diseases.[39] He further went on to say that palliative care is not only concerned with the effects and symptoms of a disease but also with the pathology of the disease itself. The aim may be the relief of suffering but it also attacks and deals with the pathology itself and not just the symptoms resulting from it. He identified that there is confusion between *Palliative Care* and employing of *the principles of good palliation, that is, the relief of suffering.*

Doyle (1993) claimed that

> *"WHO's definition of Palliative Care is more in reference to the medical Third World and to resource allocation. To propose that in the UK medical and nursing specialists in palliative care should be involved with appropriate patients from the day of diagnosis will predictably confuse patients, undoubtedly antagonise many professional colleagues, and give false, totally unjustified ideas of professional grandeur"*[39].

Doyle's solution was to move back from being *end-stage care* (terminal care) and to work alongside and in total harmony with colleagues who were coming towards the end of what they could achieve with their technical expertise linked primarily to *cure*.[39]

The European Association for Palliative Care definition[40] (1988) states:

> *"Palliative Care is care for the dying by providing active, total care at a time when disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problem is paramount. The goal of care for the dying is the highest possible quality of life for the patient and family"*

Lovel (1999) wrote that if specialist palliative care teams were to take on the care of patients with end-stage non-cancer diseases then they would need evidence-based data on outcome of interventions in these patients.[41] He argued that pressures were increasing from professionals and the general public for the specialist palliative care team to take on this role and quoted the following anecdote: "*What your team has been able to do for my brother with his lung cancer has been wonderful, tremendous. My family and I cannot thank you enough*" and then with great bitterness adds "*Why could you not have done the same for my wife when she had a stroke?"*

> *"Terminally ill people are those with active and progressive disease for which curative treatment is not possible or not appropriate and from which death can reasonably be expected within twelve months".*[42]

> *"Terminal care is an important part of palliative care and usually refers to the management of patients during their last few days or weeks or even months of life from a point at which it becomes clear that the patient is in a progressive state of decline".*[18]

Billings (2000) defined palliative care as *comprehensive, interdisciplinary care of patients and families facing a terminal illness, focusing primarily on comfort and support*.[43] It is surprising that in the United States of America (USA) palliative care is still equated with terminal illness. This article emphasised the controversies still surrounding the definition of palliative care that health professionals are comfortable with, so as to provide a uniform care immaterial of the diagnosis or stage of the illness. The word *terminal* is not very patient friendly nor does it reflect the modern definition of *palliative.*

In the UK, hospice, in the lay mind at least, tends to signify an inpatient unit with beds. Palliative or hospice home care programmes and Macmillan nurses working in multi-professional teams and usually supported by specialist palliative care resources provide expertise, advice and extra support for patients and their families in the community. These work in partnership with the district nurses and GPs, some of whom will have been caring for the patients for much longer. Wider ranges of specialist palliative care services have developed, including day-care and palliative-care teams within acute hospitals.[44]

2.1.1. Summary

Palliative care is seen as a gradually increasing component of care, from diagnosis to death and into bereavement. Concern about being unable to discharge patients with slowly progressive diseases has made many UK hospices reluctant to accept patients who have non-cancer diseases. Therefore only about five percent of patients entering hospice or palliative care services have a diagnosis other than cancer. Lack of clarity in definition leads to wide variations in practice and difficulty in making accurate comparisons between services.[45]

The definition of palliative care and when to provide it, even for cancer patients, is a universal problem as illustrated by a study in Italy by Conno (2002).[46] Their recommendation was: *Palliative care should be an integral part of the approach to the patient with cancer and not given only when treatments with curative intent have failed and the condition of the patient is extremely poor.*[46] Another issue is the extent to which the kind of concern and care that has been developed for cancer patients – once strongly neglected, but now thought by some to be relatively favoured should be extended, soon after diagnosis, to patients who are suffering from other life-threatening diseases.[47]

The main limitation to having a definition of palliative care encompassing all appropriate diseases and making it accessible depending on patients need is the lack of both human and financial resources.

2.2. The different levels of palliative care

There are considered to be three levels of palliative care: the palliative approach, palliative interventions and specialist palliative care.[48]

- **The palliative approach** is relevant to all patients with chronic progressive incurable diseases. It emphasises the importance of considering psychosocial and spiritual aspects as well as the purely physical. It includes consideration of family and domestic carers. Most hospital specialists and all GPs look after patients with life-threatening diseases; attention to the patients' concerns and fears can guide management and ensure appropriate intervention. The palliative approach should be a core skill of every clinician. It is important to know when to seek expert specialist help to ensure the best possible quality of life for the patient.
- **Palliative interventions** aim to improve the control of symptoms for example, palliative surgery, radiotherapy, or chemotherapy. They are usually carried out and monitored by a specialist in the relevant discipline.
- **Specialist Palliative Care** is delivered by clinicians who have specialist accredited training and are on the specialist register. Specialist Palliative Care teams are multidisciplinary and relate to both general and hospital practice. They are available to provide advice, care and support. They bridge the divide between home and hospital and some provide hospice care. They co-operate with others rather than take over from them. Specialist Palliative Care has a duty to carry out research and, through effective education, to disseminate widely the lessons learnt. It must be available to support those practising a palliative approach.

> *"Palliative Care has not tended to be a health service priority and that palliative medicine has only recently been recognised as a speciality and is treated with suspicion by some doctors whose training has led them to be concerned above all with curing patients, rather than with palliation where cure is no longer possible".*[49]

In practice, specialist palliative care providers usually focus upon selected diagnostic groups (especially cancer) or phase of illness (e.g. the terminal phase) but increasingly it is recognised that palliation should not be confined to specialist palliative care services or to those with cancer, and that many aspects are applicable earlier in the course of an illness, even in conjunction with active treatment[50] Clark et al's conclusion was that *since the care of dying people cuts across every clinical speciality and care setting, it is essential that it is considered and reflected in all contracts.*[50]

The diseases requiring ***palliative care*** are ***chronic, progressive*** and ***incurable*** diseases. They consist of the following two groups:

All cancer diseases

Non-cancer diseases:

- Diseases of the immune system: Acquired Immune Deficiency Syndrome (AIDS) and Human Immunodeficiency Virus (HIV).
- Diseases of the nervous system: multiple sclerosis, motor neurone diseases, dementia, Parkinsonism and Huntington's disease.
- Advanced chronic progressive diseases: respiratory, cardiac, renal and hepatic diseases and rheumatoid arthritis.
- Diseases of childhood: cystic fibrosis and hereditary, congenital and metabolic disorders (e.g. muscular dystrophy, cardiac abnormalities and Batton's disease).

3. Needs assessment

3.1. Introduction

Needs assessment is not new. It has been in use since the 1950s and was used by the social services department from the 1970s following the Seebohm Report[49] and the Chronically Sick and Disabled Person's Act 1970.[50] The Seebohm Report was published by the committee set up in December 1965 to *review the organisation and responsibilities of the local authority personal social services in England and Wales, and to consider what changes are desirable to secure an effective family service.* They considered *the needs of individuals, married couples, families and children* by inquiring about the work of health, education and housing departments that were concerned with social work. Public health has for many years advocated that service planning should be based on epidemiological need assessment[51] but this was only acknowledged by the NHS in the 1990s.

Two major pieces of legislation, the National Health Service (NHS) and Community Care Act (1990)[52] and the Children Act (1989)[53] highlighted needs assessment in the health field. Needs assessment was a new field in health service planning and the 1990s have seen it play a vital role in the health service reforms in the United Kingdom (UK)[54], New Zealand[55], Australia[56] and the USA.[56] Health service spending has doubled in most industrialised countries over the past 30 years (1960-90).[25] Government, purchasers and providers of health care and most organisations involved in health services have to justify their spending. When health care resources are allocated without a rationale a combination of waste and lost potential benefit becomes inevitable. Hence the requirement for needs assessment analysing benefits and cost. In the UK health care needs assessment has gained momentum since the introduction of the NHS and Community Care Act (1990) that led to major reforms of the NHS. [57]

Need is what people can benefit from and it is not fixed but is subject to a variety of interpretations and influences[26] (Figure 3). Specialists in the various fields of health care define *needs* in the context of their own speciality and this can subsequently be related to the whole population need.

The following are some examples proposed by Bradshaw (a sociologist)[58]:

- Normative need = need defined by the expert or professional in any given situation.
- Felt need = what people want.
- Expressed need = *felt need* turned to action, e.g. by being added to a waiting list.
- Comparative need = need identified as arising where two similar populations receive different service levels. This contrasts with the comparative approach to needs assessment, in which no prior assumption is made that the lower service level represents an unmet need.

Doyal looks at basic human need which must be satisfied in order to enable optimal social participation.[59] Basic human need includes physical survival and individual autonomy. Physical health is necessary for social participation. Autonomy is determined by degree of understanding, emotional capacity and social opportunities and the autonomy of individuals can be measured in proportion to the social opportunities they enjoy to exercise their cognitive and emotional capacities.[59] Unless these needs are optimally met, individuals will not be able to do their best to flourish as persons and as good citizens. All of this requires sufficient capital to finance it.[59]

Health Economists have tried to integrate need with supply and demand.[60,61] In rationing, needs are not absolute and it should be possible to quantify the different levels of need. Economists have developed *quality adjusted life years* (QALYs) and other scales for measuring relative benefit.[62] Public health physicians and epidemiologists take a pragmatic view by looking at the contribution of current information sources or by investigating unmet need.[63,64]

Definition of needs has been changing over time and it varies with place and situation. Needs also fluctuate from population to population depending on the circumstances. Need depends on the individual and his or her mental and physical health status.[25]

Clinicians look mostly at individual needs but epidemiologists and public health physicians look at population needs. This is because clinicians see individual patients and each case is important. This is also true for individuals, who will think of their needs as being important. The public health physician has to consider the total population and see what service will be most effective for the population as a whole.

Demand is what an individual or a population wants from the health service. The educational level of people, information available to them, their self-interest, the media and the doctor's influence have some bearing on demand (Figure 3). *Expressed need* within the context of providing a service is equivalent to the demand made upon that service. The supply of health services is unlikely to match population needs. Historical patterns, politics and public pressure control supply (Figure 3). Difficulties with phasing out services, combined with the development of new ones can create an irrational pattern of supply.

The need for health is a broad term typically measured by a variety of means. These are health questions in health surveys, surrogate measures like deprivation indices, and relative measures like standardised mortality ratio (SMR). These measures do not easily translate into what can or should be done to improve health and most of the routine sources are notoriously inaccurate.[26] Health needs are related to the overall aim of producing a healthier population, and are influenced by socio-economic status, housing, environment, cultural and social background, religious beliefs and customs.[25]

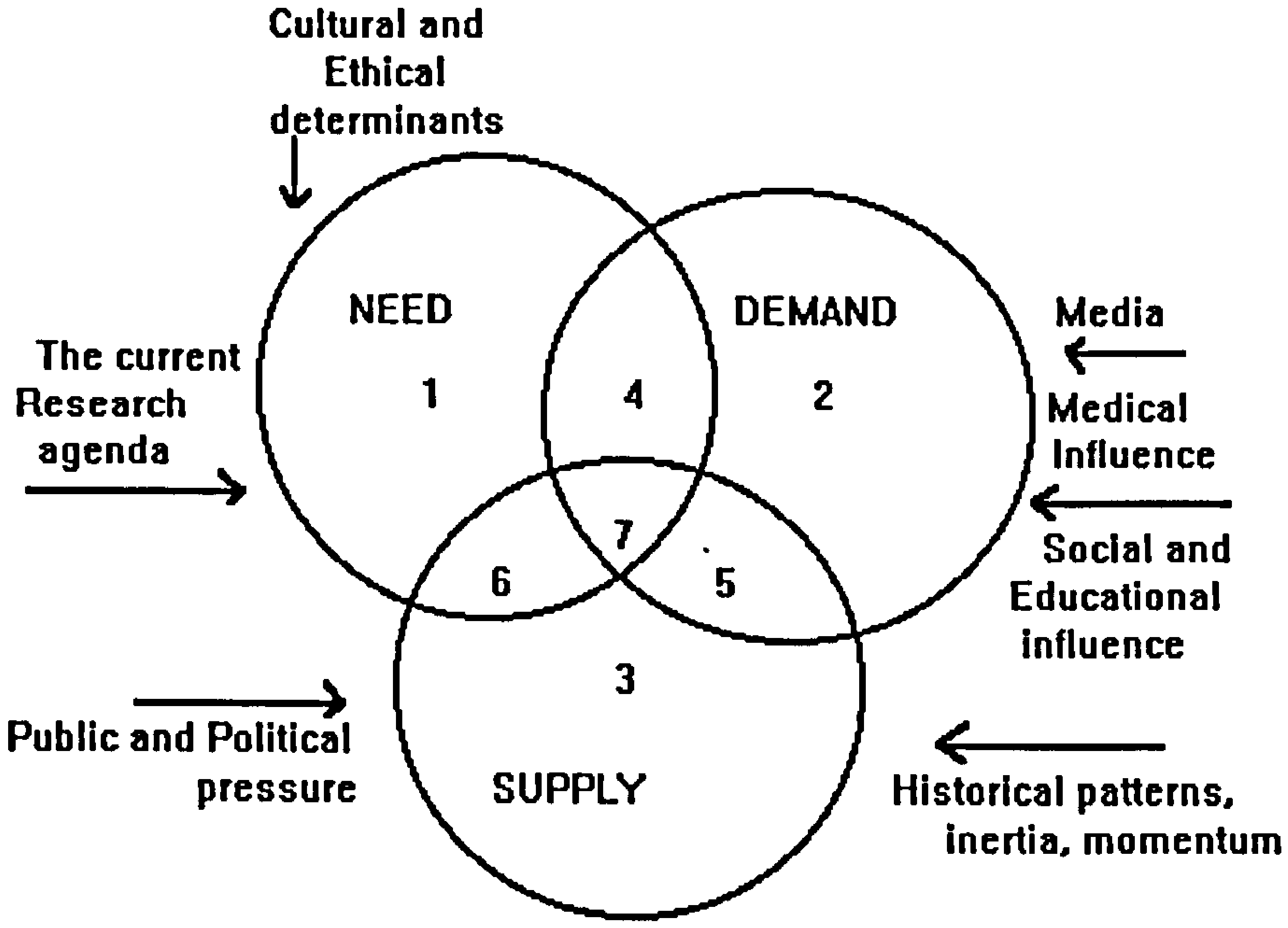
The need for health care is much more specific. It is dependent on the availability or potential availability of health care and prevention services to respond to the disease, risk factor or disability and to secure an improvement in health, i.e. the ability to benefit from effective health care or preventive service.[65,66]

The following shows the importance of each component of the definition of need.

- The population's ability to benefit from health care = the aggregate of individuals' ability to benefit (can be deduced from epidemiological data, rather than from clinical records).
- The ability to benefit does not mean that every outcome is guaranteed to be favourable, but rather that need implies potential benefit that on average is effective.
- The benefit is not only a clinical status but can include reassurance, supportive care and the relief of carers. Many individual health problems, especially infectious diseases and long term disabilities, have a social impact via multiple knock-on effects or via a burden to families and carers. Consequently, the list of beneficiaries of care can extend beyond the patient.
- Health care includes not just treatment, but also prevention, diagnosis, continuing care, rehabilitation, and palliative care.

See Figure 3 below for an outline of need, demand and supply and their influences and overlaps.

Figure 3 Need, demand and supply: influences and overlaps



From Needs Assessment, needs assessment.[26]

1. those for which there is a need but no demand and supply (unpublicised-unmet areas of potential benefit),
2. those for which there is a demand but no need or supply (unjustifiable demand not met),
3. those for which there is a supply but no need or demand (unused services),
4. those for which there is a need and a demand but no supply (publicised unmet need),
5. those for which there is a demand and a supply but no need (services supplied to meet demand not need),
6. those for which there is a need and a supply but no demand (needed services reluctantly received),
7. those for which there is a need, a demand and a supply (need and demand correctly met).

3.2. Approaches to needs assessment:

The main tool used by health service purchasers is the epidemiological approach to needs assessment that is based on incidence and prevalence along with the effectiveness of health care. This combines an epidemiological and health economics approach to needs assessment. Needs assessment usually aims to make stepwise changes to existing services.[25] Lack of information on effectiveness and prevalence and the enormous work involved in reviewing and applying the information, if it were available, tends to make health care purchasers use other simple methods like comparative, corporate and rapid assessment (especially in emergency situations). These will now be described briefly.

3.2.1. Comparative approach to needs assessment

This method contrasts the service received by the population in one area with those elsewhere.[25] This is a powerful tool for investigating health services, especially in the context of capitation-based funding. Comparative service provision needs to take into account the population outcome data. For this method one needs outcome-related health data and population health outcome indicators.

3.2.2. Corporate approach to needs assessment

This is based on the demand, wishes and alternative perspectives of interested parties including professionals, patients, press, GPs, politicians, opinion leaders, purchasers and providers.[25] This type of approach blurs the difference between need and demand, and science and vested interest. The success of this depends on important information coming from those who have been involved in local services over many years. The main party interested in change is the patient and they should be involved in the needs assessment process but this requires a clear view of the distinction between need and demand.[67]

3.2.3. Rapid appraisal approach to assess community health needs

This was developed by WHO, as a rapid and cost-effective way of assessing needs of low-income urban areas.[68] Health status was previously considered to be a sufficient measure of health improvement. It is now recognised that good health depends on many other factors such as socio-economic status and accessible, acceptable and affordable health services and health care. In rapid appraisal the health managers review the existing records, interview key informants and make observations. Then, as a team, and with community participation they try to work out community priorities for action. This was developed because there was little time and money available to collect information needed to develop plans for improving health care. This cost-effective approach also strengthens the primary health care principles of equity, participation and multi-sector co-operation. Such a method could also be used for a rapid assessment of needs in an emergency situation, which would help in the planning of health care services for those involved.

3.2.4. The epidemiological approach to needs assessment

This is the population's ability to benefit from health care.[25] It begins with a clear statement of the problem and should have an outline of the subcategories relevant to service delivery. There would be an estimate of the range of incidence and prevalence rates for the problem being investigated. The findings would contain a summary of the services available - both for care and care settings, a summary of the known effectiveness and cost effectiveness of the services and a derivation of a range of models of care. The final part would include a view on outcome measures, targets, information requirements and research priorities.

> *"Health needs assessment has more recently come to be seen as integral to the process by which primary care responds to local and national priorities. With the creation of the new health commissions, public health and primary care are now, more than ever, expected to work in partnership, and with others, towards the development of knowledge concerning local population health status and needs as well as appropriate service provision. The new Labour Government is committed to ensuring access to treatment according to need and need alone, and to locality commissioning in which GPs and nurses combine to plan local health services. Bearing all this in mind, it is clear that health needs assessment should be approached in much the same way as doing a jigsaw, so that different pieces are put together to give a complete picture of local health".*[28]

Health needs assessment was intended to inform the strategic and contracting process within the NHS and to contribute to the more effective allocation of health care resources.[69] Government guidelines combine epidemiological and economic approaches to health needs assessment and this is constrained by the definition of health, dominated by medical professionals, set within the context of existing services and limited by the information available to it.[69] This propagates a service-led provision of health care and there is a move to propose a more holistic definition of health in which subjective perceptions of health and health status are seen to be as valid as those of experts.[69] This holistic approach to needs assessment is best suited for palliative care, which in itself is a holistic approach to care of those with an incurable disease. The service users' views and frontline service providers' perceptions need to be included and will in some way overcome the conceptual and practical barriers. Should health needs assessment be more widely undertaken, it has the potential to improve the quality of information on needs and encourage the sharing of knowledge with other agencies and the public. Then perhaps the desired outcome may be achieved.[69]

4. Provision of Palliative Care

4.1. Patients' preference for place of death

The debate about the patients' preference for the place of death and its advantages and disadvantages has been documented but there seems to have been little change over the last few decades in the final outcome as to the patient's place of death. Many factors have been identified as a cause and symptom control is a major factor. Social class, age, gender, informal and formal carer and home care support, were some of the other influences deciding the place of death. Palliative care for cancer patients has helped to improve the quality of life for patients and enabled patients to have a choice of where they would like to die. The inclusion of non-cancer patients to receive palliative care and for them also to have a choice of where they would like to die is something new to palliative care. Most of the studies have been on preference of place of death for cancer patients.

Townsend (1986-87) found that of those who died in hospital, 63% had stated a last preference to die elsewhere and 82% would ideally have preferred to die elsewhere.[10] Half of the patients would have preferred to die at home. In his article he says that there was to be a change in allowance policy that would have enabled the patients to achieve their wishes.[10] To date very few changes have occurred to enable patients to achieve their wishes. A study by Herd (1990) found that there were more home deaths in a rural setting compared to metropolitan areas.[70] Those who died in hospital were likely to be over 70 years old. An acute ward was frequently criticised by nurses and relatives as being unsuitable for dying patients[70]. Jones (1993) found that in spite of good pain control there were other difficulties like control of symptoms other than pain and carer problems that were not recognised by doctors and nurses.[71] This was an obstacle to home deaths of cancer patients. Thorpe (1993) mentioned two paradoxes and outlined the need for a strategy to overcome them. The first paradox was that most dying people would prefer to remain at home but most of them die in institutions. The second paradox was that most of the final year was spent at home but most people are admitted to hospital to die.[72]

Data from 1985 to 1994 were analysed by Higginson to look at trends in place of death of cancer patients within England.[73] It was found that hospital deaths fell from 58% to 47% and home deaths fell from 27% to 25% while hospice and nursing home deaths rose from 10% to 21%. There were differences between the various types of cancers, age and gender. These trends may continue with an ageing population.[73]

Data from a survey in 1990 were analysed by Addington-Hall and it was found that in England the place of death for cancer patients was home for 29%, hospital for 50%, hospice for 14% and other institutions for 7%.[74]

Ellershaw (2003) analysed the Registrar General's data on deaths in England and Wales and found that of the cancer deaths, 55% died in the hospital, 17 % in the hospice and 23% in their homes.[75] In response to this article by Ellershaw a consultant anaesthetist wrote:

> *"How sad it is, that in 2003 the simple messages of palliative care have not reached all parts of the healthcare system"*[76]

Sims (1995) tried to answer Thorpe's paradox by analysing the social class variations in place of cancer death and found this to be a statistically significant cause.[77] Sims' findings were as follows:

- social class I and II accounted for 15% of all cancer deaths and contributed to 24% of hospice, 14% of hospital and 12% of home deaths
- social class III accounted for 24% of all cancer deaths and contributed to 58% of hospice, 9% of hospital and 35% of home deaths
- social class IV and V accounted for 61% of cancer deaths and contributed to 18% of hospice, 77% of hospital and 53% of home deaths.[77]

A review of research by Grande (1998) found that dying at home and being admitted to palliative home care depended on patient characteristics.[78] Most studies in Grande's review were post hospice movement (1980) and consistent patterns emerged particularly in relation to informal support (positive if available), age (positive for younger age), sex (positive for men) and socio-economic (positive for higher) variables and home deaths. Improved symptom control, type of cancer and early referral to specialist palliative home care services were positive factors for home death.[78] The paradox of these variables and improved palliative care was that the benefits might not reach everybody equally and may in fact exacerbate differences between patients for some variables/groups.

4.2. Palliative care for cancer

There is a tendency not to include non-cancer diseases when investigating or providing a palliative care service as will be illustrated by the following literature.

Hancock et al (1993) looked at palliative care of patients but only for those with terminal cancer.[79] They looked at various treatment methods and concluded that palliative care for terminal cancer patients should be planned, developed and analysed for its cost-benefits. Addington-Hall reported (1993) that support services for cancer were developing in a fragmented and poorly co-ordinated way with no agreed strategy and lack of evidence to provide the best service.[80] Another study by Addington-Hall (1995) reported that there was a long way to go before all dying cancer patients receive high quality care.[74] Lack of resources and lack of knowledge of principles of palliative care by all levels of the NHS were identified as possible causes.[74]

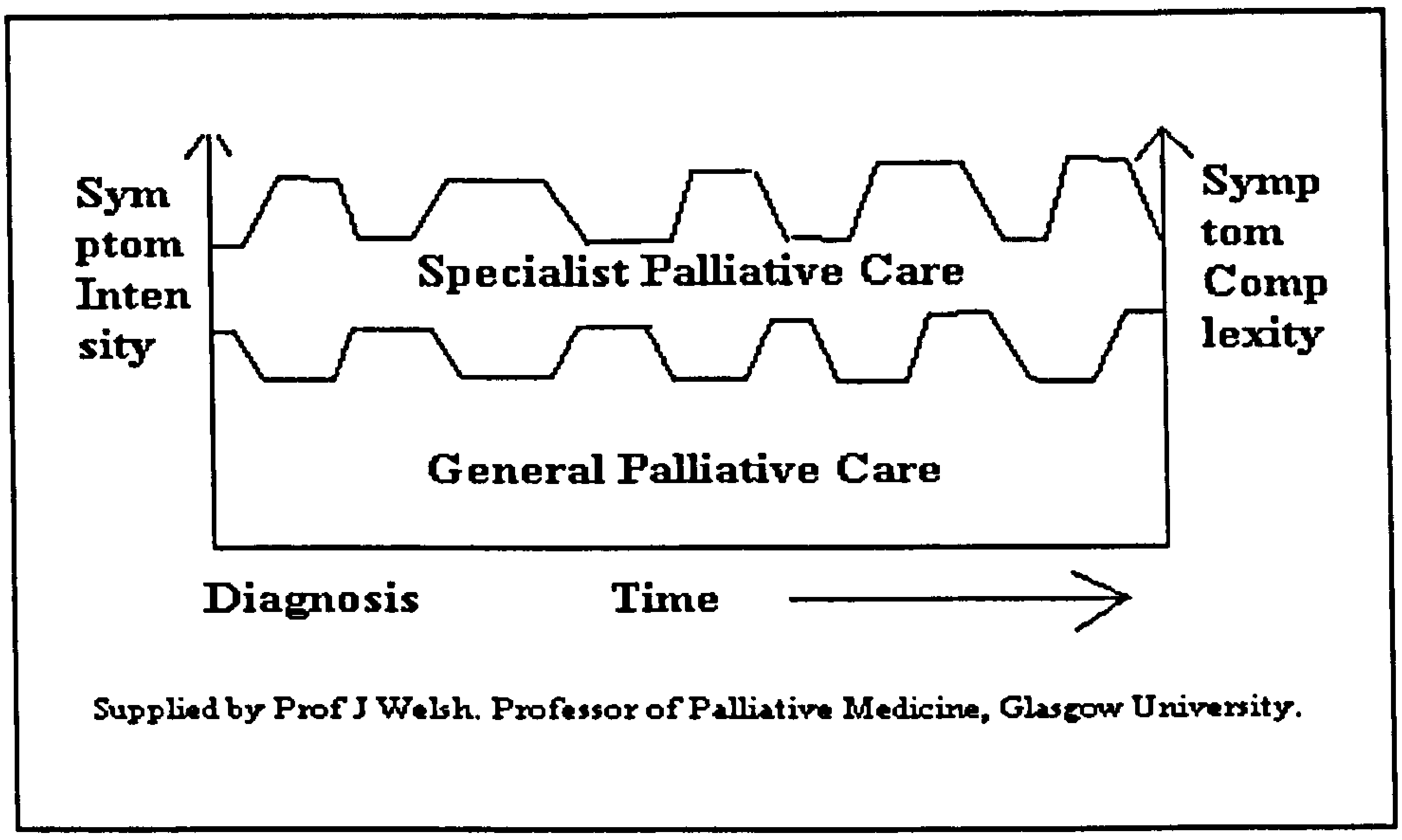
Higginson (1999) stated in an editorial that *clearly difficulties remain in the rigorous gathering of evidence about many aspects of palliative care, but these difficulties should not be allowed to stand in the way of applying palliative care where its benefits have been shown.*[81] The palliative care discussed in this editorial was for both cancer and non-cancer diseases. A letter in reply to this editorial, written by a public health consultant, a consultant in palliative medicine and a Macmillan GP facilitator, called for an evaluation of general palliative care but they only discussed palliative care for cancer diseases.[82]

There appears to be a lack of uniformity and clear definition of palliative care within the general medical profession (i.e. non-specialist palliative care)

There are a few directories of palliative care services in the UK produced by voluntary organisations e.g. St Christopher's Hospice Information Service, Macmillan, Marie Curie and the Scottish Partnership Agency (from August 2002 known as the *Scottish Partnership for Palliative Care*). These directories contain information on cancer and non-cancer related services (mainly for motor neurone disease). Franks (2000) argues that there is evidence that patients suffering from non-cancer terminal illness may require at least as much palliative care as patients dying from cancer, yet proportionally fewer resources are used to alleviate suffering in these patients.[11] Franks concludes by stating that evaluation of services for palliative care must not look only at hospices, but also at the delivery of palliative care within the general hospital and community services where the majority of patients are receiving care.[11]

According to Welsh (2003) most patients requiring palliative care receive this from their GP. However if the symptoms prove intractable or severe then referral to hospital specialist palliative care teams or to specialist palliative care unit services occurs. After this specialist intervention the GP continues the support sometimes in continuing partnership with specialist palliative care (Figure 4).[83] Then throughout the patient's care, depending on the intensity and complexity of symptoms patients should be referred at appropriate times to the specialist palliative care team. For optimum benefit to the patient there should be interaction and good communication between the general and specialist palliative care providers so that the patient has a comfortable journey throughout their care. With the introduction of managed clinical networks and integrated care pathways for palliative care this should be possible.

Figure 4 Shows the relationship between specialist and general palliative care



Supplied by Prof J Welsh. Professor of Palliative Medicine, Glasgow University.

4.3. Palliative care for non-cancer diseases

There is a lack of research and evidence on the effectiveness of palliative care for non-cancer patients when compared to cancer patients. There is also a lack of palliative care services for non-cancer conditions in comparison to cancer conditions. The following might be some of the reasons for the disparity between cancer and non-cancer diseases requiring palliative care[83]:

- Initial hospice pioneers chiefly promoted their service for cancer
- More predictable cancer course
- Perception of cancer being synonymous with pain
- Fear of cancer
- Cancer is an emotive topic.

Non-cancer conditions make it harder to plan and provide palliative care services and to allocate dedicated resources for the following reasons:

- Unpredictable course
- Longer time course
- Exacerbations and remissions.

The first book to consider specifically the palliative care needs of people who die from causes other than cancer and, in particular, to discuss how these needs might best be met, was published in 2001.[20] This book was edited by Addington-Hall and Higginson and contained chapters on all the non-cancer diseases including neurodegenerative diseases (multiple sclerosis, motor neurone disease, Parkinson's disease and Huntington's disease). The chapters of this book raise more questions on the future of palliative care for patients with non-cancer diseases.[20] The palliative care needs of cancer patients have been well documented by research but the palliative care needs of non-cancer patients are only now being recognised. There is a lack of evidence-based information and research to compare the palliative care needs of cancer and non-cancer patients.

A survey of the hospice and palliative care inpatient units in the UK and Ireland (1993) was carried out and found that there were three specialist HIV/AIDS hospices caring solely for these patients and a few other hospices would accept them.[84] Only half of hospices accept motor neurone disease patients and a quarter accept patients with multiple sclerosis.[84] Nearly a decade later (2000), a survey of the palliative day care services found that only ten percent of the patients admitted had non-cancer diseases and these were mainly HIV/AIDS, motor neurone disease or stroke.[85] The rate of progress in the recognition and acceptance of non-cancer diseases requiring palliative care on par with cancer diseases is a slow process.

Kurti (1995) assessed community based palliative care for patients with non-cancer diseases who wished to remain in their own home until death[86] and found that 25 percent of GPs considered that palliative care applied exclusively to people with cancer and 50 percent felt that it was primarily concerned with pain relief. Her conclusions were that *Palliative care is not exclusive to people with cancer but should be extended to people with non-cancer diseases, encompassing not only symptom relief but also explicitly including emotional or spiritual support, care of the family, and support in preparing for the end of life.*[86]

Scott found that in the Argyll and Clyde Health Board area (1995) hospices were principally established to meet the needs of patients with cancer and have until recently failed to provide services for patients with other progressing diseases.[87] This trend is changing at a slow rate but only for certain diseases, especially for motor neurone disease.

Addington-Hall (1998) was commissioned to review specialist palliative care for adults with non-cancer diseases and concluded that local palliative care strategies should be revised to improve palliative care for patients with non-cancer diseases.[88] There were eleven recommendations on how this could be achieved and promoting the palliative care approach was one of the possible models suggested for meeting the palliative care needs of patients with non-cancer diseases.

Higginson et al (1999) in response to an article on palliative care for anorexia nervosa stated that *the specialist palliative care services need to widen their brief so that they can include patients with diseases other than cancer. This may require resources and the development of working relationships and collaboration with those who work in other specialities.*[89]

Dharmasena (2001) looked at hospital physicians' views about referring patients with non-cancer diseases to a specialist palliative care service and found that a shared care approach would be most appropriate[90]. They had the views of physicians from various specialities and 94 percent of them were in favour of referring their non-cancer patients. The physicians agreed that motor neurone disease, multiple sclerosis, heart failure, rheumatic diseases, chest diseases, other neurological conditions, renal failure, dementia and cardio-vascular accidents would benefit from specialist palliative care in that order of preference.[90] In the study by Dharmasena the main reason for referring non-cancer patients was for *terminal care.* The term *terminal care* is not clearly defined for non-cancer patients as that for cancer patients and the use of the term *palliative care* would have been more appropriate for the present time. This choice highlights the intricacies of the definition of palliative care, the medical professionals' definition of palliative care and when palliative care starts for the patient? This study was carried out after the current study and shows that there is still a varied view of palliative care and what it can achieve for patients. The other reasons for referring their non-cancer patients included psychological support, symptom control, pain control, social care and spiritual support in that order of importance.[90]

4.3.1. HIV/AIDS

Assessing the palliative care needs for people with HIV/AIDS will depend on the underlying prevalence within the population served, the symptoms and problems experienced and the extent to which there is a palliative period. This is a complex issue.[18] The growing number of people, especially the elderly, who are likely to die from HIV/AIDS makes it important that palliative care becomes more integrated with hospitals, community and GP services and should gradually become an increasing part of care from diagnosis to death.[91] Psychosocial interventions that focus on human dignity and quality of life, normally seen as elements of palliative care, are critically important from the earliest stages of HIV/AIDS disease and should not be reserved only for those who are terminally ill.[92]

On referral HIV/AIDS community support teams identified symptom control, pain, family anxiety and patient anxiety as severe problems.[93] Patient anxiety and pain control was found to improve with care of the patients but symptom control and family anxiety remained a serious problem throughout.[94] It has been shown that the views of palliative care teams for people with HIV/AIDS are a reasonable reflection of patients' and carers' experiences.[95] But Armes' (1999) study on quality of care concluded that the six dimensions of high quality care developed by Maxwell[96] (1992) were inextricably linked from the client's point of view, especially for HIV patients.[97]

It is essential that palliative care for HIV/AIDS is available alongside and within facilities which are providing potentially curative clinical drug trials[98] and this compels the palliative care needs of HIV/AIDS patients to be categorised individually.

4.3.2. Motor neurone disease

A basic change in attitudes is required if we are to stop viewing patients with incurable illness like motor neurone disease as some kind of medical failure.[99] Hicks (1993) found that the provision of inpatient respite care for patients with motor neurone disease in hospice was variable and often found lacking.[100] Hicks' conclusions were that *Respite admissions to the hospice were valuable both for motor neurone disease patients and their carers and units not currently involved in this work may wish to reconsider their position.* Some of the reasons identified for the absence were concerns about accepting patients who may need long-term care and that respite was only for short term residential stay without nursing or medical input.[100] After nearly seven years the situation for motor neurone disease remains the same.

4.3.3. Multiple sclerosis

Ford (1995) found that patients with multiple sclerosis should be fully informed and early diagnosis will become increasingly important in the majority of cases.[101] A study by Rothwell et al (1997) showed GPs and multiple sclerosis patients did not agree on which symptoms were important.[102] If the patients' views are not taken into consideration when planning their treatment then this will have implications on the service provided and the outcome of the care to these patients.[102] The use of quality of life measures for the assessment of progress in multiple sclerosis patients would give the opportunity for the patient's views to be considered in planning their care instead of relying on medical tests that might not be as reproducible as quality of life measures.[103]

Health care professionals perceptions of what can be done for motor neurone disease and multiple sclerosis patients were found to be more negative towards motor neurone disease as compared to multiple sclerosis.[104] There were similarities with regards to resources and interdisciplinary team problems. The differences identified were related to patients care. Providing care for multiple sclerosis patients was more complex due to initial uncertainty and delay in diagnosis and the unpredictable course of the disease. Multiple sclerosis patients were found to be more demanding.[104]

4.3.4. Cardio vascular conditions

Cushen (1994) writing about palliative care for cardiac patients said that *palliative medicine is the study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus for care is quality of life.*[105] He concluded, *if the quality of life of patients with terminal heart disease is to be improved we need to lose more of our preconceptions.* Cushen highlighted the similarities between cancer and end stage heart failure e.g. dyspnoea, tiredness and cachexia and stressed the urgent need and importance of research into these issues[105] to provide the evidence to address these needs.

Gibbs et al (1998) voiced the opinion that *Palliative care, with its emphasis on the care of patients whose prognosis is limited, focusing on quality (not quantity) of life, and on a multidisciplinary approach, may benefit patients other than those with cancer.*[106] If palliative care aims to recognise the needs of other incurable progressive illnesses, then now is the time to collaborate and accelerate this change. In the 1990s in the UK only one study had investigated symptoms in terminal heart disease[107] and it was a population based retrospective survey of a random sample of people dying in 20 English health districts in 1990.

Ten years later it was found that there was very little information about the management of heart failure patients by specialist palliative care.[108] Over a 5-year period (1994 to 1999) only 0.25% of the patients referred to St Christopher's Specialist Hospice suffered from heart failure and GPs referred half of these patients. In spite of so few cardiac patients using these services, it was found that these patients made similar demands on specialist palliative care services when compared to other hospice patients.[108] There is still no evidence of the effectiveness of such service for cardiac patients and the role of specialist palliative care for them.

Cardiac failure was found to be the final common pathway in most patients with advanced cardiac disease who do not die suddenly. Cardiac failure affects one to two percent of the adult population and rises steeply with age (to more than ten percent in those above the age of 70 years).[109] Quality of life is adversely affected and up to 30 percent require hospitalisation in any year.[109] Cardiac failure has a higher mortality than any form of cancer, with a 60 percent annual mortality with grade four cardiac failure and an overall five-year mortality of 80 percent in men. Pain is not a dominant feature after the medical advances in anti-angina therapy and interventional techniques.[109]

Ellershaw (2003) found that heart failure was the most common single cause of death in many hospital medical wards and said that palliative care needs of these patients had been ignored until recently.[75] One of the reasons for this according to Ellershaw was due to the difficulty in predicting when death was imminent in heart failure patients.[75] This difficulty could be avoided or overcome if palliative care for heart failure was not only in the terminal stages as suggested by Ellershaw, but from the time of diagnosis they should be seen by a palliative care specialist who could plan when palliative care services would be beneficial and how best to provide it.

4.3.5. Respiratory conditions

Skilbeck et al (1998) were involved in a needs assessment of palliative care for chronic obstructive airways disease.[110] They concluded that the view that palliative care should be moved beyond cancer is widely endorsed, however there remains a lack of clarity about the level at which this should occur and suggested a more detailed and localised needs assessment.[110] The commonest chronic respiratory disorder requiring palliative care was chronic obstructive pulmonary disease where the clinical course is unpredictable and is usually prolonged when compared to cancer cases.[109]

4.3.6. Children

Franks et al (2000), in their systematic review of the literature on the level of need for palliative care, found that even though the numbers of patients in this group were small, the needs of this group may be quite different from those of patients with other terminal illnesses.[11] These patients were considerably younger and some were homeless, making home care problematic. Franks et al conclude that even though few children require palliative care, it must be acknowledged that they may require different care from those of adult patients. Cancer deaths in children are rare but increase with increasing age.[11] The special hospices for children were pioneered in the UK and developed in Europe and Canada in 1996.[111] In the early 1980's, for children with terminal illness the aim had been for the child to die at home,[112,113] similar to the practice in the late 1990's in the GGNHSB area as explained below.

4.3.7. Summary

Addington Hall (1998) investigated the prospect of specialist palliative care in non-cancer diseases and found that based on need (when compared to cancer patients) there would be an increase of at least 79% (conservative estimate) in caseload if specialist palliative care were made fully available to non-cancer patients.[114] This increase in the caseload will have considerable resource implications.

Acheson (2001) questioned the distribution of the slender resources of palliative care according to need in the UK and concluded that the health and social policies in the UK were one of the most unequal in the developed world.[115] Ishmael (2001) in a working group looking at palliative care in the UK, found that much of it was provided by the voluntary sector. It proved more difficult to develop and support palliative care in deprived neighbourhoods, compared to affluent neighbourhoods. This raises the issue of palliative care services for non-cancer diseases being unequal to palliative care services for cancer patients and at a time when the Labour government is tackling inequalities in health and has named this as one of its priorities. Society needs to address this inequality and social injustice to which patients with non-cancer diseases are being subjected.

Wasson (2000) a clinical ethicist in a palliative care centre summarises the ethical argument for providing palliative care to non-cancer patients as:

> *"the duty to provide care, non-maleficence, beneficence, protecting the patient's best interest and respecting patients autonomy are key responsibilities which palliative care professionals have for all their patients, regardless of their diagnosis. On the ground of justice as fairness, equality and equity, the current inconsistencies in the provision of palliative care to non-cancer patients are unfair, unequal and inequitable. Professionals can no longer ignore their moral responsibilities to address these issues and change their practice to include the provision of care for dying patients regardless of their diagnosis".*[116]

This last line opens up an entirely new and very complex definition of palliative care. Until the late 1980's and early 1990's palliative care was for cancer patients and then the WHO's definition[1] opened it up officially for non-cancer conditions that were chronic, progressive and incurable. The palliative care professionals and the palliative care services are struggling to come to terms with this and are not helped by finite resources (both financial and human) which are becoming smaller. Three other articles by Weissman (1999), Zuckerman (1997) and Reynolds (2002) discuss care for the dying in acute care hospital setting[117], end of life care and decision making[118] in nursing homes[119] respectively. They all include ALL dying patients as candidates for receiving palliative care irrespective of their diagnosis. Kite et al (1999) described the experiences of a specialist palliative care team who received referrals from the hospital ward and the out-patient clinic in London for treatment of symptoms (mainly pain) for their non-cancer patients.[120] There were a few who did not have a chronic, progressive and incurable condition in the wards but the majority of the out-patients had chronic pain due to progressive benign disease or due to longstanding disabilities or conditions of uncertain aetiology.[120]

These examples of extending palliative care to include all non-cancer conditions in the end stages will be argued to be practical by some policy makers who say that the needs of these patients can be met by encouraging generic nurses and doctors to develop a palliative approach in the acute sector. But Loftus (2000) argues that there is insufficient evidence to support this view and that registered nurses in the acute sector say that quality of life issues are insufficiently discussed when caring for these patients.[121] Bisset et al (2001) state that care for the dying has always been a part of nursing, but it has only existed as a speciality for a few decades.[122] One unfortunate consequence of this specialisation has been to mystify and de-skill general nurses and hamper their performance in this crucial area of health care. They conclude by saying that *care of the dying and newly bereaved should not be seen as a specialist art but as a skill everyone should possess.*[122] These statements reinstate the conflict and uncertainty within the nursing profession with palliative care and its definition and roles and responsibilities within the profession.

Seymour et al (2002) undertook a review of health improvement plans for 1999-2003 produced by all 99 health authorities in England.[123] Since 1987 the health authorities were required to make plans for palliative care services and Seymour's review uncovered the following information:

❖ Cancer care included	99%
❖ Palliative care included	78%
❖ Calman-Hine referenced	71%
❖ Specialist palliative care or hospice care included	38%
❖ Palliative care strategy published	35%
❖ Palliative care for non-cancer included	17%
❖ Palliative care strategy planned	13%

These were 2002 findings for services planned until 2003 and it is amazing that only 17 of the 99 health authorities had made palliative care provision for non-cancer diseases.

4.4. Community based health professionals and palliative care

Sprangers and Aaronson (1992) reviewed the role of health care providers in evaluating the quality of life of patients with chronic diseases and concluded that *there is a need for more methodologically sound studies that incorporate head to head comparison of health care providers.*[124] In this study the two groups of palliative care service providers identified in the community were the GPs and the district nurses. The service providers in the community are not always in a position to carry out a needs assessment of the population that they serve. Most service providers only assess the needs of their individual patients. The difficulties of undertaking a needs assessment in the community were highlighted as lack of planning time against the pressures of responding to the immediate needs of patients. [125]

Grande et al (1997) investigated the barriers to adequate symptom control in palliative care by surveying health care professionals to ascertain their views of symptom control.[126] Their findings were that GPs and district nurses differed greatly in the symptoms they felt confident in controlling. The study included palliative care patients who were terminal and were looked after at home. In this study there was no mention of the condition of patients and whether they were cancer patients or if non-cancer patients were included. There was no clear definition of palliative care though they defined terminal care as patients with a life expectancy of a year or less.[126]

Shipman (2000) et al found that GPs and district nurses were least satisfied with aspects of out-of-hour care for their patients requiring palliative care.[127] The GPs preferred to provide their own out-of-hour palliative care service and were reluctant to hand over the patient notes to the out-of-hour service. Shipman used semi-structured postal questionnaires with GPs and district nurses in the London and neighbouring areas. Similar results were reported by Barclay et al (1997) who looked at medical records and did a retrospective audit of palliative care in the Cambridge GP co-operative.[128] This was followed up by visits or telephone consultations with patients.[128] Higginson (1999) also found that out-of-hour access was a concern for GPs.[129] Todd et al (2002) found that more district nurses referred and admitted patients to hospital at home service than GPs and both of them thought that this service was worse than NHS services in terms of availability and duration of stay.[130]

Mitchell (2003) undertook an audit in a GP practice in a well resourced rural area and looked at patients dying of cancer or a progressive neurological illness.[131] They introduced a new concept termed *length of palliative care phase* and claimed that it was relevant when considering the workload of the primary care team and the length and intensity of engagement with the patient and their families.[131] The median length of care was nine months and this was something practised by Marie Curie nurses previously. This is not a new concept but a new name for *terminal care*, which is being slowly replaced in modern palliative care services. But this idea raises important issues especially at a time when resources for palliative care are finite and at present includes selected non-cancer diseases and when the primary care team has the major responsibility for home care. Maybe the specialist palliative care community has to rethink the concept of providing palliative care from diagnosis and place some form of time frame when it could be practically provided for all those who need it especially in the community. This was also highlighted in a hospital at home service that was provided in GGNHSB area for a heart failure patient and since no time scale had been built in from the beginning, the primary care team found that their resources were not sufficient to continue the service indefinitely (personal communication).

The following is a review of the literature on the role of GPs and district nurses in providing a community based palliative care service.

4.4.1. Role of General Practitioners

Articles in the BMJ in 1995 started discussion on the topic of palliative care and GPs role and responsibilities. Charlton in a letter to the editor of the British Medical Journal (1995) stated that *GPs do not limit their definition of palliative care and its application to patients with cancer, as many hospitals do.*[132] He was reporting about a previous article "*palliative care in general practice*" by Kenyon who suggested that a diploma in palliative care might be a necessary qualification for aspiring GPs.[133] This was discussed by Brooks who said that *GPs have other priorities and questions whether GPs should carry out palliative care at the expense of commoner problems.*[134] None of these comments were backed by evidence and sensibly Charlton comments that *conclusions reported must be based on systematic research rather than potentially biased observations.*[132]

A population based study by Addington-Hall (1995) found that hospital doctors were relieving cancer patients of pain (by 8%), breathlessness (by 11%), nausea and vomiting (by 5%) and constipation (by 2%) better than GPs.[74]

Millar (1996) evaluated the clinical experience of Scottish GPs and their views on home care in a postal survey.[135] Millar's study only included GPs and was only about cancer conditions which limits generalisability of the results to other progressive incurable diseases. Millar's study found that although trainees were being given clinical experience in dealing with patients requiring palliative care, training in the subject was virtually absent during their hospital years and inadequate during their GP year, both in the practice and on day release courses.[135]

Shipman et al (2002) found that there were 4 different ways in which GPs used specialist palliative care services. These were: i) seldom use specialist palliative care services (20%), ii) use it as a resource (55%), iii) work together as a team (10%) and iv) hand over complete responsibility to specialist palliative care services (15%)[136]. This study in 2002 shows that just over half the number of GPs would still want to be responsible for palliative care services for their patients and were willing to use specialist palliative care as a resource.[136] Only a small number work together as a team with the specialist palliative care services which is something that the GPs are not willing or have no protected time to do. Previous experience and easy access to the specialist palliative care services were also important.

Hanratty et al (2003) carried out focus groups with GPs, cardiologists, geriatricians, physicians and palliative care specialists to look at their perceptions of palliative care for heart failure.[137] The findings were that GPs supported by palliative care specialists should be the central figure in palliative care for heart failure. They recommended that the role of nurses should be developed, the role of nurses and essential community services increased.[137]

4.4.2. Role of District nurses

Hatcliffe et al (1996) evaluated the district nurses' perceptions of palliative care at home by a postal survey.[138] Hatcliffe's study only involved district nurses and there was no mention if non-cancer patients were included. Their study reported a high response rate, with additional comments illustrating the district nurses desire to provide high quality care but this was hindered by the size of caseload, lack of knowledge and experience in managing difficult symptoms as well as time constraints and these led to stress for the district nurses. They also recorded a high level of satisfaction and identified the need for further education and improved communication.[138]

Palliative care services in Forth Valley Health Board in Scotland were evaluated by Dyer[139] using a postal questionnaires to GPs and to district nurses by Hunter[140] to ascertain the GPs and district nurses perspective of the palliative care in Forth Valley. The questionnaires used for the GPs and the district nurses were different and because of this the views of the GPs and district nurses could not be compared. The study by Dyer[139] found that 26 percent of the palliative care provided by the GPs was for non-cancer diseases but there was no mention of what these diseases were.

The study by Hunter[140] reported that 50 percent of the palliative care provided by the district nurses was for non-cancer diseases and these were for stroke (16%), ischaemic heart disease (11%), others (11%), multiple sclerosis (7%), Parkinson (4%), motor neurone disease (1%) and muscular dystrophy (1%).

Gibbs (1995) found that nurses in private nursing homes felt isolated, had no access to post-basic education opportunities and their knowledge and attitude to pain management in palliative care was lacking.[141]

4.5. Comparison of palliative care needs of cancer and non-cancer diseases

The palliative care needs of non-cancer patients have been documented and highlighted by various studies mentioned above. Most studies have looked at a single disease and the needs within each disease and not had a broader approach. The comparisons between palliative care needs of cancer and non-cancer diseases have been for chest diseases, like lung cancer and chronic obstructive lung disease. No study has compared the palliative care needs of cancer and non-cancer diseases in the community by eliciting the views of both the service providers in the community, and the patients who are the service users.

Dixon's (1991) comparative study on AIDS and cancer pain relief by slow release morphine found that pain was less severe in HIV/AIDS but still required opioid use in over a third of patients of which 14 percent needed subcutaneous diamorphine infusion when seriously ill at home. Slow release morphine was used by 45 percent of those with cancer and only by 17 percent of those with HIV/AIDS.[142]

Montazeri (1996) looked at quality of life of lung cancer patients and his control group consisted of patients with chronic obstructive pulmonary disease. Most of his results were about the cancer patients.[143] The comparison was between a cancer and a non-cancer condition but they were both diseases from the respiratory system.

The findings of Montazeri's study were that:

1. there were no significant differences between the quality of life in cases and controls except for pain and loss of appetite;
2. patients of lower social class reported lower levels of quality of life;
3. deprivation and marital status were found to be significant predictors of the patients global quality of life;
4. treatment regimens were ineffective, regardless of cell type and disease stage, when comparing baseline and follow-up assessments of quality of life in patients with lung cancer;
5. patients preferred to be interviewed at home rather than filling in questionnaires in the clinic and
6. patients' perceptions of quality of life were found to differ from those of health professionals.[143]

Eve et al in a survey (1997) found that more than 96 percent of adult patients who received care from hospices or specialist palliative care services in 1994 and 1995 had cancer.[144] Only 0.6 percent of the patients were those with central nervous system diseases and a similar percent were patients with HIV/AIDS. The only other sub-group mentioned were those with cardiovascular diseases who constituted 0.3 percent of the patient population accessing palliative care services. This survey of hospice and specialist palliative care services in the UK in the year 1994-1995 highlighted the lack of usage by non-cancer and ethnic minority groups of patients (Table 1).[144] Another finding of this survey was that more than 95 percent of specialist palliative care was used by cancer patients and only just over one percent of specialist palliative care services was used by patients with a central nervous system condition.

Table 1 Specialist palliative care and hospice usage by non-cancer and ethnic groups

	CANCER	CNS	HIV/AIDS	CVS	OTHER	WHITE/ETHNIC
NEW INPATIENTS	96.7 %	1.3 %	0.5 %	0.4 %	1.2 %	98.4 / 1.6 %
NEW HOME CARE	96.3 %	0.6 %	0.6 %	0.3 %	2.2 %	96.9 / 3.1 %
NEW DAY CARE	96.3 %	2.2 %	0.2 %	0.3 %	0.9 %	97.9 / 2.1 %

The Department of Health District Health Authority research programme on needs assessment for palliative and terminal care (1997) stated that *palliative care encompasses patients who suffer from different diseases, with different rates of progression. Patients who need palliative care are not a homogenous group, although they are similar in having active, progressive disease where the emphasis needs to be on quality of life for the patient and the family.*[18]

Gore (2000) carried out an evaluation of care of chronic obstructive pulmonary disease (COPD) patients and compared the palliative care and quality of life in COPD and lung cancer[145]. The conclusion was that COPD patients had significantly impaired quality of life and emotional well being which may not be as well met as those of patients with lung cancer, nor did they receive holistic care appropriate to their needs.[145] A similar comparison by Edmonds (2001) between the palliative care needs of chronic lung diseases and lung cancer found that the chronic lung disease patients had physical and psychological needs at least as severe as those with lung cancer.[146]

4.6. Needs assessment in palliative care

The various aspects of need assessment and palliative care have been discussed individually and this section will look at the literature available on *Needs assessment in palliative care setting.* In 1986 a needs assessment of services for terminal patients in Glasgow and use of services by GPs, was carried out by interviewing 64 GPs (10 percent of the GGNHSB total).[147] The study concluded that many GPs were unaware of the existence of important services and that a majority thought the home help and night-nursing services were inadequate. A health needs assessment for cancer carried out by GGNHSB (1992) identified areas where health gain was possible and offered suggestions on how to achieve it.[148] An earlier report published by Scottish Needs Assessment Programme (SNAP) (1994) on cancer care in Glasgow reported that lung, colorectal and breast cancers use the bulk of both the services and the budget available in the GGNHSB area.[149] All these reports only evaluated the needs of cancer patients.

Robbins' (1995) study of palliative care services in all the district health authorities in England concluded *over half of the authorities had not carried out a needs assessment or service review for palliative care in the past five years. Of those that had undertaken needs assessment, about one-quarter were planning more review work, and most of the reports expressed the need for more information on many aspects of palliative care.*[150] There was no mention of whether it was intended to include non-cancer diseases. Dudgeon et al (1995) argued that according to WHO's recommendation, palliative care services should be available based on need and not on life expectancy, even though Dudgeon et al were only carrying out a needs assessment of cancer patients with recurrent disease.[3] If they had included the non-cancer diseases requiring palliative care services in their argument, then they would have been following the WHO's definition of palliative care and not the old definition of palliative care which they and many follow today, that palliative care is only for cancer patients.

Meredith et al (1996) assessed the information needs of cancer patients in the west of Scotland[151] and concluded that almost all patients wanted to know their diagnosis, but many doctors still did not tell patients that they have cancer in the belief that patients do not want to know. This study looked at information needs of cancer patients only.

Clark et al (1997) elicited factual information concerning needs assessment and contracting in all hospices and specialist palliative care in-patient units in the UK[27] and concluded that *palliative care needs assessment has considerable potential to influence future purchasing and service provision, yet not all health commissioners are undertaking it.* There is no mention in this study of whether the palliative care was for cancer alone or included non-cancer patients.

Barclay et al's (1999) evaluation of the GPs and district nurses views on the importance and adequacy of palliative care services in Cambridge[152] had three questions. The first and third questions were on adequacy of current services (mainly on specialist services) and the importance of these in future services. Unfortunately the report did not indicate if the respondent had experience of the services on which they were commenting. The second question was about bed availability in the local hospice only and no evaluation was conducted on bed availability in the local hospitals. As no patients were involved in this study, only the professionals' views on the currently available services and planning for future services in palliative care was elicited.

The SNAP report (1999) on cancer services in Scotland reported that cancer incidence in Scotland is dominated by lung and the next most common for men was colo-rectal and that for women was breast and colo-rectal.[153] There was a section on palliative care where they recommended that the three levels of palliative care[48] needed to be clearly defined and that palliative care could be considered as the fourth modality of cancer care.[153] Another recommendation was that palliative care should be available at all stages of a patient's life and be integrated with community cancer services, which should have access to a specialist palliative care team. The other recommendations were that standards of palliative care should be in the cancer services plan with the inclusion of both primary and palliative care representatives on Regional Cancer Services Groups to facilitate improvement in communication. All these were written only for cancer patients with no mention of palliative care for patients with non-cancer diseases.[153]

Ingleton (2001) highlights four key issues which have to be considered when attempting any health needs assessment for palliative care.[154] Collaboration in the form of involving all stakeholders, especially the service users. To accept the iterative process where a degree of open-endedness is allowed to refine questions and instead of *aggregate* needs assessment, it might be better to refine to focus on the needs of individual groups or specific geographical areas[154]. To have pluralistic methods and not just the traditional epidemiological or demographic methods of public health and to involve users and to improvise especially where resources are limited. Finally to build in the dissemination process from the planning stages.[154]

Krishnasamy et al (2001) looked at the health care needs of lung cancer patients and found that only 40 percent of the patients reported having received as much help as they needed from the community.[155] And in both the hospital and community settings the patients reported that they found the doctors more helpful than the nurses. Only one percent of the patients were reported to have identified the social services as being helpful.[155]

Needs assessment has been shown to have considerable potential to influence future purchasing and service provision[27] and a search of the literature has produced no needs assessment comparing the needs of cancer and neurodegenerative patients requiring palliative care. All the available literature is only on cancer diseases or only assesses the palliative care needs from the service providers' perspective.

4.7. Obstacles to recognition of evidence in palliative care

The other reason for the medical profession's reluctance to accept palliative care for non-cancer diseases may be the absence of randomised control trials (RCT) studies in most studies on palliative care, even for those studies on cancer patients. Articles have appeared in journals about the lack of evidence in studies on palliative care and other articles have defended the lack of RCTs in studies involving palliative care patients because of the ethical issues in carrying out RCTs for patients in their terminal stages. RCTs are the gold standard in therapeutic research and palliative care research has problems in this area as shown by the following articles.

Davis (1994) concluded that it is difficult to perform blinded, randomised trials in patients with advanced disease and poor performance status, yet it is these patients who may gain most from the adoption of new well evaluated treatment strategies.[2] To fulfil this role they require rigorous evaluation in properly conducted clinical trials especially in recent therapeutic advances in palliative care which are exciting and controversial.[2]

McWhinney et al (1994) wrote about their attempt to evaluate a palliative care home support team based in an inpatient unit in an article titled *Evaluation of a palliative care service: problems and pitfalls.* They identified the following issues: i) attrition due to early death, ii) opposition to randomisation by patients and referral sources, iii) ethical problems raised by randomisation of dying patients, iv) the appropriate timing of comparison points and v) difficulties of collecting data from sick or exhausted patients and care givers. Their conclusion was that randomised trials may prove to be impracticable for evaluation of palliative care.[156] McQuay in response to McWhinney (1994) wrote the article "*Need for rigorous assessment of palliative care*" arguing that *If you say that it is effective then prove it*[157] and he quoted from a previous article by Archie Cochrane (1972) that *there will be a marked reduction in the use of ineffective remedies and of the effective remedies used inefficiently.*[157]

Corner (1996) published findings in an article titled *Is there a research paradigm for palliative care* and says that rigorous research designs which for example require randomisation may not be ethically justifiable; and sample attrition may be high because patients inevitably decline and may well die during the research study period.[34] Corner concludes that any emergent paradigm for research in palliative care has to take these problems into account.[34]

Keeley (1999) in an editorial on *Rigorous assessment of palliative care revisited* wrote that *Wisdom and compassion are needed when evidence is lacking* and concluded that *commissioners of care will have to fall back on wisdom, compassion and a broad and inclusive conception of the role of health care services in reducing human suffering.*[158] Salisbury (1999) in a letter responded to Keeley by saying that well conducted observational studies, qualitative research and a careful description of the process of care and the context may provide more useful information for evaluating local services compared to small scale, under-funded and under-powered RCT.[159] On a national level it would be possible to conduct a large scale RCT of palliative home care teams in several sites with patients randomised by practice or by district.[160]

Articles questioning the need for specialist palliative medicine further complicate these obstacles. Fordham et al (1998) in the article *Palliative medicine: is it really specialist territory?* starts by saying that they examine factors that have contributed to the evolution of palliative medicine as a speciality, and conclude that its future is in doubt.[161] They argue that a decision to offer palliative care can be feared as a sign of imminent death – something akin to the last rites – heralding the withdrawal of all future active treatments and that this could be perceived as rejection and contribute to the alienation of patients and their families.[161] They conclude that rather than informing and contributing new methods to general practice, specialist palliative medicine has taken the methods and philosophy of general practice and adapted these to a specialist, disease-specific model. But they also argue that palliative medicine cannot continue to limit its scope to cancer. This would lead to expansion of the number of potential patients to include most of the population and the current model could not sustain this. They finally say that the clinician that emerged would be indistinguishable from a general practitioner with access where necessary to inpatient beds – a model that from an early stage was shown to be effective in raising standards in terminal care.[161]

Palliative Medicine has all of the following criteria's similar to other medical specialities and should be recognised as a speciality by all in the medical profession.

- Has an identified training programme for future consultants
- Practices from an evidence base
- Receives referrals from fellow consultants
- Has a representative professional association
- Has a standard reference text book and speciality specific journals.

The editorial, in the journal publishing Fordham's article, was titled *Who needs palliative care?* and written by Higginson (1998) who highlights the difficulties the general practitioner would have in providing 24 hour care where patients and families need an assurance of continuity.[162] The editorial says that when we ask whether a speciality is needed, the views of patients and families should be heard and quotes findings from various studies where it has been shown that specialist palliative care achieves better outcomes for patients with progressive illness than do existing conventional services.[162]

Higginson's editorial (1999) on *Evidence based palliative care* concluded that clear difficulties remain in the rigorous gathering of evidence about many aspects of palliative care but these difficulties should not be allowed to stand in the way of applying palliative care where its efficacy, patient and family satisfaction and cost effectiveness have been shown.[81] Goodwin et al (2001) produced a report from their workshop on research and recognised the methodological difficulties palliative care poses for RCT due to recruitment problems, attrition and the vulnerability of this patient group. They suggested more prospective studies with comparison groups.[163] This thesis compares needs of cancer and non-cancer patients by assessing their health status and the outcome of their care.

The main obstacle to palliative care research is obtaining ethics approval and this was highlighted in Jubb's (2002) article appropriately titled *Palliative care research Trading ethics for an evidence base.*[164] It highlights the point that most medical professionals consider death as a *negative clinical outcome* whereas the palliative care specialist considers death as a *natural process*. Jubb also highlights the difference in the percentage of cancer patients (70%) and non-cancer patients (few) who receive specialist palliative care. He stresses the need for research and audit to prove that resources should be allocated on the basis of need and this would justify the ever-increasing share of the NHS budget and charitable provision if the share was allocated justly for all those who need palliative care.[164] The other solutions are to be able to negotiate with the ethics committees to allow for verbal consent from relatives and to combine qualitative and quantitative research to enrich the findings and better inform the practice of palliative care (this was achieved by our current study). The biggest obstacle to funding and ethics is a shoddily conducted research due to flawed methodology. To overcome this he suggests using researchers experienced in conducting research on vulnerable groups who are familiar with the ethical and practical challenges posed by dying patients.[164]

Experienced professionals should very closely supervise all new researchers until they acquire the required skills. *Provided palliative care investigators compassionately apply ethical principles to their research, there is no justification for not endeavouring to improve the standards of palliation.*[164]

5. Conclusion

All the difficulties of recognition of palliative care research, the inclusion/acceptance of non-cancer diseases into the palliative care way and the home care approach were very well summarised by the founder of the modern hospice/palliative care movement[16] when Cicely Saunders identified "*where did we go wrong*":

> *"although we looked to a research and educational base, we were too slow in establishing full academic rigour (and still have some way to go). Indeed, learning and discovery must surely be endless"* [16]
>
> *"The focus on the diagnosis of cancer sometimes hinders the acceptance of challenges in other areas of need, HIV/AIDS being a case in point. But how do we balance need, skills and resources".* [16]
>
> *"The concentration in a building, at least in the UK, tended to outweigh the emphasis on home care. Palliative care is a philosophy based not on physical facilities but on attitudes and skills, as the many interpretations around the industrialised and developing world show forcefully".* [16]

The current review of palliative care, the needs and services for cancer and non-cancer patients has highlighted a gap in the knowledge and evidence comparing these two groups of patients. The next chapter (3) defines the aim and objectives of the current study and chapter four outlines and gives the background and also validates the selection of the cancer and non-cancer diseases to be compared in the current study.

Chapter 3

Aims and Objectives

This current study will compare the palliative care issues of cancer and non-cancer patients in the GGNHSB area by determining the service providers and service users views. It will also compare these with the available palliative care services and should assist GGNHSB in planning the provision of future palliative care services in the GGNHSB area. The following were the rationale for carrying out this current PhD study:

- most studies of palliative care have only included cancer conditions,
- studies of non-cancer diseases were few,
- there are a few studies comparing cancer and non-cancer diseases within the same body systems e.g. respiratory (lung cancer and COPD),
- routinely collected data suggest that patients with neurodegenerative diseases are the largest users of palliative care services after cancer diseases,
- needs assessment studies do not compare the palliative care needs of cancer and non-cancer patients,
- studies on specialist palliative care services far outnumber those on palliative care services in the community,
- very few studies have evaluated palliative care in the community especially comparing cancer and non-cancer diseases,

This current study will be the first to:

- undertake a comprehensive comparative quantification of the health status and measurement of the outcome of care for patients with cancer and for patients with non-cancer diseases,
- conduct a postal questionnaire survey of health care professionals in the GGNHSB area to ascertain their views on palliative care,
- compile a directory of current palliative care services available in GGNHSB area for cancer and non-cancer diseases.

1. Research Aim

To identify the palliative care needs and palliative care services of community based patients with cancer and non-cancer diseases in GGNHSB area with a view to appraise the similarities and differences between the needs and the services available for these two groups of patients.

2. Research Objectives

The research objectives will be outlined in three parts. The information obtained from the three parts will be analysed to a) identify available services, b) ascertain the views of health professionals and c) assess the health status and outcome of patients requiring palliative care.

2.1. Available services in the statutory and voluntary sector

2.1.1. Objective 1:

Identify and document the palliative care services available in GGNHSB area on two occasions 2 years apart.

2.2. Views of health care professionals

2.2.1. Objective 2:

Conduct a postal questionnaire survey of GPs and district nurses practising in GGNHSB area to identify their views and priorities for palliative care. Topics to be covered are:

- ascertain their views on current and future palliative care services for cancer and non-cancer diseases,
- evaluate their views on:
- hospice and hospital bed availability,
- time of referral to a palliative care specialist,
- their perception of where patients would prefer to die.

2.3. Views of service users (patients)

2.3.1. Objective 3:

Undertake a health status assessment and measure the outcome of care for:

- cancer patients,
- non-cancer patients,

Determine the patients' knowledge of available palliative care services in GGNHSB area.

3. Null Hypothesis

The following null hypotheses were derived from the aims and objectives of the current study and are as follows:

3.1. Statutory and voluntary sector

Null Hypothesis 1:

There will be no difference in the provision of palliative care services available in 1997 and 1999.

3.2. Health care professionals

Null Hypothesis 2:

There is no difference between the views of GPs and district nurses concerning:

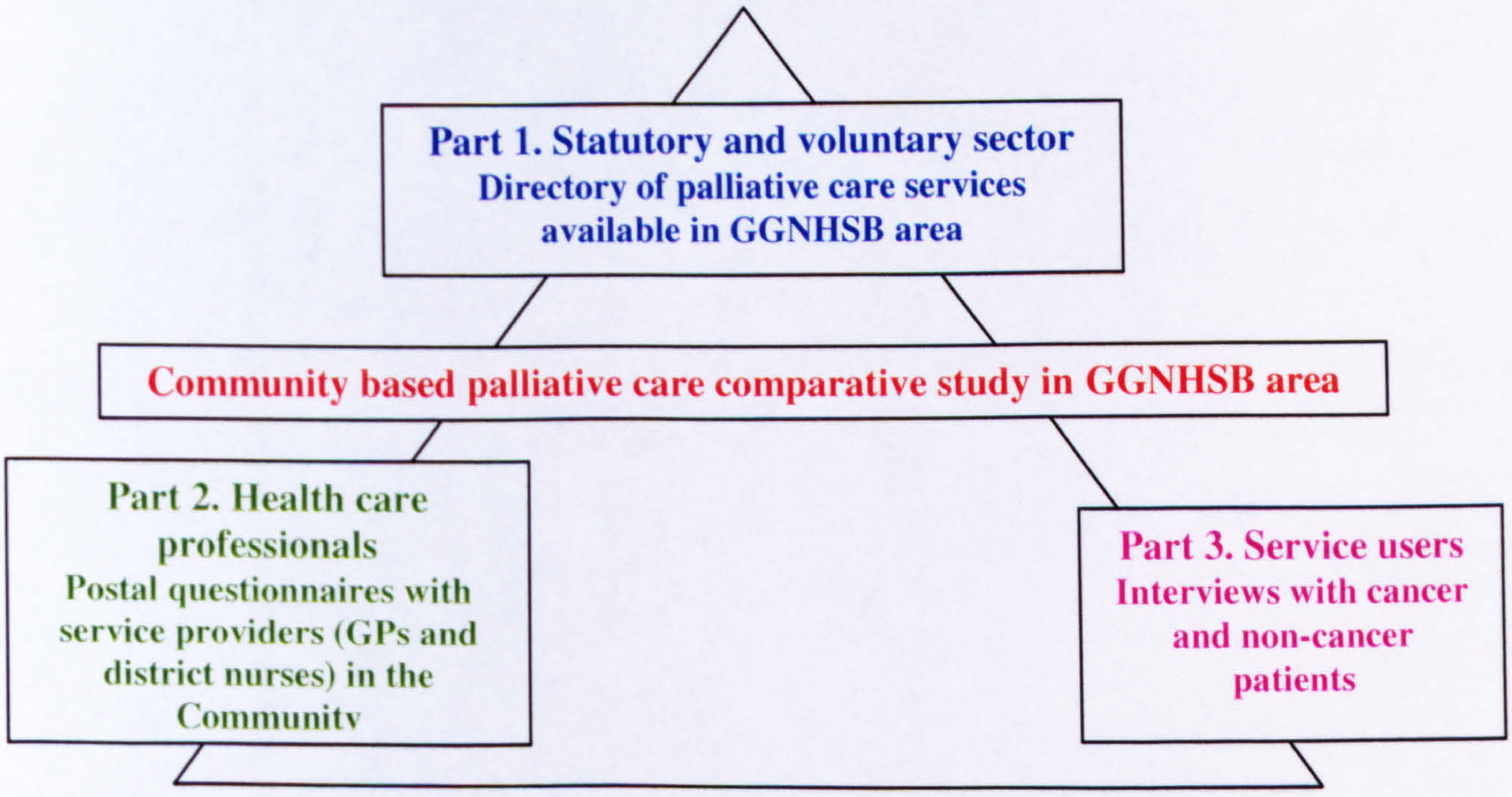
- current palliative care services for cancer patients,
- current palliative care services for non-cancer patients,
- future palliative care services for cancer patients,
- future palliative care services for non-cancer patients,
- hospice bed availability for palliative care patients,
- hospital bed availability for palliative care patients,
- place of death for their terminally ill patients,
- obstacles preventing their terminally ill patients from dying in the place of their choice,
- when first to refer their patients with incurable disease to the specialist palliative care team.

3.3. Service users

Null Hypothesis 3:

- There are no differences between the perceived health problems of patients with cancer and non-cancer diseases,
- There are no differences between the outcome of the care of patients with cancer and non-cancer diseases,
- The patients needing palliative care are aware of the palliative care services available in GGNHSB area.

Figure 5 An outline of the methods used for the needs assessment component of the comparative study



Chapter 4

Synopsis and background of current study

In this chapter there is a brief outline of i) the methods used to compile data, ii) ethics and data protection issues, iii) results and iv) the common methods used in analysing the data for this current study. This is followed by an overview of the characteristics of the population and 10 year cancer data for the GGNHSB area. The final part of this chapter includes a brief summary of the three cancer and three non-cancer (neurodegenerative) diseases that were selected for this current study.

1. Introduction to the study

Health needs assessment is the systematic approach to ensuring that the health service uses its resources to improve the health of the population or specific groups in the most efficient way[165]. It involves epidemiological, qualitative, and comparative methods to describe health problems of the population or specific groups and identify inequalities in health and access to services.[125;166;167] In order to provide a fuller picture for the assessment of the needs of a vulnerable group of patients, a number of different approaches and methods have been incorporated.[168] This current study brings together all these points in designing the methodology that comprises an initial period of preparation and then the current main study. The two sources of information for the current study were the palliative care service providers and palliative care service users of palliative care services in the GGNHSB area.

1.1. Methods used in the preparatory stage

The initial stage was to review the literature. Subsequently, after consultation with the Health Board, hospices, hospitals and voluntary organisations providing palliative care, available data sources in the GGNHSB area were identified. The first questionnaires for palliative care service providers in the statutory and voluntary sector were sent out (see Chapter 5). The community based palliative care service providers (GPs and district nurses) were identified. Pilot studies were conducted for the questionnaire for service providers (see Chapter 6). Finally palliative care service users (cancer and non-cancer disease patients) were identified and ethics approval was obtained from Stobhill NHS Trust to circulate the questionnaire to the service users (see Chapter 7). The final part of the preparation was to refine the research aims and objectives and to identify the methods for the current main study (Figure 6).

1.2. Methods used for the main study

The current main study was designed and influenced by the information collected from the preparatory stage (Figure 7). Review of the literature was a continuous process throughout the current study and until 2003. After two years a second questionnaire was sent to the palliative care service providers identified in the preparatory stage (see Chapter 5). The health care professionals (GPs and district nurses) in the GGNHSB area were sent the finalised questionnaire by post and the data collected was analysed (see Chapter 6). The palliative care service users were interviewed in their own homes and the data collected was analysed (see Chapter 7)

Figure 6 Outline of methods used in the preparatory stages.

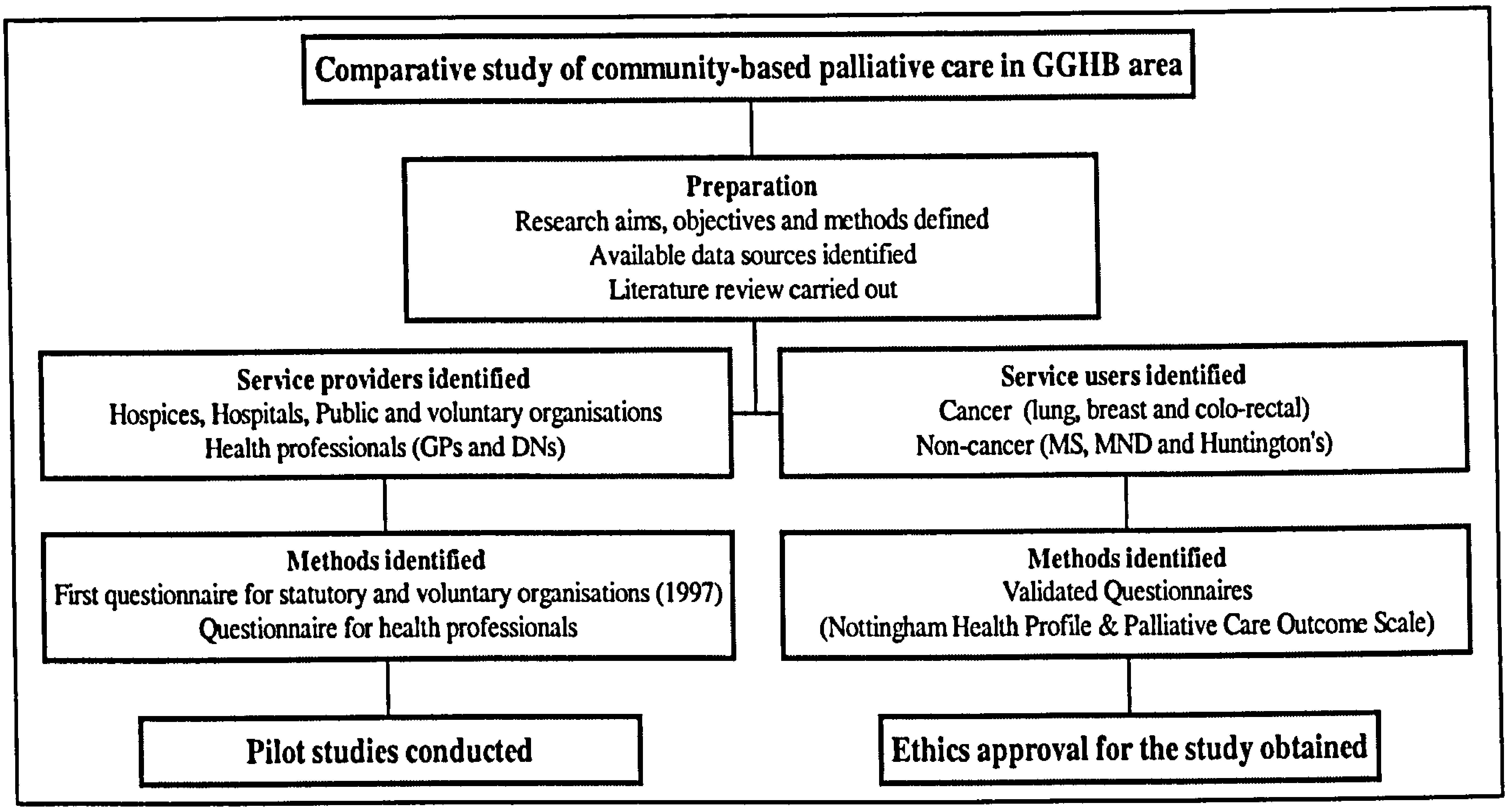
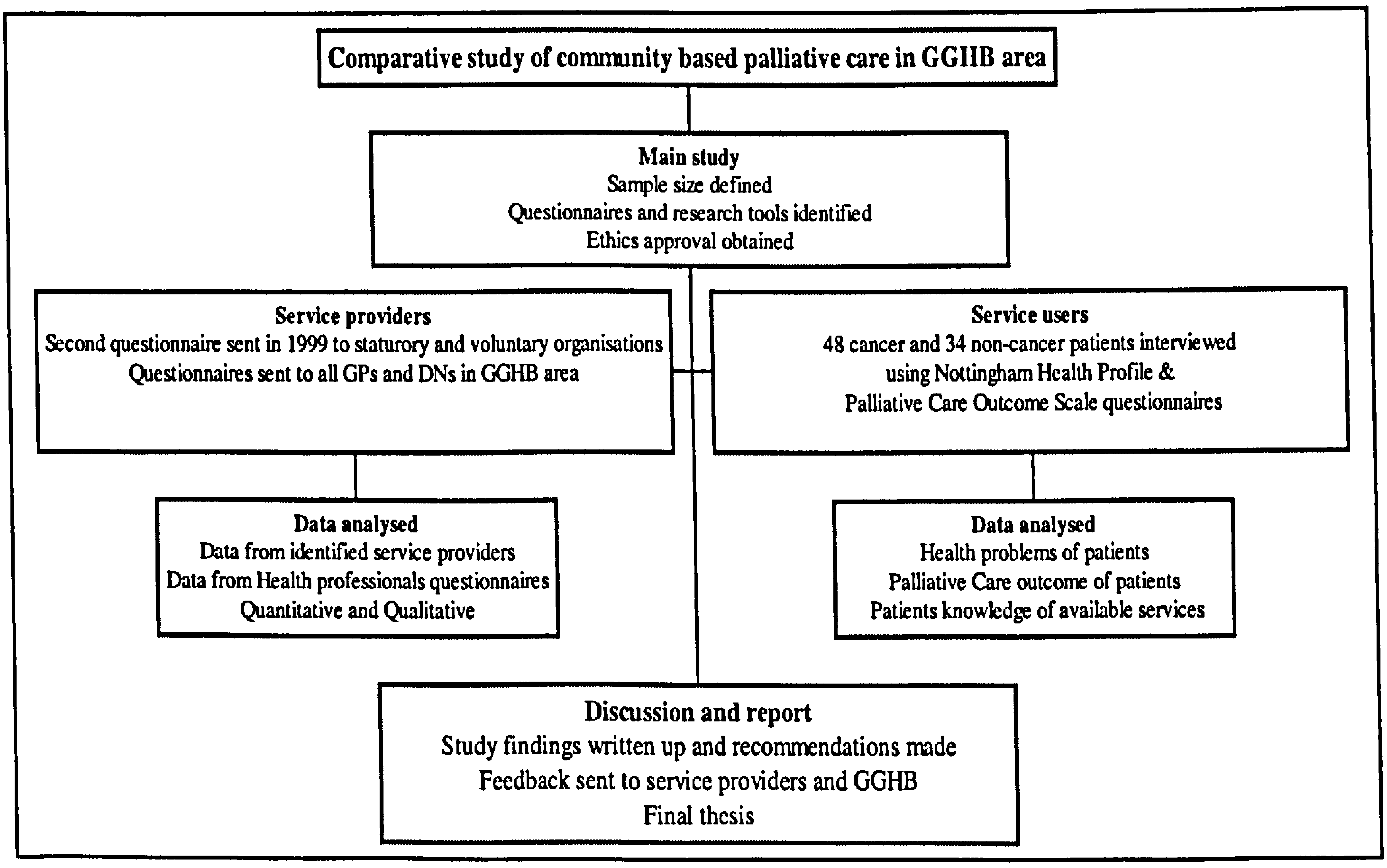


Figure 7 Outline of methods used in the main stages of the current study.



1.2.1.Ethics approval and data protection

Ethics approval was obtained from the relevant authorities. Stobhill hospital and its catchment area was the main source for identifying patients for the current study. Hence ethics approval was initially obtained from the Stobhill NHS Trust in September 1997 (Appendix 2). Approval was obtained to conduct semi-structured pilot interviews with patients (and their carers) receiving care from Stobhill hospital. This was a community-based study and GPs are the gatekeepers for their patients. A subsequent ethics request (Appendix 2a) was submitted in May 1998 to the Greater Glasgow Community/Primary Care Local Research Ethics Committee who are responsible for community-based research. Further details were submitted on request and a personal presentation of the project was carried out in June 1998. Ethics approval was granted in June 1998 (Appendix 2b). In January 1999 a letter was submitted (Appendix 2c) to the ethics committee stating that the questionnaires to be used in the patient interviews had been changed and seeking the ethics committee's approval. The committee wanted to be sure that the patients could refuse to be taped during the in-depth interviews. This assurance was already written into the patient information sheet and their carers and the committee was satisfied. They approved the revised current study in February 1999 (Appendix 2d).

At all times during this current study the participants, both health care professionals and the patients were fully informed of the process and consent was obtained wherever necessary. Confidentiality and anonymity of the participants was respected and adhered to at all times.

1.3. Results and discussion

The main summarised results are presented in the form of descriptions, figures and tables while more detailed results are found in the appendices. The results from this current PhD study are reported, analysed and discussed in three chapters. Chapter 5 is a report of the information collected from the voluntary and statutory sector palliative care service providers. Chapter 6 reports on the views of the main health care professionals (GPs and district nurses) about current and future palliative care services for their patients. In this chapter both quantitative and qualitative data are presented and discussed. Chapter 7 examines the information collected from the questionnaires with cancer and non-cancer (neurodegenerative diseases) patients. This section mainly contains quantitative data except for views of care quoted by the patients where the data is qualitative.

1.4. Analysis of data

All the data collected from the questionnaires were initially analysed for frequencies and where applicable simple cross-tabulations were carried out. Multiple significance testing was performed in this current study and the high probability of finding a significant difference just by chance was taken into account. Several methods have been proposed to deal with this problem and the Bonferroni (*new alpha = old alpha/n* where old alpha = 0.05 and n = number of comparisons reported) method was used.[169] This is a rough measure that compensates for multiple testing by indicating a newer, more restrictive alpha (p value) level. Only results that were significant after this correction was applied are presented in the current study.

1.4.1. Multiple logistic regression

Multiple logistic regression was used to assess the relationship between two or more continuous or categorical explanatory variables and a single categorical response variable.[170] Data collected from the health care professionals and the service users in this current study contained demographic data of the respondents and the patients. In both the parts there were two groups: GPs and district nurses for health care professionals and cancer and non-cancer for service users. During the initial analysis of the data using cross-tabulation and chi square tests there were significant differences between these two groups in both parts of this current study. Multiple logistic regression was used to adjust for the effect of a number of covariates and explore whether significant differences remained between the GPs and district nurses or between cancer and non-cancer patients after adjustment. Multiple logistic regression was also used to identify other covariates that were significant to the various responses from the GPs and the district nurses or cancer and non-cancer patients.

2. Population data for GGNHSB area

The 1991 census showed that GGNHSB had a total population of 894,301 (Table 2) with 65 percent of the population in the 15-64 age group, 16 percent above 65 years and 19 percent below 15 years. There was a slightly larger female population from the 15+ age groups.

At the time of this current study primary health care services in GGNHSB were divided into three health sectors - the north-east, south and the west sectors. The south sector (39 percent) had the largest population, followed by the north-east (36 percent) and the west (25 percent) (Table 3).

More than a quarter (29 percent) of the GGNHSB population lives in the most deprived areas with 17 percent in the north-east sector, nine percent in the south and only three percent in the west. The population is evenly distributed with regards to Carstairs deprivation categories[171] two, three, five and six. Only nine percent of the total population is categorised as the most affluent and five percent of these are in the south sector, three percent in the west and only 1 percent resides in the north-east. (Table 4 and Map 1)

Table 2 Population of GGNHSB from 1991 census by age and sex

	0-14 YR.	15-64 YR.	65 + YR.	ALL AGES
MALE	85,594	281,075	53,719	420,388(47%)
FEMALE	81,917	302,265	89,731	473,913(53%)
TOTAL	167,511 (19%)	583,340 (65%)	143,450(16%)	894,301

Table 3 Population of GGNHSB by health sector

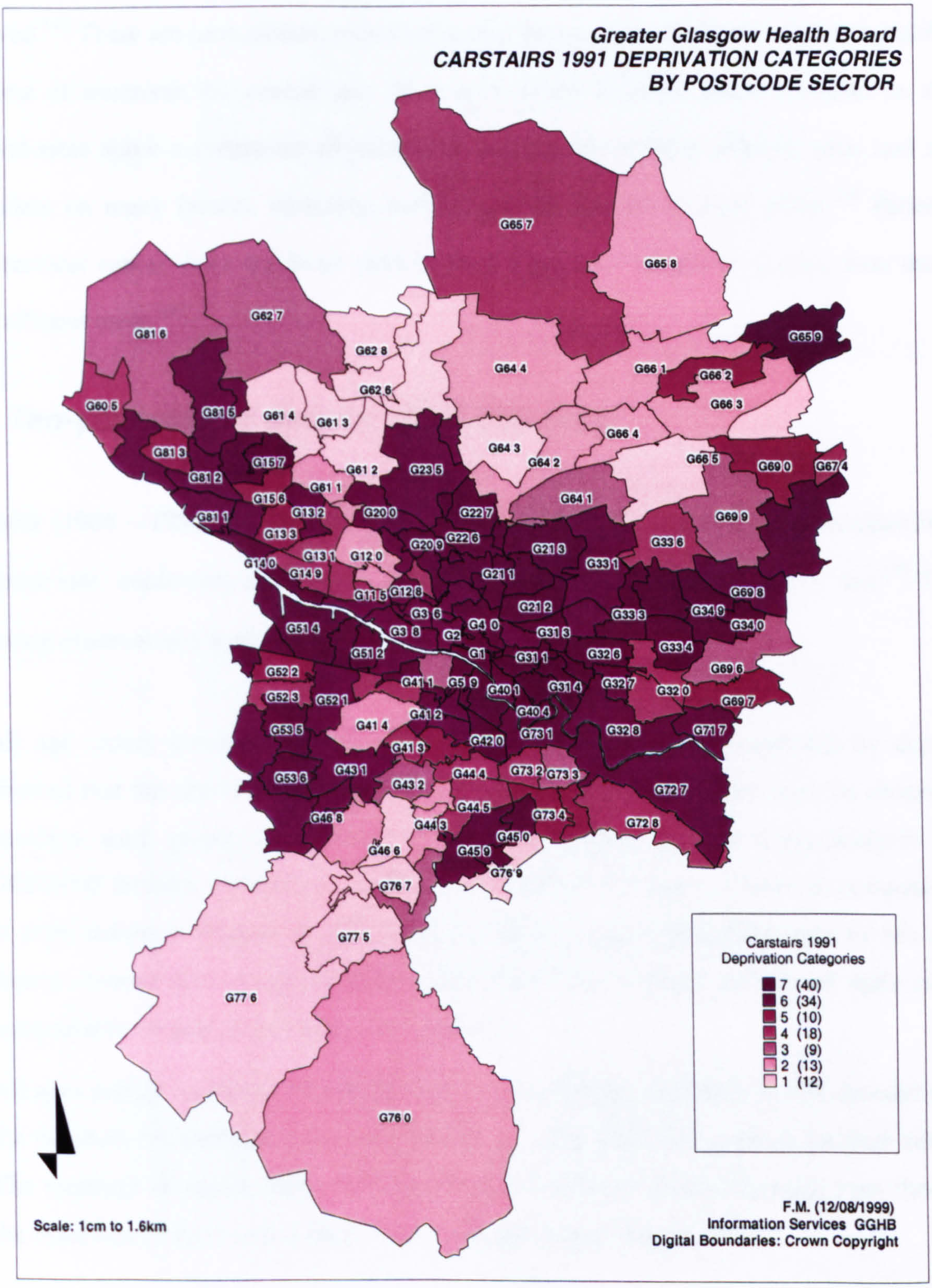
	TOTAL POPULATION	PERCENTAGE
SOUTH	349,127	39
NORTHEAST	328,543	36
WEST	216,631	25
TOTAL	894,301	100

Table 4 The population in GGNHSB health sectors by Carstairs depcat scores.

CARSTAIRS	NORTHEAST	WEST	SOUTH	TOTAL IN PERCENT
1	10836 (1)	27961 (3)	46894 (5)	9
2	30967 (3)	23304 (3)	16762 (2)	8
3	28898 (3)	14209 (2)	25117 (3)	8
4	18738 (2)	40241 (4)	65973 (7)	13
5	25026 (3)	23551 (3)	34433 (4)	10
6	60658 (7)	64130 (7)	77391 (9)	23
7	153420 (17)	23235 (3)	82557 (9)	29
TOTAL	**328543 (36)**	**216631 (25)**	**349127 (39)**	**100**

All the numbers within brackets () are percentages (%)

Map 1 GGNHSB area showing Carstairs 1991 deprivation categories by postcode sector.



3. All cancer data for GGNHSB area

Glasgow possesses the largest number of areas in the UK recognised as being socially deprived.[149] There are inequalities, related to social deprivation, in the incidence of and the outcome of treatment for cancer and other non-cancer diseases. Data available on the survival rates show a consistent advantage for patients from more affluent areas and are dependent on many factors, including early diagnosis and the therapy given.[149] Patients with cervical cancer from deprived areas present with more advanced disease than those from affluent areas.[172]

3.1. Ten-year cancer data for GGNHSB area

Ten year (1986 – 1995) cancer data for GGNHSB area were analysed using standardised incidence rate, crude rate, age standardised rate, depcat score adjusted and by sex.[173] The following observations were made:

- All age cancer incidence in GGNHSB males (observed versus expected) by depcat showed that the observed numbers were lower in depcat one to three, and the observed numbers were greater in depcat four to seven (Figure 8). The same analysis for GGNHSB females showed an overall greater number in observed cases in comparison to expected cases (Figure 9). All cancer incidence - age standardised rates by sex and depcat showed that, except for depcat one, there were a larger number of male cases compared to female cases by depcat (Figure 10).
- All ages cancer incidence (observed versus expected) in GGNHSB by sex showed that the numbers of observed cases were greater than the expected numbers for both sexes. The numbers of female cases were greater (2142) in the observed group even though the male cases (522) were higher in the expected group (Figure 11).

Figure 8 All age cancer incidences in GGNHSB Males (Observed versus Expected) by depcat 1986-95.

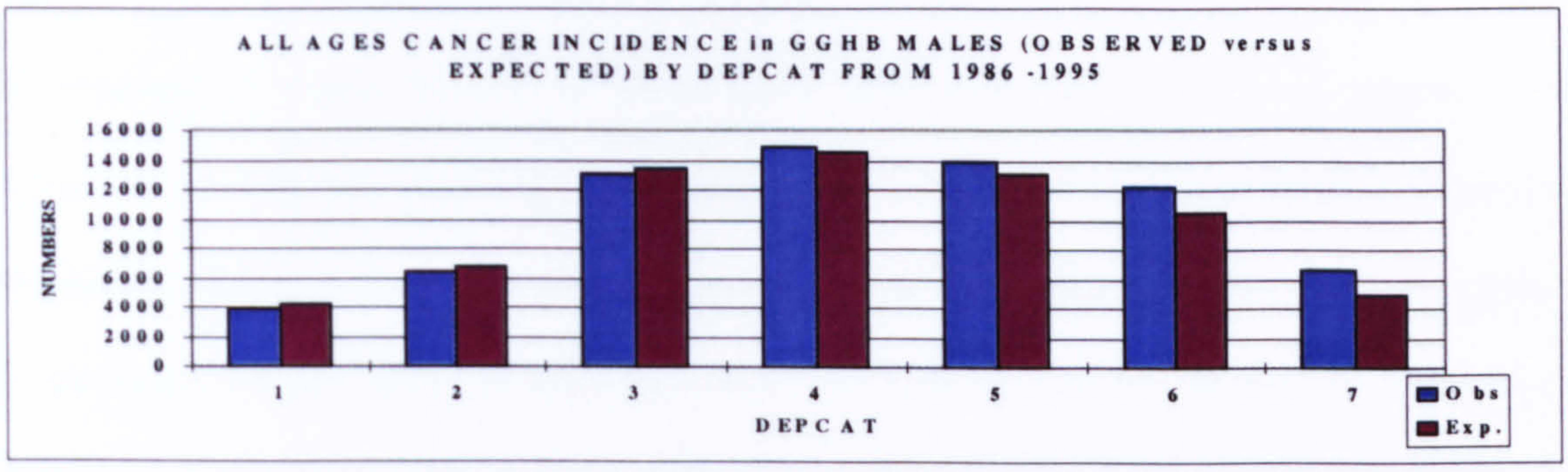


Figure 9 All age cancer incidences in GGNHSB Females (Observed versus Expected) by depcat 1986-95

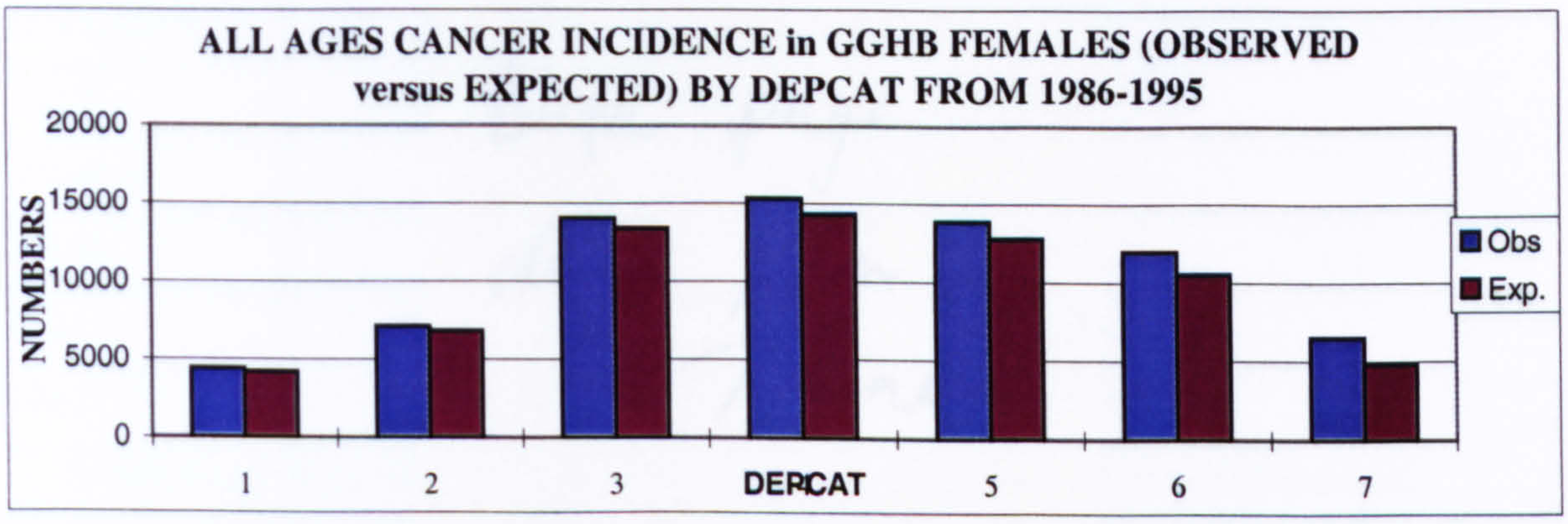
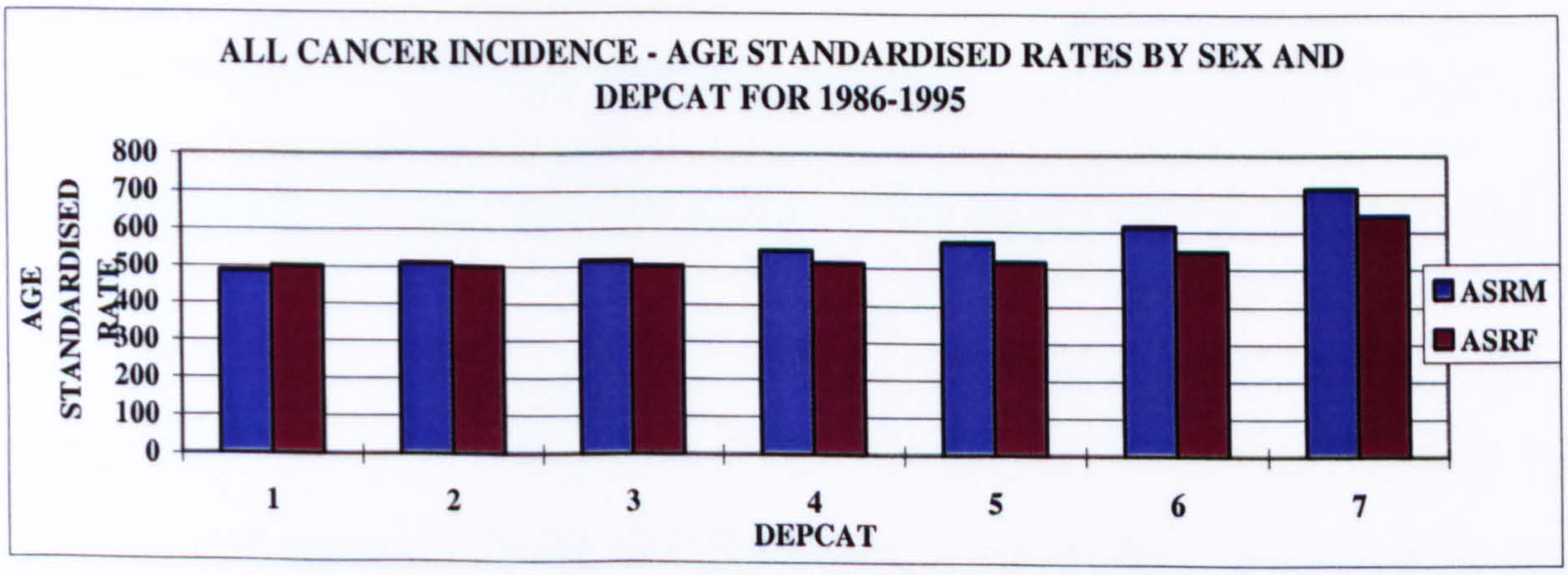


Figure 10 All cancer incidences – age standardised rates by sex and depcat 1986-95.



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3.2. Projection of cancer incidence in Glasgow

The number of cases treated in GGNHSB area will increase by six percent despite a decline in the resident population in the area.[149] This is due to a projected increase of the population (elderly) most at risk from cancer (Table 6). This increase will be even greater (25 percent) for the West of Scotland and this will be mainly among those aged over 65 years.

Table 6 Cancer incidence in GGNHSB and the remainder of the West of Scotland residents projected to year 2001

IN GGNHSB RESIDENTS PROJECTED TO YEAR 2001				
NEW CASES	1986	1991	2001	% AGE INCREASE*
MALE	2666	2694	2818	+5
FEMALE	2652	2766	2983	+8
TOTAL	5318	5460	5801	+6
(<65)	2022	1960	2084	+6
(65+)	3296	3500	3717	+6
IN THE REMAINDER OF THE WEST OF SCOTLAND RESIDENTS PROJECTED TO YEAR 2001				
MALE	3890	4496	5689	+27
FEMALE	3902	4515	5607	+24
TOTAL	7792	9011	11296	+25
(<65)	3088	3348	4051	+21
(65+)	4704	5663	7245	+28

*increase in number of cases from 1991 to 2001 expressed as a percentage of 1991 total

As lung, breast and colo-rectal cancers were the commonest cancers and used the bulk of services and resources in the GGNHSB area it was decided to select these three cancer diseases for comparison of palliative care in this current study.

4. Summary of cancer diseases included in this study

4.1. Incidence and prevalence of cancer in the GGNHSB area

Incidence and prevalence rates for lung, colo-rectal and breast cancers in GGNHSB from 1975 to 1996 were calculated by the West of Scotland Cancer Surveillance unit. They calculated age-standardised rates (ASR) for incidence based on the 1991 Scotland census. The prevalence was calculated from the number alive on 31st December 1996 and the rates were calculated using the population data from the GGNHSB for 1996. All the rates mentioned were per 100,000 population. These are discussed further under the individual cancers.

4.2. Lung cancer

4.2.1. Incidence and prevalence

In Glasgow the incidence of lung cancer for males is decreasing while it has doubled for females over the period 1975 to 1996 (Table 7). An article by Gillis et al titled *The incidences of lung cancer and breast cancer in women in Glasgow* was published in the BMJ (1992) and their finding was that lung cancer had overtaken breast cancer to become the highest incident cancer in women.[174] The more recent findings of the incidence rates of these two diseases in Glasgow women is found in Table 7 and 9. This shows that the incidence of breast cancer has overtaken lung cancer. A recent study by the UK Cancer Research Campaign shows that the incidence of breast cancer has overtaken lung cancer in women in the UK and the West of Scotland was one of the areas highlighted by this latest study released in November 2001. The low prevalence rate is due to the adverse prognosis of lung cancer, which has a four percent five year survival in GGNHSB and five percent for Scotland.

Table 7 ASR incidence rates and prevalence rates for lung cancer.

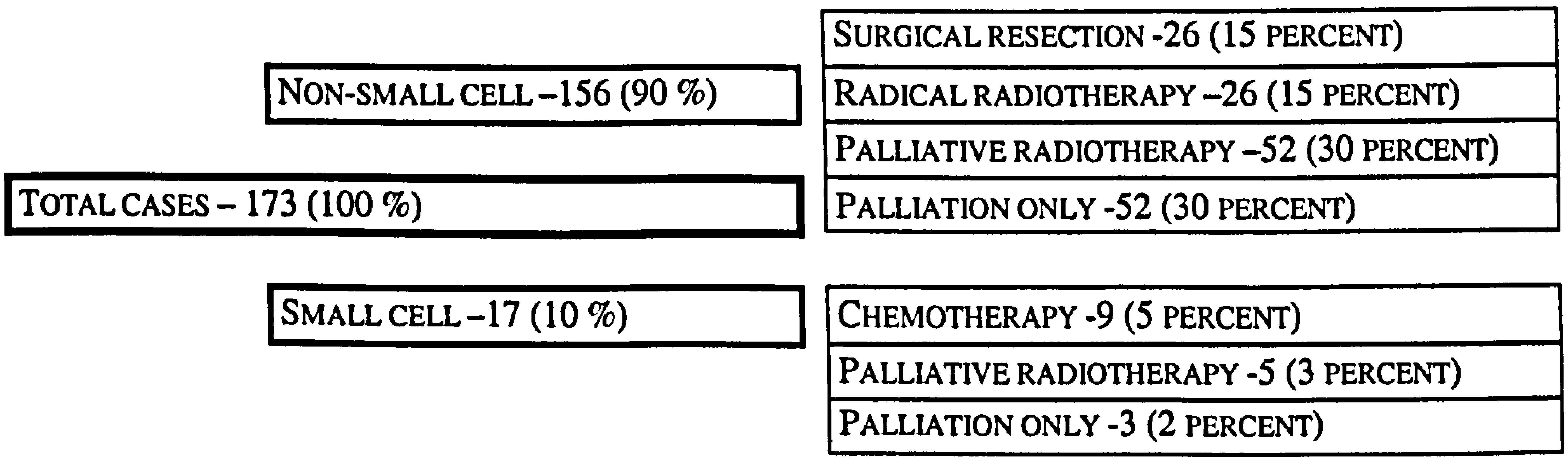
		Year	Male	Female
Lung	Incidence (ASR)	1975	184.8	45.6
		1996	139.3	94.5
	Prevalence	**1996**	**190**	**120**

For lung cancer it is projected that in males, due to reduced cigarette smoking, by 2010 lung cancer will be less common than prostate cancer. In females, the upward trend in incidence is predicted to continue but will level off and begin to decline by 2010-14. Due to poor prognosis it will remain the most common cause of cancer death.[5]

4.2.2. Management

The local symptoms are of chest pain, breathlessness, hoarseness, coughing, and haemoptysis. Metastatic symptoms are bone pain, headache, hepatic pain, fever, weight loss and malaise. Diagnosis is mainly by chest X-ray, bronchoscopy and biopsy. The majority of patients will require palliative care, as 95 percent will die from their cancer. Treatment varies and a summary is shown in Figure 12.

Figure 12 Different ways of treating lung cancer.



From Cancer of the Lung[175]

4.3. Colorectal cancer

4.3.1. Incidence and prevalence

The incidence of colorectal cancer is higher in Scotland than in England and Wales and within Scotland there are significant differences in distribution. Incidence rates in the late 1970's showed a higher than national average in males from Grampian, GGNHSB and the Highlands and in females in the Borders, Grampian, Highland and Tayside.[176] It also showed lower rates for males from Argyll and Clyde, Forth Valley and Lanarkshire and in females in Lanarkshire and the Western Isles. These variations were maintained in the Cancer Registration Statistics published in 1998.[177] Outcome and survival have been shown to be influenced by deprivation.[4;178]

The incidence rates in the UK at present are 120 cases per 250,000 population per year and this is expected to rise by eleven percent by 2006. The survival at five years is 37.5 percent. It has a variable progression and prognosis depending on time and stage of detection of the disease.

The incidence of colorectal cancer is increasing for both sexes but at a higher rate for males (Table 8). That the prevalence rates are higher than those for lung cancer is because the five-year survival is 26 percent in GGNHSB and 30 percent in Scotland.

Table 8 ASR incidence rates and prevalence rates for colo-rectal cancer.

		Year	Male	Female
Colo-Rectal	Incidence (ASR)	1975	50.5	58.6
		1996	71.4	62.5
	Prevalence	**1996**	**330**	**340**

The risk of colorectal cancer is predicted to increase in males over the next decade, with a small increase in females; the gap between the sexes is predicted to increase. Mortality is predicted to decrease due to continuing improvements in survival in large part secondary to earlier diagnosis.[5]

4.3.2. Management

Of the patients for whom cure is not achieved, 50-65 percent will need palliative care during the final stages, especially for pain.[179] These patients may require palliative surgery (relieve obstruction [resection bypass] or colostomy), palliative chemotherapy (use of 5 Fluoro-Uracil), palliative radiotherapy (relief of symptoms for local recurrence) and palliative care (hospice, hospital or home care). It is recommended that more information on the appropriate criteria for referral and better knowledge of availability of services is made available through information and education. Continuing education for GPs, hospital doctors and nurses to provide quality care either in the community or in the hospital is important. Mountney et al (1994) also recommended that there is a co-ordinated policy on community palliative care (hospital, hospice and home).[179] There is a lack of research on the cost, benefit and value of these resources and the preferences of the patient.

4.4. Breast cancer

4.4.1. Incidence and prevalence

Even though the incidence of breast cancer is increasing the higher prevalence is due to breast cancer having the best prognosis of the three cancers included in this current study (Table 9). The five-year survival in GGNHSB is 53 percent and it is 56 percent for Scotland. Breast cancer is now (2001) the most common cancer in women in the UK. In Scotland there were 3,148 new cases and 1,244 deaths in 1995 and survival after diagnosis of one, three and five years were 90 percent, 75 percent and 65 percent respectively.[180]

Table 9 ASR incidence rates and prevalence rates for breast cancer.

		Year	Male	Female
Breast	Incidence (ASR)	1975		97.3
		1996		117.1
	Prevalence	**1996**		**1,000**

Breast cancer will remain the most common cancer in females and will continue to increase in incidence rapidly, widening the gap between this and other most common cancers in females, lung and colo-rectal cancers. Due to its good prognosis, the survival rates will continue to increase and breast cancer deaths will remain fairly constant and it will be the second most common cause of cancer deaths in Scottish women.[5]

4.4.2. Management

Treatment generally involves lumpectomy or mastectomy, depending on the lesion (including the axillary lymph nodes), followed by radiotherapy and chemotherapy and/or hormonal therapy.[181] Lymphoedema is one of the complications of surgery, radiotherapy and the cancer itself. A study in the West of Scotland showed that care by units with a specialist interest in breast cancer compared to non-specialist care showed a ten percent survival advantage at five years and eight percent survival at ten years and this rose to 17 percent when age, social class and nodal status were taken into account.[182]

Review of the literature in chapter two showed that CNS diseases were the commonest non-cancer condition that was receiving palliative care in hospices. HIV & AIDS started in the 1980s and presented a major concern to the overtly Christian ethos of many hospices. This was off-putting to many people with the illness as many of them were from the gay community at that time.*[20] *This led to the formation of AIDS specific hospices and there is one in Edinburgh. As such it was decided to select the neurodegenerative diseases for comparison of palliative care in this current study. The three neurodegenerative diseases selected for the current study are multiple sclerosis, motor neurone disease and Huntington's disease.

5. Summary of non-cancer diseases included in this study

5.1. Multiple sclerosis

5.1.1. Incidence and Prevalence

There are few incidence or prevalence rates published for multiple sclerosis and even these vary from area to area. A recent study in the Lothian and Borders regions gave a crude incidence rate of 12.2 in the Lothian region and 10.1 in the Borders region and a prevalence rate of 203 in the Lothian and 219 in the Borders regions.[183] They also reported that cases were more likely to have a Scottish surname (risk ratio of 1.24). Orkney and Shetland have the highest prevalence world-wide (309 and 184/100,000 respectively) [184] but the study in the Lothian and Borders regions showed that the prevalence in south east Scotland was equally high,[183] suggesting a Scottish genetic susceptibility. A study showed that the prevalence in the northern UK appeared to be 180 / 100,000 whereas the maximum in the southern part was less than 160 / 100,000.[185] Other studies in Rochdale[186] and Leeds[187] have shown that Scotland has the highest incidence in the UK.

It has been suggested that in multiple sclerosis the number of possible cases exceed the true number by a factor of five. Table 10 gives an estimate of the prevalence of multiple sclerosis in Scotland and is based on the assumption that the prevalence rate is 203/100,000 and the male to female ratio is 1:2 though this ratio does vary amongst surveys. Males are more likely to suffer the progressive form and females are more likely to develop the disease at younger age. Usually the age of onset is between 16 and 60 years.

5.1.2. Management

Multiple sclerosis is an inflammatory demyelinating condition of the central nervous system (brain and spinal cord). The name *multiple sclerosis* signifies both the number (multiple) and condition (sclerosis, from the Greek term meaning scarring or hardening) of the demyelinated areas. Symptoms of multiple sclerosis include muscle weakness, spasticity, impairment of sensations (pain, temperature and touch), pain (moderate to severe), ataxia, tremor, speech and vision disturbances, vertigo, bladder/bowel and sexual dysfunction, depression, euphoria, cognitive abnormalities and fatigue. There are various subtypes of multiple sclerosis but for this current study they were not taken into account in the selection of the patient sample.

Table 10 Prevalence of multiple sclerosis in Scotland by Health Board.

PREVALENCE OF MULTIPLE SCLEROSIS IN SCOTLAND			
HEALTH BOARD	ALL	MALES	FEMALE
ARGYLL AND CLYDE	867	276	591
AYRSHIRE AND ARRAN	762	240	522
BORDERS	216	68	148
DUMFRIES AND GALLOWAY	299	96	203
FIFE	708	226	482
FORTH VALLEY	560	179	381
GRAMPIAN	1066	350	716
GGNHSB	**1850**	**589**	**1286**
HIGHLAND	423	137	286
LANARKSHIRE	1138	364	774
LOTHIAN	1571	503	1068
ORKNEY	40	13	27
SHETLAND	47	16	31
TAYSIDE	791	251	540
WESTERN ISLES	57	19	38
SCOTLAND	**10,394**	**3,327**	**7,092**

5.2. Motor neurone disease

5.2.1. Incidence and Prevalence

The incidence and prevalence data for motor neurone disease in Scotland has been collected for the last 10-years in the Department of Neurology of Ninewells Hospital and Medical School in Dundee. They have maintained a Scottish Motor Neurone Disease register and their data shows the following:

Incidence rate for Scotland is 2.40/100,000 (males 2.74/100,000 and females 2.1/100,000)

Survival of the 600 registered cases	48 percent die within one year of diagnosis
	45 percent survive between one to five years
	7 percent survive over five years.

Of the 600 registered cases 327 (54.5 percent) were males and 273 (45.5 percent) were females.

Their records over the past ten years were analysed in two five-year groups for the GGNHSB area and the following were found:

- For the period 1989 to 1993 the total number of cases registered was 99 (56 females and 43 males and only three were recorded as alive in 2000).
- For the period 1994 to 1998 the total number of cases registered was 106 (53 females and 53 males and only 23 were recorded as alive in 2000).

5.2.2. Management

In motor neurone disease there is progressive degeneration of the motor neurones resulting in the loss of strength of the muscles supplied by them. Sensory nerves are not affected and usually the memory and intellect remains normal. It normally affects people over 40 years of age, most commonly between 50 and 80 years. There is no genetic link although in a small subgroup (five- percent) it seems to run in the family.

There are three forms of the disease:

- Amyotrophic Lateral Sclerosis is the commonest and main symptoms are progressive muscle weakness and stiffness and it affects walking and hand co-ordination.
- Progressive Muscular Atrophy is less common (eight percent of cases) and initially involves small muscles of one hand followed by weakness and wasting of other muscles.
- Progressive Bulbar Palsy involves muscles of speech, chewing and swallowing.

5.3. Huntington's disease

5.3.1. Incidence and Prevalence

Huntington's disease is a progressive, neurodegenerative, hereditary disorder and is autosomal dominant and affects both sexes equally. It was named after the physician who described it in Ohio (1872) USA although it was known for centuries before that. True incidence rates are difficult to establish and are estimated to be eight to ten times the number of reported cases.[188] Estimated prevalence in the UK ranges from 25-100 cases per million population. In Scotland a study in the Grampian region quoted a prevalence rate of 9.94/100,000 and is one of the highest described in the world literature (similar to multiple sclerosis studies in Orkney and Shetland).[189] The age of onset varies and symptoms appear between the ages of 30-50.[190] Other studies have shown that up to five percent occur before 20 or after 60 years and that symptoms could be present three to seven years prior to diagnosis.[191] Survival is from ten to fifteen years from diagnosis.

5.3.2. Management

There is a triad of symptoms which are emotional (depression, irritability and apathy), cognitive (loss of cognitive speed and flexibility) and motor disturbances (both voluntary and involuntary esp. choreiform). The genetic aspect involves the whole family and the needs become complex and this is a challenge for service providers.[192] Reviews in England [193] and Scotland [194] have investigated Huntington's disease together with brain injury and early onset dementia and have highlighted issues related to the patient, carers and the health care professionals. The Scottish report identified key issues and gaps in service.

6. Conclusion

This chapter summarised the general outline of the current study and the population characteristics in the GGNHSB area. The reasons for selecting the three cancer (lung, breast and colo-rectal) and the three non-cancer diseases (neurodegenerative diseases) were explained and main characteristics of these diseases were highlighted. In the previous chapter (chapter three) the aims and objectives of this study were defined into three areas (statutory and voluntary service providers, health care professionals and the service users). The next three chapters will illustrate how these objectives were accomplished and the results obtained from this exercise.

Chapter 5

Identification and documentation of palliative care services provided by statutory and voluntary sector in GGNHSB area

Objective = *to identify and document palliative care services available in GGNHSB area.*

Null hypothesis = *There is no difference in palliative care services available in 1997 and 1999*

Introduction

This part of the current study (Figure 5) involved a comprehensive postal survey of the identified palliative care services available in GGNHSB area. A questionnaire determining services offered by palliative care service providers in GGNHSB area (NHS hospitals; hospices; private nursing homes, voluntary and statutory organisations) was conducted initially in autumn of 1997 and was repeated in spring of 1999 to assess if there had been any changes. The data collected were used to compile a list of palliative care service providers and also to record the changes that had occurred to the service provision during this period. The list of service providers obtained was also used to assess patients' knowledge of and usage of these services.

1. Methods used in the preparatory stage

In autumn of 1997 a total of 67 providers of palliative care services in GGNHSB area were identified after referring to various existing palliative care directories, talking to key personnel in the field of palliative care in Scotland, to key voluntary sector organisations and the hospices. These 67 providers consisted of the seven NHS hospitals and the three hospices (see Map 2), three private nursing homes and various voluntary and statutory organisations including those for ethnic minority groups. A letter about the current study inviting participants and outlining the criteria for inclusion in the current study was sent to these service providers (Appendix 4). There was also a two-page questionnaire listing the various palliative care services and the personnel involved in these services (Appendix 4a).

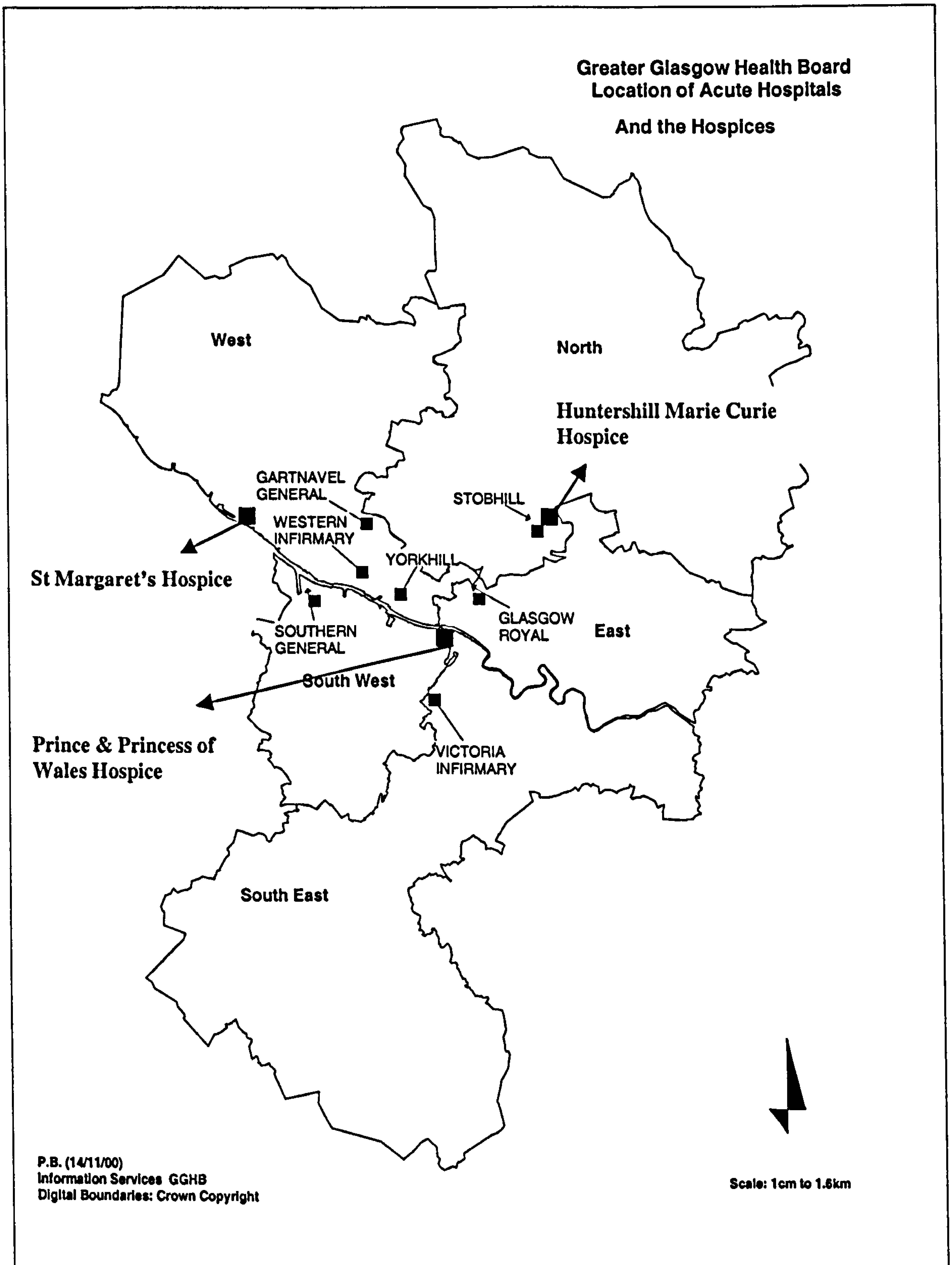
Respondents were asked to document the services that they provided and the personnel involved and also to comment on any other details relevant to the current study. At the end of October 1997 the non-respondents were contacted by phone and after discussion with them it was decided to remove those who were not providing palliative care services. Reminders were sent to service providers who had not responded and in December 1997 the remaining non-respondents were contacted by phone and all of them responded. A list of palliative care service providers in GGNHSB area for 1997 was compiled (see Appendix 5).

2. Methods used for the main study

The same process used in the first survey was repeated to enable new and discontinued services to be identified. After two years, in June 1999, the respondents to the first questionnaire were sent a second letter (Appendix 6) so as to update the details. They were sent the initial questionnaire that they had completed so as to help them complete the second questionnaire. (There were no new service providers identified during the two-year period). The second questionnaire (Appendix 6a) was further modified into two categories, one for hospitals and hospices and another for voluntary organisations. This was to simplify the questionnaire as these two groups were providing different services and the personnel involved were different. A summary table was produced from the data collected in 1997 and 1999 (Appendix 7). All the hospitals nursing managers/directors were contacted by phone before sending out the questionnaires.

The data collected from the questionnaires of the service providers was entered into Excel spreadsheets. There was data in 1997 and 1999 and these were entered next to one another for each of the providers. The activity data of the three hospices in the GGNHSB area (Appendix 8) was collected over a two-year period and the results presented include percentages of averages over this period.

Map 2 GGNHSB area showing location of acute hospitals and hospices.



2.1. Strengths of method used

- All the voluntary sector service providers were very helpful and were prompt in their replies.
- The hospice data was also collected over two financial years and allowed the identification of changes in the services provided by the three hospices in the GGNHSB area. The hospices were helpful over the two-year period.
- Over years 1998 to 2000 GGNHSB had been working with the Scottish Information Services Department, Trinity House in Edinburgh to write a computer programme that would enable the data collected by the three hospices to be collated into one database. (Latest communication in February 2002 with the group suggests that the common data set was used for one six month period and then the planning stopped[195])
- There were two hospitals where they had posts for Macmillan palliative care nurse co-ordinators and they were very helpful in the data collection.
- Overall this was a very useful learning process in communication skills and reiterated that patience and persistence are vital virtues of researchers.

2.2. Research realities of methods used

- The hospices were helpful but the difficulty was that each hospice had a different computer software package for recording their activities. Each of the hospice software was programmed to collect data specific for their individual needs. The data collected were for different hospice activities.
- For this current study data from the three hospices has been manually recorded and then compared for their activity over a two-year period.
- It is not obligatory for the statutory service providers to respond to the questionnaires and to be helpful.
- The difficulties were with the various hospitals where persuasion and pleading sometimes yielded results. This may be because there were no designated palliative care services in four of the six hospitals in the GGNHSB area. (Of the seven non-respondents to the second questionnaire, there were three hospitals, one nursing home and 1 voluntary organisation. Two of the voluntary organisations closed down).
- The hospital staff had a very busy schedule and questionnaires are an extra burden.

Part one was over a two-year period and the information recorded was over and above the research objectives and hypothesis for this thesis. For the purpose of better understanding of the background of palliative care services in the GGNHSB area all the information is presented and discussed in this section. A more detailed assessment, comparisons and analysis was not possible from the data except to fulfil the aims and objectives of this thesis. In the voluntary sector there were organisations specifically providing services for the various diseases and there were general service providers, who provided various aspects of palliative care. (Table 12 and Appendix 2 have full list, with contact details, of service providers identified for the GGNHSB area and Appendix 7 has details of palliative care services provided).

3. Results

3.1. Questionnaires to service providers

Questionnaires (Appendices 2, 2a, 7 and 7a) were used to gather this information. Results of responses to the first questionnaire sent to 80 service providers in 1997 showed an initial number of 67 palliative care service providers identified but eight of them were later identified as not providing any form of palliative care services and the final number of providers identified was 60. The initial response before reminders were sent was 35 (58 percent). After the first reminder all but one of the identified palliative care service providers responded. The response to the second questionnaire in 1999 was better than the first as there were only seven non-respondents and no reminders were sent. The one respondent who did not reply in 1997 completed the questionnaire in 1999. The seven non-respondents were contacted by phone. Five of the respondents to the first questionnaire declined to complete the second questionnaire. Two voluntary organisations that were identified in 1997 had closed down by the time the review of services was conducted in 1999. Table 12 gives a summary of the various palliative care service providers identified in the GGNHSB area (Appendix 7 for full details), their staff and their role. Appendix 2 is a directory of the 60 service providers and only contains the organisations' name and the contact details.

3.2. Response to questionnaires

The numbers of new/increase in services/personnel posts in palliative care, provided by the voluntary and statutory/private sector in the GGNHSB area, that were identified during the two-year period from 1997 to 1999 was ninety-four (94).

A breakdown of the increases is as follows (changes in services and personnel posts are within brackets):

Increases

- 3 **Hospices**: There were five new services (hospice at home, help-line, directory of available services x 2 hospices and support group).
- 3 **Hospices**: There were two new personnel posts (occupational therapist and chiropodist) and 5 increases in personnel posts (matron, sister, registered nurse, and auxiliary nurse x 2 hospices).
- **Marie Curie services**: There were two new services (training in palliative care and networking with other providers).
- **Macmillan services**: There were two new services (funding and networking with other providers).
- **Macmillan services**: There were two new personnel posts (Breast cancer nurse specialist and Paediatric Clinical Nurse Specialist) and 1 increases in personnel post (Macmillan lecturers in palliative medicine).
- **Hospitals**: There were twenty-three new services as follows:
- 11 in the two hospitals with palliative care co-ordinators (in-patient care, rehabilitation, pain clinic, cancer care x 2 hospitals, MND care, other terminal illness, use volunteers, hospice at home, HIV & AIDS Care and funding).
- Eight in the regional children's hospital (symptom control, rehabilitation, home care nursing, respite, bereavement service, pain clinic, directory of available services and network with other providers).

- **Hospitals**: There were six new personnel posts:
- Five in the two hospitals with palliative care co-ordinators (sister, paediatric CNS, radiographer, volunteer co-ordinator and volunteers).
- One clinical psychologist.
- **Nursing homes**: There were two new services (rehabilitation and networking with other providers) and one new personnel post (enrolled nurse).
- **Voluntary services for cancer**: There were seven new services (information leaflets, bereavement counselling, cancer care, training in palliative care, support group, bereavement services and training in counselling).
- **Voluntary services for cancer**: There were six new personnel posts (volunteer co-ordinator x 2 organisations, administrator x 3 organisations and Marie Curie nurse).
- **Voluntary services for neurodegenerative diseases**: There were four new services (help-line, support group, occupational therapy and other terminal illness).
- **Voluntary services for neurodegenerative diseases**: There were four new personnel posts (enrolled nurse, auxiliary nurse, volunteers and occupational therapist).
- **Voluntary services for HIV & AIDS**: There were four new services (help-line x 2 organisations, directory of available services and support group) and one new personnel post (counsellors).
- **Other voluntary services:** There were eleven new services (day care, networking with other providers, help-line, information leaflets x 2 organisations, directory of available services, support group, services for children and youth x 2 organisations, respite and counselling for parents).
- **Other voluntary services:** There were six new personnel posts (counsellors, social worker, administrator x 2 organisations, chaplain and volunteers).

The number of services/personnel post discontinued/decreased in palliative care, provided by the voluntary and statutory/private sector in the GGNHSB area, that were identified during the two-year period from 1997 to 1999 was ninety-nine (99). A breakdown of the discontinued/decreased services shows the following:

Decreases

- **Hospices**: Four services were discontinued (counselling for parents, counselling for carers, services for children and youth and training in counselling).
- **Hospices**: Five personnel posts were decreased (consultant in palliative medicine, registered nurse, enrolled nurse x 2 hospices and lymphoedema nurse specialist) and two personnel posts were discontinued (alternative medicine therapist and counsellors).
- **Macmillan services**: Two personnel posts were discontinued (speech therapist and paediatric oncology CNS) and one personnel post was decreased (palliative care CNS).
- **Hospitals**: Three services were discontinued in the children's hospital (support group, funding and other services) and three services were discontinued in another hospital (number of beds, counselling for carers and help-line).
- **Hospitals**: Eleven personnel posts were discontinued in the regional children's hospital (oncology CNS, cancer genetic nurse specialist, palliative care CNS, paediatric oncology CNS, occupational therapist, speech therapist, oncology dietician, social worker, chaplain, administrator and pharmacist). Only one personnel post was discontinued from the two hospitals with palliative care co-ordinators (cancer genetic nurse specialist).
- **Nursing homes**: One service was discontinued (terminal care) and two personnel posts were decreased (registered and auxiliary nurses) and one personnel post was discontinued (sister).
- **Voluntary services for cancer**: Three services were discontinued (directory of available services, terminal care and palliative care) and one personnel post was discontinued (volunteer co-ordinator).
- **Voluntary services for neurodegenerative diseases**: Twelve services were discontinued (bereavement service, MND care, terminal care x 2 organisations, palliative care x 2 organisations, alternative therapy, chaplaincy service, home care nursing, respite, training in counselling and directory of available services).
- **Voluntary services for neurodegenerative diseases**: Four personnel posts were discontinued (Marie Curie nurse, clinical nurse specialist, social worker and volunteer co-ordinator).

- **Voluntary services for HIV & AIDS**: Three services were discontinued (respite, occupational therapy and day care) and two personnel posts were discontinued (occupational therapist and volunteer co-ordinator).
- **Other voluntary services**: Twenty services were discontinued (volunteers x 4 organisations, networking with other providers x 2 organisations, information leaflets x 3 organisations, bereavement service, support group x 2 organisations, services for children and youth x 2 organisations, training in counselling, help-line, palliative care, directory of available services and other services x 2 organisations).
- **Other voluntary services**: Six personnel posts were discontinued (volunteer co-ordinator, volunteers, chiropodist, counsellors x 2 organisations and administrator).

A detailed list of the various service providers and the services that they provided in 1997 and in 1999 are available in Appendix 7. (In Appendix 7 the first column for each service provider represents data collected from the 1997 questionnaire and the second column for each service provider represents data collected in the 1999 questionnaire.)

The voluntary organisations were questioned about their present workload and staffing. Only 43 percent were able to respond to all the requests but 90 percent were willing to accept more requests. Only 37 percent agreed that they had sufficient staff but 95 percent wanted more staff. (Table 11). The obstacle identified by more than 80 percent was insufficient resources, both, human and financial.

Table 11 Response by service providers (n=27) to questions on staff requirement and work capacity.

Question asked	YES	NO	Total	Missing
Are you able to respond to the entire request?	9	12	21	6
Will you be able to accept more requests?	18	2	20	7
Do you have sufficient staff now?	7	12	19	8
Would you like to have more staff?	17	1	18	9

3.3. Response from hospices in the GGNHSB area

There are three hospices in the GGNHSB area, one in each of the three health sectors. They provide a specialist palliative care service for the GGNHSB area and much more detailed information was collected from them. The hospices initially collected activity data from April 1996 to March 1997. This was repeated for the period April 1998 to March 1999 (see Appendix 8 for the type of information collected). The data collected included in-patient, outpatient, day-care, home-care, services provided and personnel available. The computer packages used by the three hospices for recording data were different and not compatible with each other. King et al in 1993 from Edinburgh conducted a survey of the availability of palliative care in Scotland.[196] Their survey titled *Purchasing palliative care: Availability and Cost Implications* sent questionnaires to twelve of Scotland's fifteen voluntary hospices with in-patient beds. One of their conclusions was that statistical information on their activity was not routinely available and was not always comparable across units. GGNHSB is working with the Information Services Department in Edinburgh to develop a software package that will be able to analyse the different data entry systems.

3.3.1. Activity of the hospices

Annual activity data (in-patient, day-care, outpatient and home care) for the three hospices was recorded over two separate time periods. The full details are in Appendix 8 and the following are a few of the findings. Over the two-year period only one hospice reduced the number of available beds. The number of patients admitted increased by five in one hospice and reduced by four in another hospice while the third hospice had an increase of 49 patients. The percentage of new patients admitted varied and was 75 percent, 93 percent and 82 percent of the total admissions in the three hospices. The percentage of patients admitted from home was 72 percent, 65 percent and 80 percent of the total admissions for the three hospices. The remainder were admitted from hospital and very few (1 to 6) from nursing/residential homes. The percentage of deaths occurring in the three hospices was 60 percent, 78 percent and 52 percent of the total admissions.

Day-care, out patient and home care data was not provided by the three hospices and as such comparisons are not possible except in a few instances as follows. The number of new day care patients varied and increased in two of the hospices over the two-year period but decreased in one hospice. The percentage of available places in day care accepted by patients varied and was 55 percent, 45 percent and 65 percent for the three hospices. The percentage of death of patients in home care varied and was 51 percent, 40 percent and 75 percent of the number of new home care patients for the three hospices. Only one of the hospices admitted a significant number of patients from the other two health sectors.

4. Discussion

There were both discouraging and encouraging experiences encountered during this process.

4.1. Changes in palliative care services - 1997-1999

There are three hospices, one regional oncology centre in a hospital and various voluntary services providing palliative care in the GGNHSB area. Over the two-year period of this current study there has been a reduction of 99 palliative care services/personnel posts and an increase of 94 palliative care services/personnel posts with closure of two voluntary organisations (Appendix 7). There were important findings when the increase and decrease in the various service provider sectors were analysed.

4.2. Service providers obstacles

> *"The 'quality' of the service is usually adequate but the 'quantity' is inadequate". – Quote by a GP taken from the responses to the questionnaire survey of GPs and district nurses in part II of this current study.*

Table 12 showed the palliative care services available in Glasgow between 1997-1999. Table 13 below shows the palliative care services that were found to be available by Higginson and McCarthy (1989) in their UK wide evaluation of palliative care.[197] There are many similarities but a striking finding is there are more non-cancer services available now than a decade ago. The awareness of these services and their usage will be demonstrated in Part II and III.

4.2.1. Hospitals

Two out of the six hospitals in the GGNHSB area had palliative care co-ordinators appointed by Macmillan Cancer Care and these two hospitals seemed to have increased palliative care services in the hospitals' activities. One of these hospitals working with one of the hospices produced a directory of palliative care services for the GGNHSB area. This emphasises the importance of having a person responsible for palliative care in each of the hospitals. The difficulty is in finding the resources. Macmillan Cancer Care funds the two co-ordinator positions in the two hospitals for a period of three years and thereafter the funding has to be continued by the Health Board.

Table 12 Summary of palliative care services provided in GGNHSB area (1997-1999)

Service	Type of staff	Role
Specialist palliative care units (3 Voluntary / NHS hospices)	Consultants in Palliative Medicine; Registered Nurses; Marie Curie Nurses; Macmillan nurses; Various Specialist Nurses for palliative care; AHP's; Pharmacists Social workers; Chaplain	Provide specialist palliative care
Hospital based specialist and services Hospital B Oncology centre)	specialist palliative care physicians Specialist nurses (Macmillan Nurses) Related specialist personnel (includes clinical psychologist, physiotherapist, social workers) specialist palliative care services and palliative care clinics	Responsible for palliative care as an integral part of treatment Responsible for elements of palliative care as an integral part of treatment Ranges from pain clinics to breast prosthesis services
Community based services by NHS health professionals / specialist nurses / social services	General Practitioners District Nurses Nursing Homes Home care nurses (includes Macmillan nurses, hospice home care nurses, and Marie Curie palliative care nurses) Stoma care nurses Social workers	Responsible for overall care Provide skilled nursing care and support to patients being cared for in their own home. Complement the services provided by district nurses (can be community based or located within a hospice or hospital) Provide community based care Complement health services, assist with social problems
Support groups and branches of national organisations	Cancer: Marie Curie Nurses; Macmillan Cancer Relief (nurses); Breast Cancer care; TAK TENT; BACUP Scotland; Hawthorn House; Sargent cancer care for children; Yorkhill support groups; Look Good Feel Better; Non-cancer: HIV/AIDS (Body Positive, PHASE West, ACET and carer support groups); Scottish Motor Neurone Disease Association; Scottish Multiple Sclerosis therapy centre; Scottish Huntington's Disease Association; Alzheimer Scotland Cancer and non-cancer: CRUSE; Counselling groups; Carer groups; Ethnic minority groups; Carer support groups; ENABLE; Pain Association Scotland; Health Council. Scottish Partnership Agency; National Council for Hospice and specialist palliative care Services in England and Wales.	Provide 24 hour home nursing, Provide care, support, respite, alternate therapy Provide counselling and bereavement support; Provide information and advocacy; Provide funding for research Networking with other organisations

Table 13 Palliative care services in 1989 in United Kingdom

Service	Type of staff	Role
Voluntary and NHS Specialist palliative care units	Multi-professional team Home care services (Rapid response teams, Hospice at home)	Provide total care
Hospital based specialist and services	Specialist physicians	Responsible for palliative care as an integral part of treatment
	Specialist nurses (include liaison nurses in palliative care, oncology, breast care)	Responsible for elements of palliative care as an integral part of treatment
	Related specialist personnel (includes clinical psychologist, physiotherapist, social workers)	Responsible for elements of palliative care as an integral part of treatment
	Specialist services and clinics	Ranges from pain clinics to breast prosthesis services
Community based specialist and services	General Practitioners	Responsible for overall care
	District Nurses	Provide skilled nursing care and support to patients being cared for in their own home.
	Home care nurses (includes Macmillan nurses, hospice home care nurses, and Marie Curie palliative care nurses)	Complement the services provided by district nurses (can be community based or located within a hospice or hospital unit)
	Stoma care nurses	Provide community based care
	Social workers	Complement health services, assist with social problems
Support groups and branches of national organisations	Cancer link; British Lung Foundation; Cancer care; British Association of Cancer; United Patients Cancer Relief; Macmillan Cancer Relief; Scottish Partnership Agency; National Council for Hospice and Specialist Palliative Care Services.	Provide Support, funding for research and information.

4.2.2. Voluntary sector palliative care services

The voluntary sector organisations were not able to cope with all the referrals but despite this were willing to redesign their services to accept more referrals. All the voluntary organisations were short of staff and would like to have more staff but did not have the resources to do so. The hospices were cutting back on their services and reorganising their structure due to lack of resources. There was a lack of specialist palliative care staff in both the statutory and voluntary sectors. Most of the services identified said that they were able to cope with the cancer patients' needs. Addington-Hall et al (1991) in a national survey found that cancer support services were developing in a fragmented and poorly co-ordinated way with no agreed strategy.[80] Information gathered by informal discussions with the various service providers, the responses from the GPs and district nurses questionnaire and the information from patient interviews all suggest similar trends in the present palliative care service provision in the GGNHSB area. Inter agency communication in all sectors of palliative care service provision was poor.

4.2.3. Voluntary sector palliative care services for neurodegenerative diseases

The main reason given by the neurodegenerative disease associations for the discontinuation of some of their services was insufficient human and financial resources. The three neurodegenerative diseases assessed in this current study had voluntary organisations bearing the name of their condition (Multiple Sclerosis Therapy Centre, Huntington Association and Scottish Motor Neurone Disease Association). These organisations were only providing respite care and help as required but there was no one in these organisations to co-ordinate the *palliative care needs* of these patients. None of these organisations envisaged their patients as requiring *palliative care.* The patient's concept that palliative care was terminal care was one of the reasons that made the patients with neurodegenerative diseases and the organisations supporting them not want to be labelled as palliative care providers. The other factor was that none of the hospices or the main stream specialist palliative care service providers were in a position to open up their services to many non-cancer patients due to finite resources.

5. Conclusion

This chapter dealt with the first objective of the current study and involved the statutory and voluntary palliative care service providers. The objective of this chapter was achieved by identifying and documenting the palliative care services available in GGNHHSB area. The results showed that there were increases and decreases in the various palliative care services in the GGNHSB area. This rejects the null hypothesis that there was no difference in palliative care services available from 1997 to 1999 in the GGNHSB area.

Chapter 6

The views and perceptions of health care professionals of palliative care services in the GGNHSB area

Objectives

To conduct a postal questionnaire survey of GPs and district nurses practising in GGNHSB area to identify their views and priorities for palliative care. Topics to be covered are:

- ascertain their views on current and future palliative care services for cancer and non-cancer diseases,
- evaluate their views on:
- hospice and hospital bed availability,
- time of referral to a palliative care specialist,
- their perception of where patients would prefer to die.

Null hypothesis

There is no difference between the views of GPs and district nurses, concerning:

- current and future palliative care services for cancer patients
- current and future palliative care services for non-cancer patients
- hospice bed availability for palliative care patients
- hospital bed availability for palliative care patients
- place of death for their terminally ill patients
- obstacles preventing their terminally ill patients from dying in the place of their choice
- when first to refer their patients with incurable disease to the specialist palliative care team.

This chapter investigates the second objective as stated above and involves the community based health care professionals namely the GPs and district nurses.

1. Methods used in the preparatory stage

1.1. Introduction

In this current study the term *health care professional* was used to solely represent GPs and district nurses who were working in the GGNHSB area. The two main health care professionals providing care in the community are the GPs and district nurses. There are many other health care professionals who are also providing palliative care in the community and are included in the category Allied Health Professionals (AHPs). In this current study only the GPs and the district nurses were included because they were providing generic palliative care in the community while the AHPs were providing health care in their own individual fields. Also the GPs, working together with the district nurses, are the gatekeepers for health care in the community where this current study was based. Dyer's study in Forth Valley identified GPs (59%) and district nurses (55%) as the main practice staff with a special interest in palliative care and only ten percent identified health visitors and four percent practice nurses. No other practice staff were identified by the GPs in Dyer's study.[139] This was the first time that an attempt was made to assess the view of GPs and district nurses in the GGNHSB area on issues relating to palliative care for both cancer and non-cancer diseases. The GPs and district nurses responded to a comprehensive questionnaire on various aspects of palliative care for both cancer and non-cancer patients.

The second part (Figure 5) involved determining the views and perceptions of the community health care professionals on current and future palliative care services for cancer and non-cancer patients in GGNHSB area. A questionnaire (collecting both quantitative and qualitative data) was prepared and tested in two pilot studies.

1.2. Health care professionals questionnaire

Palliative care studies conducted in Cambridge[152] and Forth Valley[139;140] (mentioned above) used questionnaires to elicit views of GPs and district nurses on available and future palliative care services. The authors of both studies were contacted and they gave permission to study their questionnaires. These questionnaires were assessed for use in this current study. Two studies were conducted in the Forth Valley area, one for GPs[139] and one for district nurses.[140] There were differences in these two questionnaires. The GPs responded to 20 detailed questions whereas the district nurses responded to only 14 simple questions. The results derived from the questionnaires used in these two studies could not be compared due to the difference in the questions in the two questionnaires. As such the Forth Valley questionnaire was found not to be suitable for this current study which was designed to compare the views of the GPs and district nurses in GGNHSB with regards to palliative care.

In the Cambridge study the same questions were used for GPs and the district nurses, and had questions on current services presently available in the area and asked about desirable future services. This included a question on bed availability in the local hospice and a general question for comments. After consulting the author and obtaining permission the questionnaire used in Cambridge was used as a basic model for this current study. The general layout of this questionnaire was used as a template to build upon. Relevant questions were incorporated so as to accomplish the research objectives. Dr Barclay recommended that detailed demographic data of the respondents was of value as it aided interpretation of the results. As such the first page of the questionnaire included questions regarding the respondents professional/personal data.

1.2.1. Internal pilot study

The questionnaire was first piloted internally with palliative medicine specialists from two hospices, Masters in Public Health students and staff at the Public Health department, Glasgow University (Appendix 9). The responses to the questionnaire were analysed and the results (see Appendix 9) enabled the following changes to be executed.

Changes made to the questionnaire after internal pilot

The initial questionnaire contained six tables with 17 rows in each (Appendix 9) and this was reduced to two tables with 16 rows in each (Appendix 9a). This reduced the overall size of the questionnaire. There were no questions on *appropriate time of referral for patients requiring palliative care* and a question on this was included. This information would help in identifying the different views and difficulties encountered by GPs and district nurses. A new question was included on *the number of palliative patients treated by the GPs and district nurses in the last year.* This was to assist in analysis of results and to assess if the number of patients treated affected the responses.

A question on their place of work was irrelevant for GPs and district nurses and was deleted. A suggestion to give a choice for respondents to receive a summary of the current study findings was included. It was hoped this would instil a feeling of participation and ownership. The questionnaire was modified and an external pilot was conducted with GPs (identified by GGNHSB) and district nurses (identified by a Nurse Manager in GGNHSB). The frequent comment on the length and complex nature of the questionnaire could not be fully addressed.

1.2.2. External pilot study

The questionnaires were piloted with a small number (ten each) of GPs and district nurses to evaluate their content and presentation. The questionnaires were posted in August 1998. Reminders were sent in early September 1998 and by late September 1998 analysis of the responses was carried out (Appendix 9a). The overall structure of the questionnaire was welcomed by all. The main complaint especially from the doctors was on length of the questionnaire.

Changes made to the pilot questionnaire

In the covering letter the length of time required to complete the questionnaire was increased from ten minutes to 15 to 20 minutes. This was in response to the actual time taken to complete the questionnaire in the pilot studies. Two new definitions, *Palliative Medicine Specialist* and *Palliative Care Specialist*, were included to clarify these terms in the questionnaire. The statement about only including diseases of the central nervous system for comparative interviews was omitted. This was to avoid influencing the respondents into focusing on palliative care for non-cancer diseases to only central nervous system diseases. The main complaint from the GPs was on the length and the crowded nature of the questionnaire. As the views of the GPs are an important component of this questionnaire the following changes were made without compromising the core issues of this current study.

The space for *Name* was removed and was replaced by an identity number to permit sending a reminder or to send a summary of the results of the current study. The prize draw number space was removed as respondents to the pilot felt that palliative care was a sensitive issue. The age groups were increased from five to ten year groups to achieve an organised and practical appearance. The nine personal data questions were reduced to three so as to reduce the overall length of the questionnaire. A similar outcome was achieved by deleting the first three services mentioned in Questions II and I in the pilot questionnaire as they were repeated in Questions (IV a) and (IV b).

The format of the options in Question II were changed. The change made it easier for the respondent to read and follow it. The column for *No experience* was deleted because this is a future service and so everyone has a right to give an opinion. Question III was shortened so the emphasis was only on issues that might highlight differences of opinion. Question V and VII were rewritten to be more specific and clearer.

2. Methods used for the main study

2.1. Questionnaire

The current study's final questionnaire is in Appendix 10. There was a covering letter describing the purpose of the survey and the benefits of responding to the questionnaire. The reply envelopes were numbered so as to help identify the health sector and Carstairs depcat code[171] of the respondents. This ensured reminders were not sent to those who had already replied and also enabled copies of the findings to be sent to those requesting them. The participants were informed of this and were reassured about confidentiality. There was also a one-page information sheet explaining the concept of palliative care in this survey and the diseases (cancer and non-cancer) that required palliative care. There were also definitions for terms used in the questionnaire (Appendix 10).

The question on the first page was designed to collect demographic data (age, sex and current post) about the respondents. There were also questions about their past and present palliative care educational experiences (attendance at courses, conferences/seminars), the usefulness of more information on palliative care and their preference for the mode of future palliative care training.

- Question I was about their usage of and the adequacy of the current palliative care services for both cancer and non-cancer patients. (If they ***had used*** the service listed in the left column, then they ***circle the Y*** in the ***first column in that section,*** and then continue to tick ***one box*** in the other two columns in that section. If they ***had not used*** the service listed in the left column, then they ***circle the N*** in the ***first column in that section,*** and then proceed to ***the next section/row).***

- Question II was about their views and the importance that they would place on future palliative care services for both cancer and non-cancer patients. Sixteen items were identified from the palliative care services available in Glasgow, for questions I and II. These were:
- hospital and hospice palliative out-patient and palliative medicine specialist services
- palliative care at home provided by various palliative care workers
- home help, social workers and occupational therapist from the social services
- access to equipment from social services and health board
- and finally concerning 24 hour telephone advice.
- Question III was to elicit the importance placed on 13 statements regarding the role of GPs, nurses (district and specialist) and community pharmacist. There were questions on ethnic group, young adults, those with learning difficulties and on bereaved carers.
- Question IV was about their experience of the availability of hospice and hospital beds for palliative care. This included a section for comments on their experiences and any suggestions.
- Question V and VI were about their perception of patients preferred place of death and the obstacles preventing this choice being realised.
- Question VII was about their views on appropriate referrals to a specialist palliative care team.
- Question VIII was about the number of cancer and non-cancer patients they had cared for in the past year.
- Question IX contained a section for general comments about palliative care and their wish for a copy of the results.

2.2. Sample for the study

2.2.1. Power calculation

It was calculated that a random sample of one-third of the GPs and district nurses in GGNHSB area would achieve 80 percent power and five percent significance level for the current study, allowing a difference of 17 percent to be detected (30 percent Vs 47 percent).[198] This would be possible if the response rate was 60 percent.

2.2.2. Random sample

The random sampling was conducted from November 1998 to January 1999. The sample was sorted by using their work place post-codes and by using a Minitab computer package a one in three random sample was obtained. There were 209 GPs and 203 district nurses in the random sample. The initial questionnaires were sent in November 1998 and the first response was received in December 1998. Reminders were sent out in January 1999.

2.2.3. Second sample

The second sampling was conducted from February to June 1999. Since the response to the random sample was low (43 percent) and would not have enabled the power and significance levels intended for the current study to be achieved it was decided to include all the GPs (see Map 3) and district nurses in GGNHSB area. The initial questionnaire for the second sample (total number of GPs and district nurses minus those included in the initial random sample) was posted in February 1999. Reminders were sent to the non-respondents. It was decided to hand deliver most of the reminders to see if there was any difference in the response rates and post the rest. The hand deliveries were executed from the end of April 1999 to the middle of May 1999. The survey was completed in June 1999.

2.2.4. Response rate

Templeton et al conducted a study on a large number (2884) of non-responders in a national postal survey and concluded that

> *"A low response rate need not affect the validity of the data collected, but it is still necessary to test for non-response effects and make corrections to the original data in order to maximise validity".*[199]

One of the issues raised and discussed was about GPs response rate to questionnaires. Deehan[200] in London and Asch[201] in United States showed that response was positively affected by the offer of an inducement but Schweitzer's[202] study showed that timing of inducement might influence the profile of respondents. MacPherson[203] in Aberdeen and Wilkinson[204] in a letter proposed that a poor response rate from GPs was due to the large number of questionnaires they are asked to complete. The response rates from postal questionnaires will not be improved if received just before a weekend. This was the conclusion of a nation-wide survey on doctors' attitudes carried out in Denmark by Olivarius.[205] In the current pilot study it was suggested that a prize draw would be available for all the respondents but this was not well received by the pilot respondents who felt that an important and sensitive issue like palliative care should encourage the medical professionals to respond spontaneously without inducement. Clark et al study *Assessing palliative care needs in Southern Derbyshire* included a postal questionnaire for GPs and district nurses and their response rate was approximately 50 percent in each group.[206]

Asch et al (1997) calculated mean response rate among mail surveys published in medical journals and found it to be 60 percent.[207] Their findings also revealed that mean response rate from physicians was 54 percent and that of non-physicians was 68 percent.[207] Hanlon et al's study *To determine how needs assessment is being used to improve health* conducted a postal survey of a one in two sample of all Scottish GP principals in 1996 and achieved a response rate of 54 percent.[208] The final response rate in this current study was 44 percent for GPs and 51 percent for district nurses.

2.3. Strengths of the method used

- All the GPs and district nurses in the GGHB area were given an opportunity to express their views on palliative care for both cancer and non-cancer patients.
- Reminders were sent to those who had not responded the first time around and this provided them with an opportunity to express their views in spite of their commitments.
- This method highlighted the obstacles and difficulties faced by the community based service providers.
- There were opportunities in the questionnaire for the respondents to express their views qualitatively.
- The same questionnaire was provided for GPs and district nurses and this enabled the district nurses to express their own views on community based palliative care. This also created the opportunity to compare the views of GPs with those of the district nurses.
- The first questionnaires were ALL delivered by post. Reminders to the questionnaire were hand-delivered and this allowed comparison of postal and hand-delivered response rates.
- Those who responded to the questionnaire were keen to express their views and have their say in the provision of future palliative care in the GGHB area.
- Demographic details of ALL the GPs in the GGHB area were obtained and this allowed comparison with the respondents for age and sex.

2.4. Research realities of the methods used

- Only GPs and district nurses were selected. Other health professionals providing community based palliative care were not included due to logistic reasons.
- Demographic details of ALL the district nurses in the GGHB area were not obtained and this did not allow comparison with the respondents for age and sex.

- The questionnaire was lengthy (6 pages with quantitative and qualitative data) as it had to be comprehensive and this might have reduced the response rate.

> *"I will be very interested in your response rate to this questionnaire! If it is >50% you can assume that GPs are committed to good palliative care". GGHB GP Principal/Research Fellow.*

2.5. Data analysis

2.5.1. Quantitative data

The data collected from the GPs and district nurses questionnaire were entered into the SPSS package for analyses. The basic analysis carried out with the data were:

- calculation of frequency,
- cross tabulations of GPs and district nurses responses and
- chi square test for significance (p values).

2.5.2. Qualitative data

There were open-ended questions where the respondents expressed their views and these qualitative data was transferred to word documents. A three stage manual method was used to analyse the qualitative data from the respondents as follows:

- ordering and developing a thematic framework,
- summarising and synthesising,
- interpreting and abstracting.

2.5.3. Multiple logistic regression

The covariates (demographic data) used in regression analysis were:

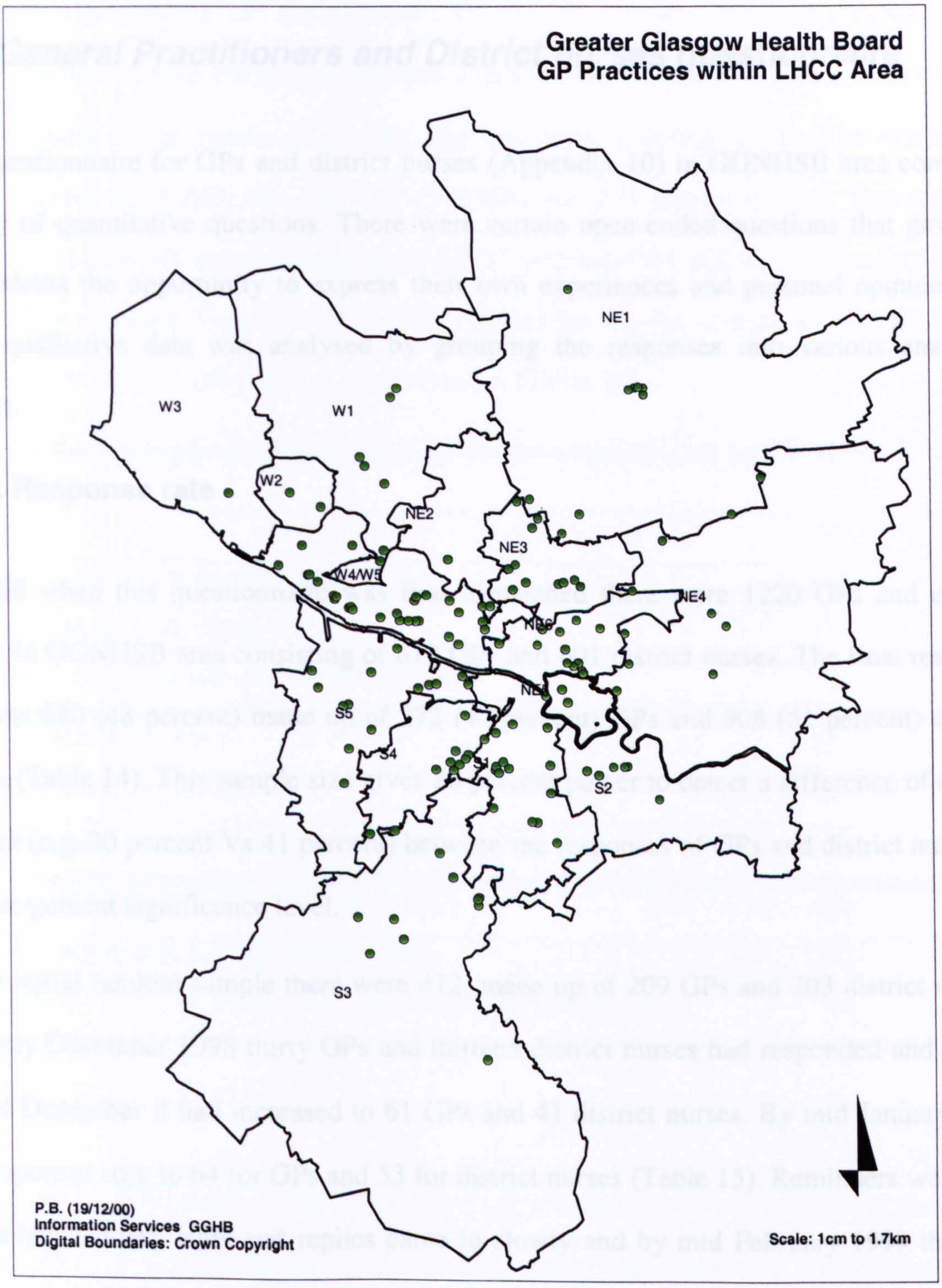
- Respondent's occupation (GP or district nurse)
- Age groups of respondents (20-39, 40-49 and 50-69 years)

- If respondent had attended a course on palliative care (Yes/No)
- If respondent attended a conference/seminar in palliative care in last year (Yes/No)
- If respondent felt it would be useful to have more information on palliative care (Yes/No).

The covariates (demographic data) not used in regression analysis were:

- Sex of respondent (this was not used as 98 percent of the district nurses were females)
- Health sector and Carstairs depcat scores of the practice of the GPs and district nurses. These were not used as the district nurses were working for more than one GP and in more than one GP practice
- The model of palliative care training that the respondents preferred. This was not included as only around two-thirds (380) of the sample (580) replied to these questions.

Map 3 GGNHSB area showing GP practices within LHCC area



3. Results

3.1. General Practitioners and District nurses questionnaire

The questionnaire for GPs and district nurses (Appendix 10) in GGNHSB area consisted mainly of quantitative questions. There were certain open-ended questions that gave the respondents the opportunity to express their own experiences and personal opinions and these qualitative data was analysed by grouping the responses into various emergent themes.

3.1.1. Response rate

In 1998 when this questionnaire was first dispatched there were 1220 GPs and district nurses in GGNHSB area consisting of 619 GPs and 601 district nurses. The final response rate was 580 (48 percent) made up of 272 (44 percent) GPs and 308 (51 percent) district nurses (Table 14). This sample size gives 80 percent power to detect a difference of eleven percent (e.g. 30 percent Vs 41 percent) between the responses of GPs and district nurses at the five percent significance level.

In the initial random sample there were 412, made up of 209 GPs and 203 district nurses. By early December 1998 thirty GPs and thirteen district nurses had responded and by the end of December it had increased to 61 GPs and 41 district nurses. By mid January 1999 the responses rose to 64 for GPs and 53 for district nurses (Table 15). Reminders were sent out in late January 1999 and replies came in slowly and by mid February 1999 the total response was 167. By the end of the survey in June 1999 the total response for the random sample was 177 (43 percent), made up of 92 (44 percent) GPs and 85 (42 percent) district nurses (Table 15).

There were 808 participants in the second sample (total GPs and district nurses in GGNHSB minus the initial random sample) made up of 410 (51 percent) GPs and 398 (49 percent) district nurses. The response by the end of February 1999 was 190 of which 94 were GPs and 96 were district nurses. The response by the middle of March 1999 was 239 (30 percent) comprising 107 (26 percent) GPs and 132 (33 percent) district nurses (Table 16). The response from the 62 (58 GPs and 4 district nurses) postal reminders was only 11 and consisted of ten replies from GPs and one from a district nurse. The number of questionnaires hand delivered was 523 (249 GPs and 274 district nurses). The response was 153 (29 percent) and was made up of 63 (25 percent) GPs and 90 (33 percent) district nurses. The response from the 808 participants for the second sample was from 180 (44 percent) GPs and 223 (56 percent) district nurses (Table 16).

Table 14 Total sample of GPs and district nurses response rate in GGNHSB Area.

	GP	DN
TOTAL PARTICIPANTS IN THE STUDY	619	601
TOTAL REPLIES AFTER FIRST POST	171	185
PERCENTAGE (%) OF REPLIES AFTER FIRST POST	28	31
TOTAL REMINDERS SENT	448	416
TOTAL REPLIES AFTER REMINDER	101	123
PERCENTAGE (%) OF REPLIES TO REMINDER	23	30
TOTAL PARTICIPANTS IN THE STUDY	**619**	**601**
TOTAL REPLIES AFTER REMINDER.	**272**	**308**
PERCENTAGE (%) OF **TOTAL REPLIES AFTER REMINDER**	**44**	**51**

There was no difference in the percentages of responses between replies to the initial questionnaire and replies to the hand delivered reminders. There was a difference in the percentages of responses between replies to the random sample reminders and the hand delivered reminders to the second sample (Table 17).

Table 15 Random sample responses

RANDOM SAMPLE IN GGNHSB AREA.	GP	DN
PARTICIPANTS IN RANDOM SAMPLE	209	203
REPLIES	64	53
PERCENTAGE (%) OF FIRST REPLY	30	26
REMINDERS SENT FOR RANDOM SAMPLE	148	156
REPLIES	28	32
PERCENTAGE (%) OF REPLIES TO REMINDER	19	20
PARTICIPANTS IN RANDOM SAMPLE	**209**	**203**
REPLIES AFTER ONE REMINDER	**92**	**85**
PERCENTAGE (%) OF REPLIES FROM RANDOM SAMPLE	**44**	**42**

There were a few questionnaires that were returned because the person had moved or stopped working in that place (five GPs [one percent] and 16 district nurses [three percent]) and these were removed from the sample numbers. The final sample size for the survey was 1220 made up of 619 GPs and 601 district nurses (Table 14). The final response rate was 48 percent (580), made up of 44 percent (272) GPs and 51 percent (308) district nurses (Table 14).

Table 16 Second sample responses

SECOND SAMPLE IN GGNHSB AREA	GP	DN
PARTICIPANTS IN SECOND SAMPLE	410	398
REPLIES	107	132
PERCENTAGE (%) OF FIRST REPLY	26	33
REMINDERS SENT FOR SECOND SAMPLE	307	279
POSTAL DELIVERIES	58	4
REPLIES FROM POSTAL DELIVERY	10	1
PERCENTAGE (%) OF REPLIES TO POSTAL REMINDER	17	25
REMINDERS HAND DELIVERED	249	274
REPLIES FROM HAND DELIVERY	63	90
PERCENTAGE (%) OF REPLIES TO HAND DELIVERED REMINDER	25	33
REPLIES TO REMINDER FROM SECOND SAMPLE	73	91
PERCENTAGE (%) OF REPLIES TO REMINDER FROM SECOND SAMPLE	24	33
PARTICIPANTS IN SECOND SAMPLE	**410**	**398**
REPLIES AFTER ONE REMINDER	**180**	**223**
PERCENTAGE (%) OF REPLIES FROM SECOND SAMPLE	**44**	**56**

Table 17 Percentage of response to the GP and district nurse questionnaire

	GPs	DNs
Random sample reply to initial letter	30	26
Random sample reply to reminder letter	19	20
Second sample reply to initial letter	26	33
Second sample reply to hand delivered reminder letter	25	33

3.2. Demographic data of respondents to the General Practitioners and District nurses questionnaire

This section contains the data collected from the first page of the questionnaire sent to the GPs and district nurses in GGNHSB area (Appendix 10).

3.2.1. Age and sex

The highest response from the GPs was in the 30-39 age group (39 percent) while for the district nurses it was in the 40-49 age group (39 percent). There were less than five percent in the below 29 and over 60 age groups for both the GPs and the district nurses (Table 18). GGNHSB supplied the list of all the GPs practising in their area with their age groups. The age groups of the sample for the GPs showed that 15 percent were in the age group 30-39 years, 33 percent were in the 40-49 years group, 19 percent were in the 50-59 year group and only four percent were in the 60-69 year group. The age of more than a quarter (29 percent) of the GPs was unknown. The age groups of the GPs who responded to the questionnaire were similar in all the age groups to the original sample except the 30-39 year group. The age groups of all district nurses who received the questionnaire were not available. The GPs and district nurses respondents were similar in age distribution (Table 18).

The percentage of males and females for GPs and district nurses who received the questionnaire were found to be similar to that of those who responded (Table 19). The sex differences for the district nurses could not be analysed as 98 percent were females. In the GPs sample there were more males (56 percent) than females (44 percent) who received the questionnaire but despite this there was a higher percentage of responses from the females (45 percent) compared to the males (38 percent).

Table 18 Age group of respondents

AGE GROUP	20-29	30-39	40-49	50-59	60-69	TOTAL
GPs	9 (3)	105 (39)	96 (36)	52 (19)	8 (3)	270 (100)
DNs	14 (5)	107 (36)	116 (39)	59 (20)	3 (1)	299 (100)

Missing: GPs = 2 and DNs = 9

All the numbers within brackets () are percentages (%)

Table 19 Sex characteristics of GPs and district nurses

SEX	MALE	FEMALE	TOTAL
GPs SENT QUESTIONNAIRES	347 (56)	272 (44)	619 (100)
GPs RESPONDED	131 (52)	122 (48)	253 (100)
DNs SENT QUESTIONNAIRES	12 (2)	589 (98)	601 (100)
DNs RESPONDED	8 (3)	298 (97)	306 (100)

Missing: GPs = 19 and DNs = 2. All the numbers within brackets () are percentages (%)

Table 20 Health sector data of GPs and district nurses practices

HEALTH SECTOR	NE	WEST	SOUTH	TOTAL
GPs SENT QUESTIONNAIRES	235 (38)	167 (27)	217 (35)	619 (100)
GPs RESPONDED	98 (37)	56 (21)	113 (42)	267 (100)
DNs SENT QUESTIONNAIRES	234 (39)	114 (19)	253 (42)	601 (100)
DNs RESPONDED	111 (37)	67 (22)	121 (40)	299 (100)

Missing: GPs = 5 and DNs = 9

All the numbers within brackets () are percentages (%)

Table 21 Carstairs depcat score of the GPs and district nurses practices

CARSTAIRS DEPCAT SCORES	1 AND 2	3-5	6 AND 7	TOTAL
GPS SENT QUESTIONNAIRES	106 (17)	142 (23)	371 (60)	619 (100)
GPS RESPONDED	51 (19)	60 (23)	156 (58)	267 (100)
DNS SENT QUESTIONNAIRES	51 (9)	69 (11)	481 (80)	601 (100)
DNS RESPONDED	32 (11)	36 (12)	230 (77)	298 (100)

Missing: GPs = 5 and DNs = 10

All the numbers within brackets () are percentages (%)

3.2.2. Health sector and depcat

The percentages of the GPs and district nurses in the three health sectors in GGNHSB who received the questionnaires (all the GPs and district nurses in the GGNHSB area were sent questionnaires) were similar in proportion to that of the respondents (Table 20). More GPs in the north-east sector and more district nurses in the south sector received questionnaires. The west sector had the least number of GPs and district nurses who received the questionnaires. The highest number of responses was received from the GPs and district nurses in the south sector and the least number of responses was from those in the west sector. The only differences were for the GPs, where there was a higher response from the south sector compared to the percentage of questionnaires sent out to the south sector. (Table 20). Table 21 illustrates the similarities in the Carstairs depcat between the respondents and all those who received the questionnaires.

The similarities in the percentages of the age groups, sex, health sector and the depcat area of practice, of the total sample and the respondents, support the view that the findings of this current study provide a representative view of GPs and district nurses working in GGNHSB area.

3.3. Palliative care educational exposure

Table 22 Palliative care training and preferences of respondents

TYPE OF TRAINING		YES	NO	TOTAL
ATTENDED COURSE IN PALLIATIVE CARE	GP	150 (56)	117 (44)	267 (100)
	DN	123 (40)	182 (60)	305 (100)
Missing: GPs = 5 and district nurses = 3				
ATTENDED CONFERENCE/SEMINAR IN PALLIATIVE CARE IN LAST YEAR	GP	65 (24)	201 (76)	266 (100)
	DN	79 (26)	226 (74)	305 (100)
Missing: GPs = 6 and district nurses = 3				
USEFUL TO HAVE MORE INFORMATION	GP	243 (91)	25 (9)	268 (100)
	DN	303 (99)	3 (1)	306 (100)
Missing: GPs = 4 and district nurses = 2				
USEFUL TO HAVE MORE TRAINING IN PALLIATIVE CARE	GP	242 (90)	26 (10)	268 (100)
	DN	302 (98)	5 (2)	307 (100)
Missing: GPs = 4 and district nurses = 1				
TRAINING – SEMINAR	GP	169 (89)	22 (11)	191 (100)
	DN	212 (95)	12 (5)	224 (100)
Missing: GPs = 81 and district nurses = 84				
TRAINING – TUTORIALS	GP	152 (84)	29 (16)	181 (100)
	DN	201 (94)	13 (6)	214 (100)
Missing: GPs = 91 and district nurses = 94				
TRAINING – HOSPICE ATTACHMENTS	GP	93 (56)	74 (44)	167 (100)
	DN	195 (90)	21 (10)	216 (100)
Missing: GPs = 100 and district nurses = 91				
TRAINING – WRITTEN INFORMATION	GP	128 (75)	43 (25)	171 (100)
	DN	199 (94)	13 (6)	212 (100)
Missing: GPs = 101 and district nurses = 96				

All the numbers within brackets () are percentages (%)

There were questions regarding respondents' exposure to palliative care in the form of courses/conferences/seminars. The responses on attending courses illustrated (Table 22) that the percentage of GPs (56 percent) who had attended courses was greater than that of the district nurses (40 percent). The percentages of GPs and district nurses who had attended conferences/seminars were similar. In excess of 90 percent of both GPs and district nurses agreed that it would be useful to have more information and training in palliative care (Table 22). When they were asked to choose the type of training that they preferred, there was a mixed response. In excess of 80 percent of both GPs and district nurses preferred seminars and tutorials. More than 90 percent of district nurses chose hospice attachments, as a form of training, compared to only 56 percent of GPs. More than 90 percent of district nurses preferred training, in the form of written information, compared to only 75 percent of GPs (Table 22).

3.4. Results and analysis of quantitative data from the General Practitioners and District nurses questionnaire

3.4.1. General Practitioners and District nurses views on current palliative care services

The GPs and district nurses were asked to indicate their views from their experience on the currently available palliative care services (See Appendix 11 for full results). Table 23 (for cancer patients) and Table 24 (for non-cancer patients) contains summaries of the results from the tables in Appendix 11. The GPs and district nurses responses are recorded in two columns. The first column for the GPs and district nurses represents the percentages of respondents who have used the services. The second column indicated (in percentages) the views of GPs and district nurses who have used these services.

Hospital and hospice palliative care services were used for cancer patients and found to be adequate in terms of service provision (Table 23). These services generally were under-used for non-cancer patients and the GPs and district nurses using these services found them to be inadequate in hospitals and adequate in hospices (Table 24). Marie Curie Cancer Care and Macmillan Cancer Relief (unavailable for non-cancer patients) services were used more frequently for cancer patients. For cancer patients the GPs used the Macmillan services more than the district nurses. The GPs did not differentiate between Marie Curie or Macmillan services but the district nurses preferred the Marie Curie services. Social services were regularly accessed by GPs and district nurses but the majority found the availability of these services was limited. Home helps were favoured by both over other types of social services care for cancer and non-cancer patient groups. Health Board equipment was used significantly more by district nurses for both patient groups. Fifty percent of GPs and district nurses found it to be adequate. The majority of GPs and district nurses found palliative care services to be adequate but social services in general and Health Board and social services equipment access in particular was found to be very inadequately provided.

Table 23 Summary of responses to current services for cancer patients

Current Services	**Cancer patients**			
	Percentage of GPs		**Percentage of DNs**	
	Used	**Adequate**	**Used**	**Adequate**
Palliative Outpatient service in hospital	56	73	50	73
Palliative Outpatient service in hospice	**93**	93	**69***	93
Palliative Medicine specialist in hospice	**96**	97	**66***	96
Palliative Medicine specialist in hospital	**46**	**87**	**40***	**71***
Palliative Medicine specialist for home visit	**81**	**92**	**61***	**85***
Palliative day care in the hospice	**88**	**96**	**78***	**91***
Palliative home care by DNs	**97**	**96**	**87***	**85***
Marie Curie services	85	91	85	87
Macmillan services	**91**	88	**65***	82
Home help by social service	**94**	**56**	**88***	**43***
Social workers from social service dept.	73	44	75	41
Occupational therapist from social service dept.	**62**	**36**	**79***	**58***
Access to equipment from social service dept.	76	28	79	33
Access to equipment from health board	**59**	48	**91***	51
Telephone advice (24 hours) for palliative care	25	90	24	79

**** = Statistically significant differences (p=<0.001) between the GPs and DNs.***
All numbers in Bold show statistically significant differences between GPs and DNs.

Table 24 Summary of responses to current services for non-cancer patients

Current Services	**Non-cancer patients**			
	Percentage of GPs		**Percentage of DNs**	
	Used	**Adequate**	**Used**	**Adequate**
Palliative Outpatient service in hospital	**23**	**53**	**30***	**69***
Palliative Outpatient service in hospice	25	**89**	29	**69***
Palliative Medicine specialist in hospice	26	**95**	25	**82***
Palliative Medicine specialist in hospital	**12**	54	**23***	58
Palliative Medicine specialist for home visit	**8**	75	**24***	59
Palliative day care in the hospice	**17**	81	**32***	69
Palliative home care by DNs	**54**	95	**73***	89
Marie Curie services	**14**	**86**	**29***	**64***
Macmillan services	15	83	15	71
Home help by social service	**79**	48	**89***	46
Social workers from social service dept.	**69**	39	**82***	44
Occupational therapist from social service dept.	**66**	37	**83***	44
Access to equipment from social service dept.	**70**	26	**81***	29
Access to equipment from health board	**46**	42	**90***	48
Telephone advice (24 hours) for palliative care	9	82	14	67

**** = Statistically significant differences (p=<0.001) between the GPs and DNs.***
All numbers in Bold show statistically significant differences between GPs and DNs.

3.4.2. General Practitioners and District nurses views on future palliative care services

The GPs and district nurses were told that the current study was attempting to prioritise the current services and they were asked to indicate the importance that they would like to see given to each of the identified services, when planning future services. If they were given finite resources, where would they put the emphasis? (See Appendix 12 for full results) Table 25 (for cancer patients) and Table 26 (for non-cancer patients) contain summaries of the results (in percentages) from the tables in Appendix 12.

There were significant differences between district nurses and GPs in their views about future hospice service provision for non-cancer patients. GPs were less in favour of hospital based palliative care compared to district nurses but both were in favour of hospice based care, especially for cancer patients. The future need for various social services care for non-cancer patients scored higher than that for cancer patients and this was the only time that non-cancer patient's needs were selected in favour of those of cancer patients. The GPs placed less importance than district nurses on all future social services care especially on access to equipment. This difference was even greater for access to equipment from the Health Board for both patient groups. There is still a dilemma to include non-cancer patients in hospice palliative care. The future need for improved community services with respect to social service provision and ready access to health board equipment has been recognised by the health professionals. Both GPs and district nurses recognised the inadequacy of the present equipment services. However when asked about the future priorities for this service only the district nurses rated it as a high priority (40 percent GPs Vs 80 percent district nurses) for both cancer and non-cancer patients.

Table 25 Summary of responses to future services for cancer patients

Future Services (all numbers are percentages)	Cancer patients					
	A		B		C	
	GPs	DNs	GPs	DNs	GPs	DNs
Palliative Outpatient service in hospital	32	57	42	35	25	8*
Palliative Outpatient service in hospice	72	82	23	16	5	2*
Palliative Medicine specialist in hospice	82	87	15	11	4	2
Palliative Medicine specialist in hospital	41	65	37	29	22	5*
Palliative Medicine specialist for home visit	57	77	31	20	12	3*
Palliative day care in the hospice	67	73	28	23	6	4
Palliative home care by DNs	80	87	15	11	5	2
Marie Curie services	62	75	27	21	10	7*
Macmillan services	64	63	25	28	11	8
Home help by social service	55	63	39	31	5	7
Social workers from social service dept.	25	39	39	44	37	17*
Occupational therapist from social service dept.	31	50	44	38	25	12*
Access to equipment from social service dept.	47	78	36	16	18	7*
Access to equipment from health board	39	89	41	9	19	2*
Telephone advice (24 hours) for palliative care	34	68	37	21	29	11*

** = Statistically significant differences (p=<0.001) between the GPs and DNs.*
All numbers in Bold show statistically significant differences between GPs and DNs.
(A = Very important/High priority; B = Fairly important/Moderate priority; C = unimportant/Low priority):

Table 26 Summary of responses to future services for non-cancer patients

Future Services (all numbers are percentages)	Non-cancer patients					
	A		B		C	
	GPs	DNs	GPs	DNs	GPs	DNs
Palliative Outpatient service in hospital	30	49	45	39	25	11*
Palliative Outpatient service in hospice	33	44	44	40	23	16*
Palliative Medicine specialist in hospice	39	56	37	30	25	14*
Palliative Medicine specialist in hospital	31	58	42	29	27	13*
Palliative Medicine specialist for home visit	31	56	44	32	25	12*
Palliative day care in the hospice	37	50	42	39	21	12*
Palliative home care by DNs	68	80	23	15	9	6*
Marie Curie services	33	52	39	34	28	15*
Macmillan services	31	42	35	37	34	21*
Home help by social service	57	70	35	25	7	6
Social workers from social service dept.	29	45	39	42	32	13*
Occupational therapist from social service dept.	35	54	43	38	22	8
Access to equipment from social service dept.	46	75	40	21	15	4*
Access to equipment from health board	37	83	41	14	22	2*
Telephone advice (24 hours) for palliative care	26	56	38	31	37	13*

** = Statistically significant differences (p=<0.001) between the GPs and DNs.*
All numbers in Bold show statistically significant differences between GPs and DNs.
(A = Very important/High priority; B = Fairly important/Moderate priority; C = unimportant/Low priority):

3.4.3. Ranking of General Practitioners and nurses views on current and future palliative care services

The findings in Table 23 and 24 on current services for cancer and non-cancer patients respectively were analysed and the results in the adequate column were ranked for both the GPs and the district nurses. These rankings are found in Table 27 and 28. The results in Tables 25 and 26 show the importance GPs and district nurses place on these services in future planning for palliative care for cancer and non-cancer patients. The results in column A were those who would place very important/high priority on these services (averages of column A and B produced similar results). The results in this column were ranked and the findings were recorded in Table 27 and 28 for cancer and non-cancer patients respectively. For cancer and non-cancer patients the ranking of the adequacy of the current services by the GPs and nurses was very similar. Both GPs and district nurses ranked all the services provided by Social Services Department and the provision of equipment by the Health Board, for both cancer and non-cancer patients, lowest for adequacy. Differences lay in the ranking of future services (Table 27 and Table 28).

For cancer patients the change in rankings by the GPs, between the adequacy and future importance of services, was not as great as the change with the rankings by district nurses. Overall there was no change in four services for GPs and in one service for district nurses. There were changes of one rank for three services by GPs compared to five services by the district nurses. Access to equipment from Social Services Department and the Health Board had an upward change of 10 and 11 ranks respectively for the district nurses. The maximum upward change for the GPs was by six places for access to equipment from Social Services Department (all the figures within brackets in Table 27 and 28 show the change [+ve and -ve] in ranking). The rankings by both GPs and district nurses had minimal changes (nil to 2 downwards) in the three palliative medicine specialist services.

For non-cancer patients, the changes in rankings between the adequacy and future importance of services were nearly equal between the GPs and district nurses. The greatest upward change (12 places) in ranking for both GPs and district nurses was for access to equipment from Social Services Department. Current access/availability of social workers were ranked 3rd lowest in importance by GPs and district nurses. This ranking did not change for their importance for future services. Both GPs (-7 ranks) and nurses (-12 ranks) gave low rankings for future Macmillan services for non-cancer patients but this may have been because Macmillan services does not cover non-cancer cases.

Table 27 Summary of responses to services for cancer patients by Rank

Current Services	Cancer patients					
	Rank by GP (shift)			Rank by DN (shift)		
	Adequate		Future	Adequate		Future
Palliative Medicine specialist in hospice	1	(0)	1	1	(-1)	2
Palliative day care in the hospice	2	(-2)	4	3	(-5)	8
Palliative home care by DNs	2	(0)	2	5	(+2)	3
Palliative Outpatient service in hospice	4	(+1)	3	2	(-2)	4
Palliative Medicine specialist for home visit	5	(-2)	7	5	(-1)	6
Marie Curie services	6	(0)	6	4	(-3)	7
Telephone advice (24 hours) for palliative care	7	(-5)	12	8	(-1)	9
Macmillan services	8	(+3)	5	7	(-4)	11
Palliative Medicine specialist in hospital	9	(-1)	10	10	(0)	10
Palliative Outpatient service in hospital	10	(-3)	13	9	(-4)	13
Home help by social service	11	(+3)	8	13	(+1)	12
Access to equipment from health board	12	(+1)	11	12	(+11)	1
Social workers from social service dept.	13	(-2)	15	14	(-1)	15
Occupational therapist from social service dept.	14	(0)	14	11	(-3)	14
Access to equipment from social service dept.	15	(+6)	9	15	(+10)	5

Adequate is for present services. A +ve sign means a ranking increase in terms of priority for future palliative care services. A -ve sign means a ranking decrease in terms of priority for future palliative care services.

Table 28 Summary of responses to services for non-cancer patients by Rank

Current Services	Non-cancer patients					
	Rank by GP (shift)			Rank by DN (shift)		
	Adequate		Future	Adequate		Future
Palliative Medicine specialist in hospice	1	(-3)	4	2	(-6)	8
Palliative home care by DNs	1	(0)	1	1	(-1)	2
Palliative Outpatient service in hospice	3	(-5)	8	4	(-10)	14
Marie Curie services	4	(-5)	9	8	(-2)	10
Macmillan services	5	(-7)	12	3	(-12)	15
Telephone advice (24 hours) for palliative care	6	(-9)	15	7	(0)	7
Palliative day care in the hospice	7	(+2)	5	4	(-7)	11
Palliative Medicine specialist for home visit	8	(-2)	10	9	(+3)	6
Palliative Medicine specialist in hospital	9	(-2)	11	10	(+5)	5
Palliative Outpatient service in hospital	10	(-3)	13	4	(-8)	12
Home help by social service	11	(+9)	2	12	(+8)	4
Access to equipment from health board	12	(+6)	6	11	(+10)	1
Social workers from social service dept.	13	(-1)	14	13	(0)	13
Occupational therapist from social service dept.	14	(+7)	7	13	(+4)	9
Access to equipment from social service dept.	15	(+12)	3	15	(+12)	3

Adequate is for present services. A +ve sign means a ranking increase in terms of priority for future palliative care services. A -ve sign means a ranking decrease in terms of priority for future palliative care services.

Table 29 Results of multiple logistic regression on future services

Future Services / Variables	Group (GPs and DNs)		Attended conference/seminar in last year.		Useful to have more information on palliative care.	
*** results in bold are statistically significant.**	Cancer p=	Non-cancer p=	Cancer p=	Non-cancer p=	Cancer p=	Non-cancer p=
1. Palliative outpatient services in hospital	**<0.001**	**<0.001**				
2. Palliative outpatient services in hospice		0.04	0.03		**0.01**	
3. Palliative Medicine specialist in hospice		**0.003**		**0.003**		
4. Palliative Medicine specialist in hospital	**<0.001**	**<0.001**		0.02		
5. Palliative Medicine specialist for home visits	**<0.001**	**<0.001**		**0.007**	**0.01**	
6. Palliative Day-care in the hospice		**0.003**				
7. Palliative home care by DNs		0.04		0.01		
8. Palliative home care by Marie Curie Community nursing services		**<0.001**				
9. Palliative Home-care by Marie Curie Home care Sisters		**0.004**				
10. Palliative Home-care by Macmillan community nurses		**<0.001**				
12. Social workers from Social Services Department	**<0.001**	**<0.001**				**0.008**
13. Occupational therapist from Social services department	**<0.001**	**<0.001**		0.03		
14. Access to equipment from Social	**<0.001**	**<0.001**				
15. Access to equipment from health board	**<0.001**	**<0.001**				
16. Telephone advice (24 hours) for palliative care issues	**<0.001**	**<0.001**			0.03	0.04

3.4.4. Multiple logistic regression

Multiple logistic regression analysis was carried out on responses by the GPs and district nurses for current and future services for both cancer and non-cancer patients. For the question on adequacy of current services there were many non-responses as only those who had used the service could respond to its adequacy. The variables due to non-response were excluded where there were more than 100 missing cases. All the variables on current services had between 150 to 400 missing cases or had no significant findings (see Appendix 11). Table 29 is a summary of only the significant findings from the regression analyses carried out on the responses from the GPs and district nurses to questions on future services.

Eight significant differences were found between views of GPs and district nurses for cancer services but a total of 13 significant differences were found for non-cancer services after adjusting for other variables mentioned in the methodology section. Respondent's previous attendance at a conference or seminar was not significant for cancer service but was significant for two non-cancer services. On the question of whether it was useful to have more information on palliative care, it was found to be significant in two cancer and one non-cancer services (Table 29). Age was a significant covariant only in the response to Palliative Home-care by Marie Curie Home Care Sisters for cancer patients (Appendix 13).

3.5. The views of General Practitioners and District nurses on test statements on palliative care

The GPs and district nurses were requested to evaluate twelve test statements on palliative care (Table 30 and 31). There were significant differences in the views of GPs and district nurses. The district nurses placed greater value on all the statements. There were two test statements about GPs, three test statements regarding nurses, three test statements for special group patients, two aspects on bereaved carers and two points concerning pharmacists.

The health care professionals placed more emphasis on protected time for GPs to deal with palliative care issues than on whether hospital consultants should consult the GPs before referring to hospice services. More than two thirds of district nurses were of the opinion that it was very important that the specialist palliative care nurses should be encouraged to develop and have an active role in the care of their patients while only about half of the GPs considered these to be important. The biggest difference between the GPs and district nurses was concerning the issue of further training for nurses in palliative care (Table 30 and 31).

On the test statement about ethnic minority communities' access to hospice and specialist palliative care, only a quarter of GPs who responded considered it to be very important while half of district nurses who responded thought that it was very important. The issue of improving specialist palliative care for young adults had a similar response rate from GPs but the district nurses response rate increased to nearly two thirds. There were greater differences between the GPs (less than a quarter) and district nurses (just over half) on the need for improvement of specialist palliative care services for people with learning difficulties (Table 30 and 31).

The issue of routine formal assessment of bereaved carers was given high priority by only thirteen percent of GPs but by nearly half of district nurses. A higher percentage of respondents considered that access to information after assessment was very important. The health care professionals were more in favour of pharmacists working closely with GPs rather than with the patients on drug related issues (Table 30 and 31).

Table 30 Importance given by GPs and district nurses to test statements

	1	2	3	4	P value
A) Hospital consultants who wish to refer patients to a hospice service should consult the GP first.					
GPs (Total = 260)	50 (19)	70 (27)	82 (32)	58 (22)	<0.001
DNs (Total = 299)	137 (45)	106 (36)	39 (13)	17 (6)	
Missing: GPs = 12 and DNs = 9					
B) General practitioners ideally need protected time to deal competently and sensitively with this patient group and their families.					
GPs (Total = 254)	138 (54)	101 (40)	12 (5)	3 (1)	0.054
DNs (Total = 303)	244 (81)	51 (17)	8 (3)	Nil	
Missing: GPs = 18 and DNs = 5					
C) Community and practice nursing staff require further training in palliative care.					
GPs (Total = 258)	104 (40)	135 (52)	18 (7)	1 (1)	0.005
DNs (Total = 303)	243 (80)	53 (18)	7 (2)	Nil	
Missing: GPs = 14 and DNs = 5					
D) In health centres and/or localities one or more nurses trained in palliative care should be encouraged to develop this as a special interest.					
GPs (Total = 249)	117 (46)	98 (38)	34 (13)	7 (3)	<0.001
DNs (Total = 303)	227 (75)	64 (21)	10 (3)	2 (1)	
Missing: GPs = 16 and DNs = 5					
E) The nurse trained in palliative care should provide assessment, advice about symptom control, and be involved in promoting psychosocial well being.					
GPs (Total = 251)	130 (52)	89 (36)	28 (11)	4 (2)	0.002
DNs (Total = 303)	219 (72)	68 (22)	13 (4)	3 (1)	
Missing: GPs = 21 and DNs = 5					
F) Access to hospice and specialist palliative care services by members of ethnic minority communities, requires to be improved.					
GPs (Total = 221)	52 (24)	105 (48)	54 (24)	10 (5)	<0.001
DNs (Total = 287)	153 (53)	104 (36)	26 (9)	4 (1)	
Missing: GPs = 51 and DNs = 21					

All the numbers within brackets () are percentages (%)

1 = very important/high priority; 3 = fairly unimportant/low priority;

2 = fairly important/moderate priority; 4 = unimportant/very low priority

*** Statistically significant p values are in bold**

Table 31 Importance given by GPs and district nurses to test statements

	1	2	3	4	P VALUE
G) ACCESS TO HOSPICE AND SPECIALIST PALLIATIVE CARE SERVICES BY YOUNG ADULTS (PARTICULARLY THOSE IN THE 16-24 YEAR AGE GROUP) REQUIRES TO BE IMPROVED.					
GPs (Total = 227)	59 (26)	89 (39)	68 (30)	11 (5)	<0.001
DNs (Total = 283)	175 (62)	93 (33)	11 (4)	4 (1)	
Missing: GPs = 45 and DNs = 25					
H) ACCESS TO HOSPICE AND SPECIALIST PALLIATIVE CARE SERVICES OF PEOPLE WITH LEARNING DIFFICULTIES REQUIRES TO BE IMPROVED.					
GPs (Total = 230)	35 (15)	100 (44)	83 (36)	12 (5)	<0.001
DNs (Total = 277)	151 (55)	110 (40)	12 (4)	4 (1)	
Missing: GPs = 42 and DNs = 31					
I) THERE SHOULD BE ROUTINE FORMAL ASSESSMENT OF BEREAVED CARERS TO IDENTIFY THOSE AT HIGH RISK.					
GPs (Total = 261)	34 (13)	127 (49)	81 (31)	19 (7)	<0.001
DNs (Total = 294)	139 (47)	126 (43)	27 (9)	2 (1)	
Missing: GPs = 11 and DNs = 14					
J) AFTER FORMAL ASSESSMENT BEREAVED CARERS SHOULD HAVE ACCESS TO INFORMATION ON THE FULL RANGE OF BEREAVEMENT SERVICES AVAILABLE.					
GPs (Total = 261)	83 (32)	130 (50)	39 (15)	9 (3)	<0.001
DNs (Total = 300)	206 (69)	82 (27)	12 (4)	Nil	
Missing: GPs = 11 and DNs = 8					
K) PHARMACISTS SHOULD BE ENCOURAGED TO WORK CLOSELY WITH PATIENTS AND THEIR FAMILIES TO ADVICE ON DRUG REGIMENS.					
GPs (Total = 262)	71 (27)	127 (49)	51 (20)	13 (5)	<0.001
DNs (Total = 300)	187 (62)	94 (31)	15 (5)	4 (1)	
Missing: GPs = 10 and DNs = 8					
L) THERE SHOULD BE GREATER LIAISON WITH PHARMACISTS AND GENERAL PRACTITIONERS. WHERE DRUG REGIMENS MAY BE CAUSING CONFUSION FOR THE PATIENTS AND THEIR RELATIVES					
GPs (Total = 262)	111 (42)	116 (44)	31 (12)	4 (2)	<0.001
DNs (Total = 300)	244 (81)	49 (16)	6 (2)	1 (0)	
Missing: GPs = 10 and DNs = 8					

All the numbers within brackets () are percentages (%)

1 = very important/high priority;	3 = fairly unimportant/low priority;
2 = fairly important/moderate priority;	4 = unimportant/very low priority

*** Statistically significant p values are in bold**

Table 32 Multiple logistic regression on test statements

Covariates	**Group (GPs and DNs)**	**Age Group**	**Useful to have more information on palliative care**
Dependent variable	**p=**	**p=**	**P=**
a) Hospital consultants who wish to refer patients to a hospice service should consult the GP first.	**<0.001**	0.02	
b) General practitioners ideally need protected time to deal competently and sensitively with this patient group and their families.			**0.003**
c) Community and practice nursing staff require further training in palliative care.	0.03		**0.009**
d) In health centres and/or localities one or more nurses trained in palliative care should be encouraged to develop this as a special interest	**<0.001**	0.05	0.01
e) The nurse above (e) trained in palliative care should provide assessment, advice about symptom control, and be involved in promoting psychosocial well being	0.01		0.01
f) Access to hospice and specialist palliative care services by members of ethnic minority communities requires to be improved	**<0.001**		0.03
g) Access to hospice and specialist palliative care services by young adults (particularly for 16-24 age group) requires to be improved	**<0.001**	0.03	0.01
h) Access to hospice and specialist palliative care services of people with learning difficulties requires to be improved	**<0.001**	0.05	0.05
i) There should be routine formal assessment of bereaved carers to identify those at high risk	**<0.001**	**0.006**	
j) After formal assessment bereaved carers should have access to information on the full range of bereavement services available	**<0.001**	**0.008**	
k) Pharmacists should be encouraged to work closely with patients and their families to advice on drug regimens	**<0.001**	0.02	
l) There should be greater liaison with pharmacists and general practitioners where drug regimens may be causing confusion for the patients and their relatives	**<0.001**		0.01

*** Statistically significant p values are in bold**

3.5.1. Multiple logistic regression

Table 32 above shows the significant differences for the responses by GPs and district nurses to test statements relating to their work. There was a total of 13 test statements and differences in nine of them were between the GPs and district nurses even after adjusting for the covariates mentioned in the methodology section. The other two covariates that were significant were *age* and *whether the respondents found it useful to have more information on palliative care.* Age was a significant covariant in one of the statements. Test statements b and c had those who found it useful to have more information on palliative care as a significant covariant (see Appendix 13 for details). This may be related to a greater interest in palliative care than other respondents.

3.6. General Practitioners and District nurses experiences on bed availability

Table 33 contains responses from GPs and district nurses about their experiences of the availability of beds when admission to a Hospice/Hospital had been requested for palliative care. They were able to choose from four options (always, usually, rarely available and no experience). A third of the GPs could always find a bed in the hospital while less than a tenth of GPs were always able to find a bed in the hospice. Less than a tenth of district nurses were always able to find places in both hospitals and hospices. More than two thirds of both GPs and district nurses were usually able to secure a bed for their patients in a hospice and over half of GPs and district nurses were usually able to admit their patients to a hospital bed. Overall the health care professionals found it easier to admit their patients requiring palliative care to a hospital bed than to hospice (Table 33). There were significant differences in their quantitative responses ($p = < 0.001$). Multiple logistic regression tests found significant differences between the GPs and district nurses responses to bed availability in hospices (see Appendix 13 for details) after adjusting for the covariants mentioned in the methodology section.

Table 33 Personal experiences on availability of beds for palliative care.

	ALWAYS	USUALLY	RAREL	NO	P VALUE
		HOSPICE			
GPS (TOTAL = 266)	17 (6)	189 (71)	58 (22)	2 (1)	<0.001
DNS (TOTAL = 303)	9 (3)	226 (76)	36 (12)	27 (9)	
		Missing: GPs = 6 and DNs = 10			
		HOSPITAL			
GPS (TOTAL = 264)	86 (33)	137 (52)	27 (11)	14 (5)	<0.001
DNS (TOTAL = 298)	29 (10)	192 (64	38 (13)	39 (13)	

Missing: GPs = 8 and DNs = 10

All the numbers within brackets () are percentages (%)

3.7. General Practitioners and District nurses opinions on place of death

The responses of GPs and district nurses to a question on their opinion of where their terminally ill patients would prefer to die are shown in Table 34. They were able to choose from four options, home, hospice, hospital and nursing home. They were requested to rank their choices in order of importance [1 = most important and 4 = least important]

The GPs and district nurses were unanimous in choosing home as first choice and hospice as second choice. More than 90 percent of the health care professionals were of the opinion that their patients preferred place to die was in their own home. Over 80 percent health care professionals selected hospice as the second choice. The third choice for the GPs (50 percent) was nursing home while the district nurses (60 percent) selected hospitals. These choices were reversed for the fourth choice where the GPs (57 percent) selected hospitals and the district nurses (62 percent) selected nursing homes. These findings are reflected in Table 34.

Table 34 GPs and district nurses opinions on where their terminally ill patients prefer to die.

HOME (P=0.98)

	1st	2nd	3rd	4th
GP (TOTAL = 255)	237 (93)	10 (3)	4 (2)	4 (2)
DN (TOTAL = 298)	277 (93)	11 (3)	5 (2)	5 (2)
Missing: GPs = 17 and DNs = 10				
HOSPICE (P=0.95)				
GP (TOTAL = 248)	10 (4)	214 (86)	21 (9)	3 (1)
DN (TOTAL = 296)	15 (5)	252 (85)	25 (8)	4 (2)
Missing: GPs = 24 and DNs = 12				
NURSING HOME (P<0.001)				
GP (TOTAL = 246)	5 (2)	17 (10)	123 (50)	101 (41)
DN (TOTAL = 296)	6 (2)	13(4)	91 (30)	186 (62)
Missing: GPs = 26 and DNs = 12				
HOSPITAL (P<0.001)				
GP (TOTAL = 250)	3 (1)	5 (2)	100 (40)	142 (57)
DN (TOTAL = 296)	3 (1)	8 (3)	178 (60)	107 (36)

Missing: GPs = 23 and DNs = 12 All the numbers within brackets () are percentages (%)

3.7.1. Multiple logistic regression

The significant differences between GPs and district nurses opinions (see Appendix 13 for full details) on where their terminally ill patients prefer to die lay between hospital (p= 0.001) and nursing homes (p=<0.001) (after adjusting for covariants mentioned in methodology section). Multiple logistic regression tests showed that the one other significant factor in both was whether the respondents had attended a course in palliative care (hospital p=0.02 and nursing home p=0.01) (see Appendix 13 for details).

3.8. General Practitioners and District nurses views on time of referral

The next question was regarding the appropriate time for initial referral of their patients with incurable disease to the specialist palliative care team. Health care professionals were provided with five situations and were requested to complete all the options.

The GPs and district nurses (55 percent of GPs and district nurses) were in agreement on when to refer to a specialist palliative care team, only in the situation *when family can no longer cope* (55 percent of GPs and district nurses). The differences between the GPs and district nurses, on when to refer to a specialist palliative care team, were significant in three instances. They were *at diagnosis* (40 percent of GPs and 76 percent of district nurses), when *death was imminent* (13 percent of GPs and 33 percent of district nurses) and when *further problems anticipated* (91 percent of GPs and 79 percent of district nurses). The differences between the GPs and district nurses are also shown in Table 35 and Figure 13.

The combined views of the GPs and district nurses as to the time of first referral to the specialist palliative care team is shown in Figure 14. The health care professionals give the highest priority to *when further problems anticipated* (85%) and the lowest priority to *when death imminent* (23%). The other times for first referral were *difficult symptom control* (80%), *at diagnosis* (58%) and *when family can no longer cope* (55%) in the order of priority.

Table 35 First referral to the specialist palliative care team, when appropriate?

	GPs		DNs	
	YES	**NO**	**YES**	**NO**
AT DIAGNOSIS (P<0.001)	**98 (40)**	**147 (60)**	**221 (76)**	**69 (24)**
Missing: GPs = 27 and DNs = 18				
DIFFICULT SYMPTOM CONTROL (P = 0.006)	**208 (85)**	**37 (15)**	**197 (75)**	**65 (25)**
Missing: GPs = 27 and DNs = 46				
FURTHER PROBLEMS ANTICIPATED (P<0.001)	**226 (91)**	**22 (9)**	**210 (79)**	**55 (21)**
Missing: GPs = 24 and DNs = 43				
FAMILY NO LONGER COPE (P = 0.91)	130 (55	107 (45)	144 (55)	116 (45
Missing: GPs = 35 and DNs = 48				
DEATH IMMINENT (P<0.001)	**30 (13)**	**202 (87)**	**85 (33)**	**172 (67**
Missing: GPs = 40 and DNs = 51				

All the numbers within brackets () are percentages (%)

Figure 13 When the patient should be referred for the first time to the specialist palliative care team.

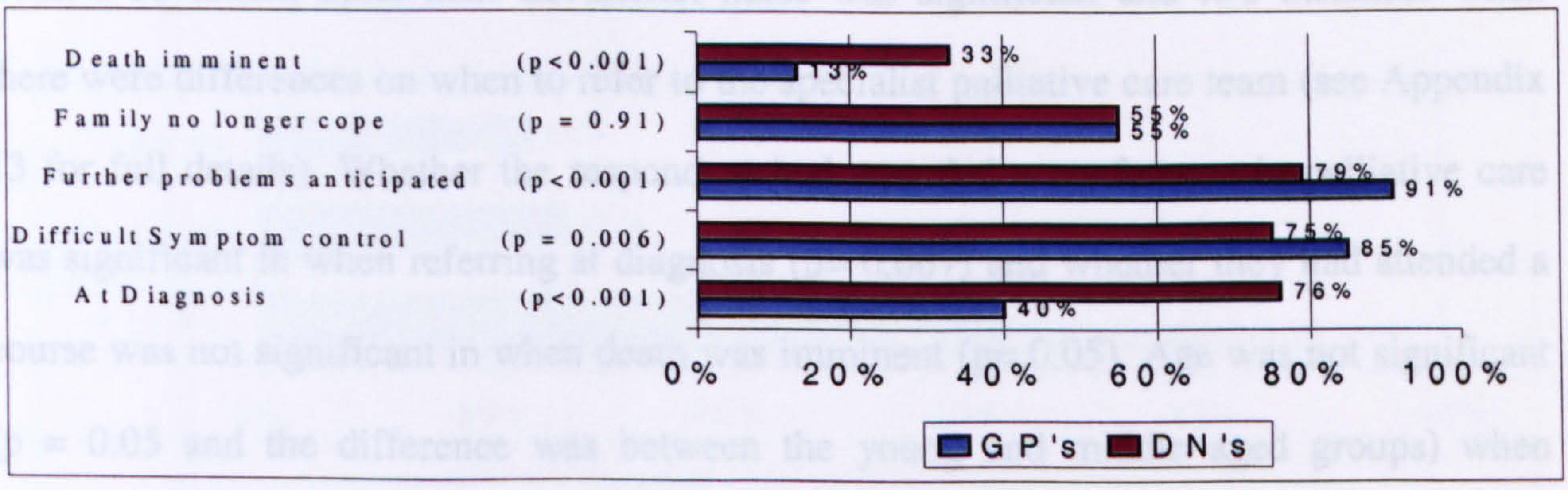
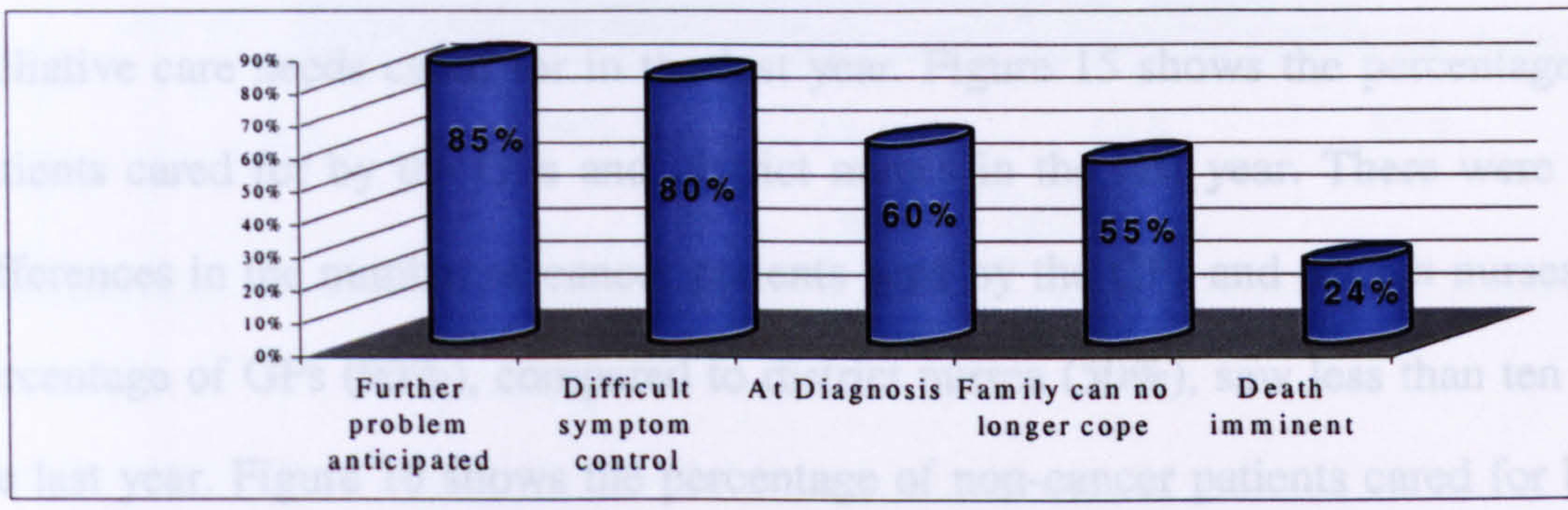


Figure 14 Combined GPs and district nurses views on when the patient should be referred for the first time to the specialist palliative care team.



3.8.1. Multiple logistic regression

The differences between GPs and district nurses were still significant, in all but one instance (when family can no longer cope), after adjusting for the covariants mentioned in methodology section. Multiple logistic regression tests showed that there was one instance when a covariant, other than GP/district nurse was significant and two instances when there were differences on when to refer to the specialist palliative care team (see Appendix 13 for full details). Whether the respondent had attended a conference in palliative care was significant in when referring at diagnosis (p= 0.007) and whether they had attended a course was not significant in when death was imminent (p= 0.05). Age was not significant (p = 0.05 and the difference was between the young and middle aged groups) when referring to a specialist team when symptom control was difficult (see Appendix 13 for details).

3.9. General Practitioners and District nurses palliative care caseload

The final question was regarding the number of cancer and non-cancer patients, with palliative care needs cared for in the last year. Figure 15 shows the percentage of cancer patients cared for by the GPs and district nurses in the last year. There were significant differences in the number of cancer patients seen by the GPs and district nurses. A higher percentage of GPs (90%), compared to district nurses (50%), saw less than ten patients in the last year. Figure 16 shows the percentage of non-cancer patients cared for by the GPs and district nurses in the last year. There were significant differences in the number of non-cancer patients seen by the GPs and district nurses. A higher percentage of GPs (95%), compared to district nurses (70%) saw less than ten patients in the last year. This may reflect lack of awareness of palliative care needs in non-cancer patients by GPs.

Figure 15 Cancer patients with palliative care needs cared for in the last year.

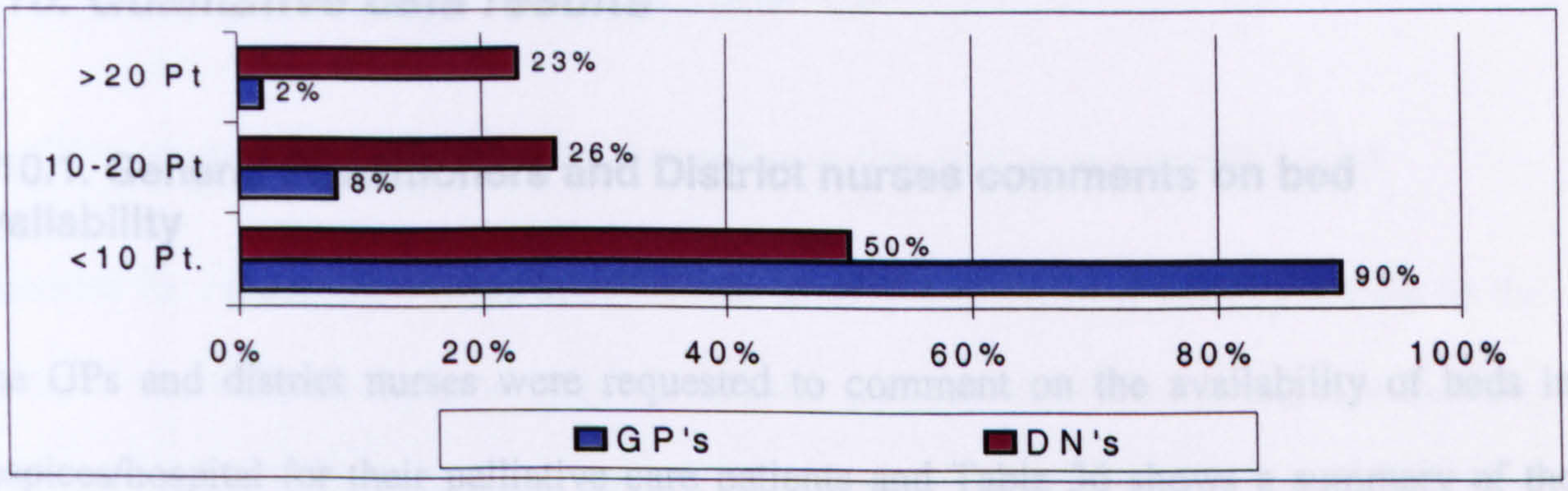
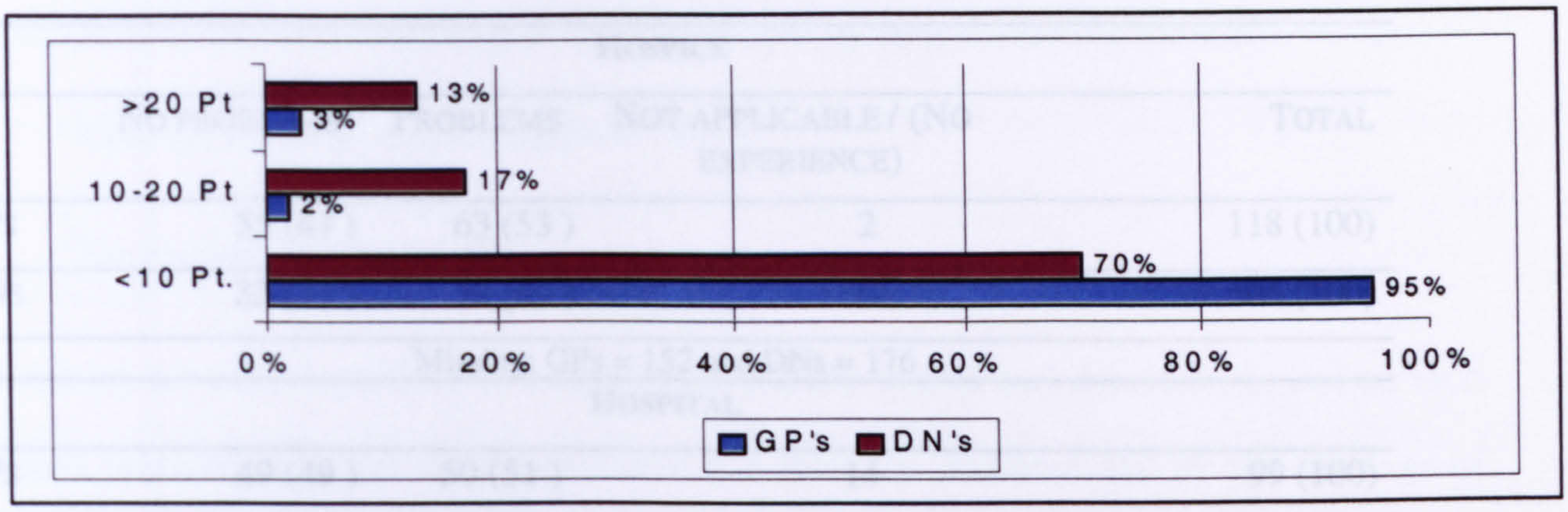


Figure 16 Non-cancer patients with palliative care needs cared for in the last year.



3.9.1. Multiple logistic regression

There were significant differences between GPs and district nurses, after adjusting for covariants mentioned in the methodology section, on the number of cancer patients ($p=<0.001$) and non-cancer patients ($p=<0.001$) seen in the last year. Whether they had attended a conference in palliative care had a significant bearing on the number of cancer patients ($p=0.005$) seen in the last year (see Appendix 13 for full details).

3.10. Qualitative data results

3.10.1. General Practitioners and District nurses comments on bed availability

The GPs and district nurses were requested to comment on the availability of beds in hospices/hospital for their palliative care patients and Table 36 shows a summary of the responses.

Table 36 Number of respondents who commented on bed availability

	NO PROBLEMS	PROBLEMS	NOT APPLICABLE / (NO EXPERIENCE)	TOTAL
HOSPICE				
GPs	55 (47)	63 (53)	2	118 (100)
DNs	33 (31)	72 (69)	27	105 (100)
Missing: GPs = 152 and DNs = 176				
HOSPITAL				
GPs	49 (49)	50 (51)	14	99 (100)
DNs	16 (21)	61 (79)	39	77 (100)
Missing: GPs = 159 and DNs = 192				

All the numbers within brackets () are percentages (%)

The quotes by GPs and district nurses on beds in hospice and hospitals were analysed and the summary is shown below.

3.10.2. Themes derived from quotes:

Admission for non-cancer patients to hospice was found to be difficult by both GPs and district nurses as highlighted by their following quotes:

> *"Difficult for admission for non-cancer patient "GP*

> *"Non-cancer disease patients requiring palliative care have poor availability." DN*

Admission for cancer patients to hospice was usually successful if already known to the hospice. It was difficult if unknown to the hospice (district nurses found that it is easier to achieve admission if the patient has had previous contact with the hospice or the specialist palliative care team). The following quotes by GPs and district nurses illustrate this:

> *"Usually ask if patient already known to hospice. Difficult if patient not seen previously" GP*

> *"If the patient has been assessed at home by a palliative medicine specialist it is usually easier to get a bed" DN*

Admission for cancer patients to hospice was identified as a problem by both the GPs and the district nurses due to shortage of beds as shown by their following quotes:

> *"More are required; availability poor" GP*

> *"Too few beds available" DN*

Admission for cancer patients to hospice was usually urgent and due to crisis and as such forward planning was not always possible and this was compounded by the shortage of beds. These views were expressed by both GPs and district nurses as shown below:

> *"Most admissions are urgent. Therefore immediate availability of beds is essential" GP*

> *"Planning admission is not possible as need for a bed usually occurs due to some type of crisis e.g. exhausted stressed family/carer" DN*

Admission for cancer patients to hospital was found to be always available. GPs and district nurses found it easier to get a hospital bed in emergency situations as seen by their quotes below:

> *"It is much easier to get admission to hospital than hospice" and "Always available but often not appropriate" GP*

> *"Admission quicker; easier to have patients admitted to hospital" and "Beds usually available, but not always appropriate" DN*

Admission for cancer patients to hospital was found to be inappropriate. 99 out of 272 (36 percent) GPs made a spontaneous statement that hospital is usually inappropriate and district nurses also commented on its appropriateness as shown by their comments below:

> *"Often inappropriate in acute receiving ward" and "Site of bed not suitable in hospital" GP*

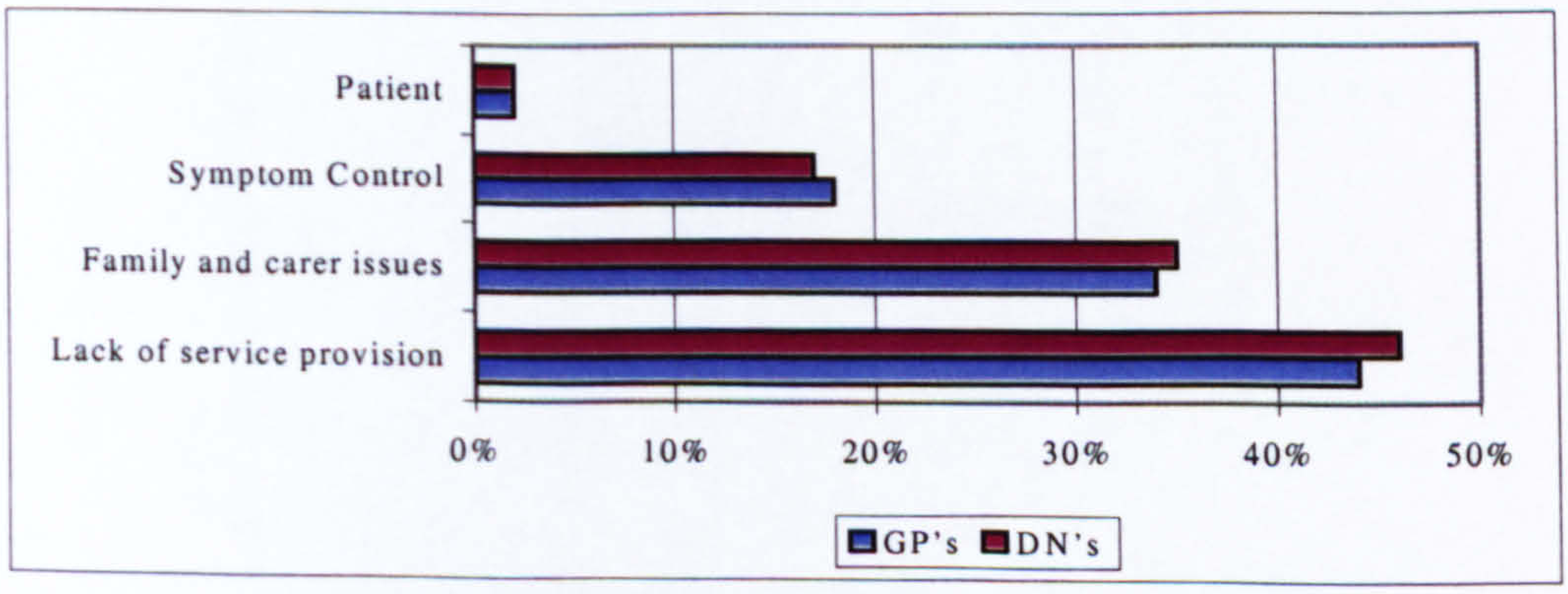
> *"This will be a bed in the acute setting. Not an area of palliative care" and "Too complex. Frightening in hospital setting" DN*

The themes emerging from the quotes by GPs and district nurses are very similar qualitatively although different quantitatively. Resources either in the form of increased hospice beds, hospice at home service or a special palliative care ward in hospitals seem to be one of the ways whereby patients can receive palliative care in an appropriate environment if hospital admission is required.

3.11. General Practitioners and District nurses perception of obstacles, which prevent the patients dying in the setting of their choice

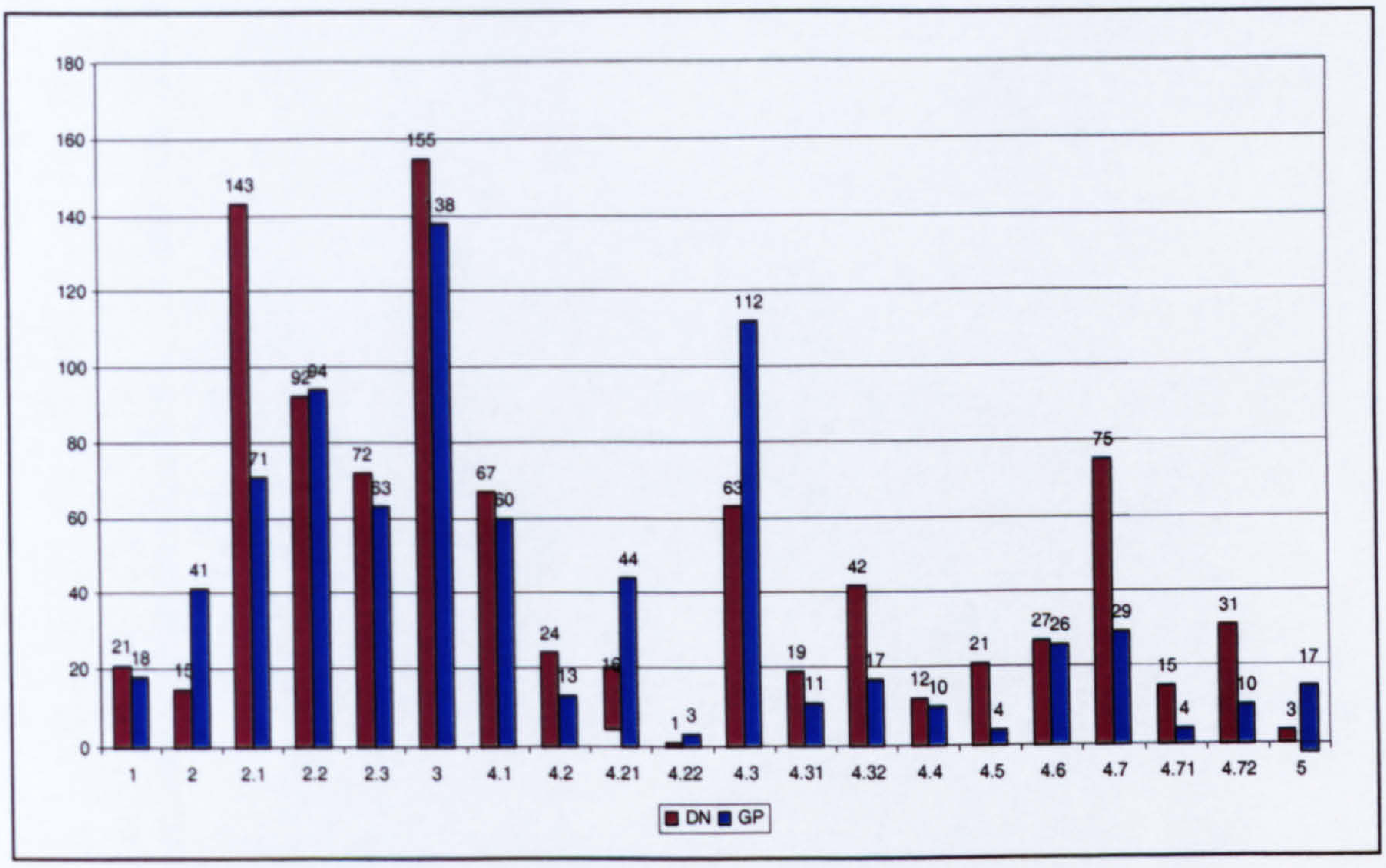
There were 1699 responses from the health care professionals when requested to mention three main obstacles which prevented their patients dying in the setting of their choice (Figure 17). The setting of choice of their patients was home (Table 34). The obstacles to remaining at home consisted of 4 main groups and were equally weighted by both the GPs and district nurses (Figure 18). The highest score was for service provision, identified by 44 percent of GPs and 46 percent of district nurses. The second and third obstacles were family and carers (34 percent by GPs and 35 percent by district nurses) and symptom control (18 percent by GPs and 17 percent by district nurses). The lowest score by both the GPs and district nurses was for the patient (2%) themselves (Figure 18).

Figure 17 Main obstacles to patient remaining at home



percentages quoted are of total obstacles mentioned [768 for GPs and 911 for DNs] rather than percentages of respondents

Figure 18 List of all the obstacles, which prevented patients achieving their choice of place of death.



The following are the codes used in the figure above.

1 = Patient (39)

2 = Family and carer (56)

  2.1 = lack of support (214)

  2.2 = physical (186)

  2.3 = emotional, problem coping (135)

3 = Symptom Control (293)

4 = Service provision (See Figure 19 and 20)

  4.1 = Lack of home help (social work) (127)

  4.2 = Lack of bed (37)

    4.2.1 = hospice (60)

    4.2.2 = hospital (4)

  4.3 = Lack of palliative home-care (175)

    4.3.1 = night support (30)

    4.3.2 = 24 hour nursing support (59)

  4.4 = Lack of communication among providers (22)

  4.5 = Lack of information to make choice (25)

  4.6 = GPs difficulties (53)\

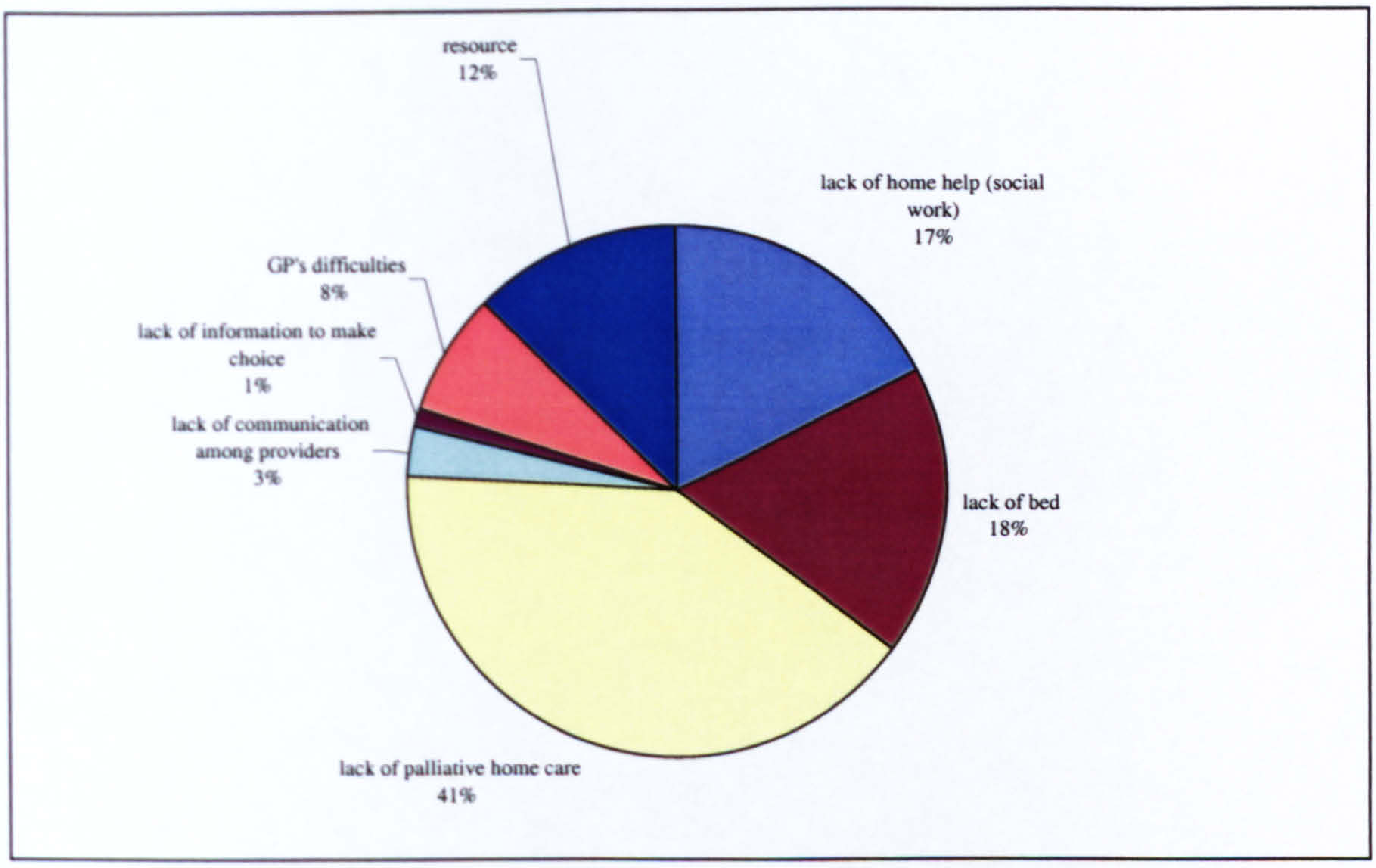
  4.7 = Resource (104)

    4.7 1 = facilities at home (19)

    4.7.2 = equipment (41) 5 = Others (20)

Numbers within brackets ( ) are totals of GPs and district nurses

Figure 19 Service provision obstacles mentioned by GPs

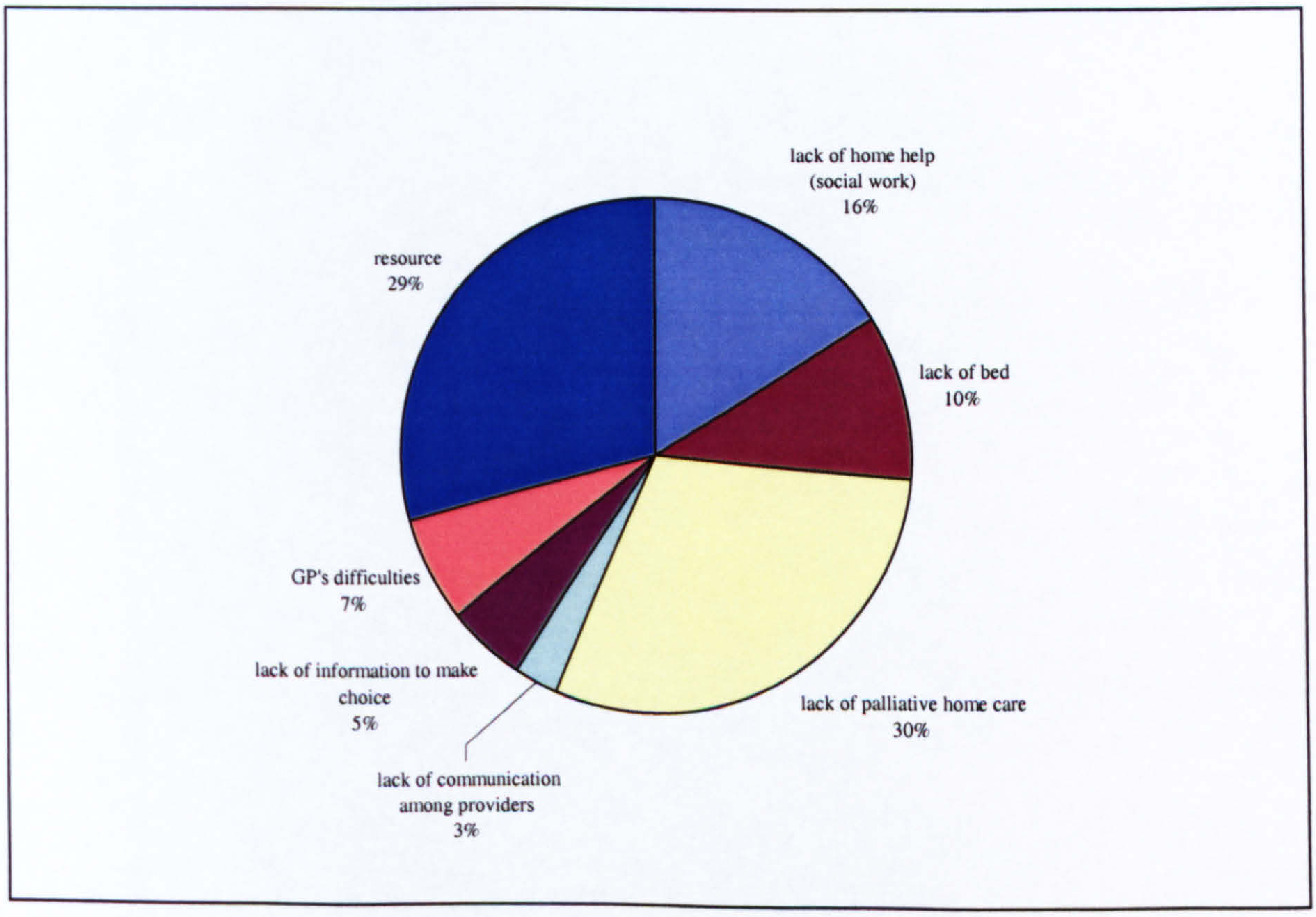


Service provision sub-groups were lack of home help by social service (17 percent of GPs and 16 percent of district nurses), and 18 percent of GPs and ten percent of district nurse identified general lack of beds (Figure 19 and 20). Lack of communication among the service providers was mentioned by three percent of GPs and district nurses. Lack of information to enable the patient to make the choice was only identified by one percent of GPs and by five percent of district nurses. Seven percent of GPs and district nurses (Figure 19 and 20) highlighted service provision obstacles that were due to problems for individual GPs.

When the issues of family and carers and service provision were further analysed it revealed that family and carer as a general obstacle was quoted by 15 percent of GPs and five percent of district nurses (Figure 21 [p=0.001]). Further sub-groups identified were lack of family support (26 percent of GPs and 44 percent of district nurses; p value was 0.001), physical reasons (35 percent of GPs and 29 percent of district nurses) and lastly emotional and coping problems were mentioned by 24 percent of GPs and 22 percent of district nurses (Figure 21).

Lack of hospice beds specifically was mentioned by 16 percent of GPs and five percent of district nurses (p=0.001). Lack of generalised palliative home care was mentioned by 41 percent of GPs and 30 percent of district nurses (p=0.000). The sub-groups were night support (three percent of GPs and five percent of district nurses) and 24 hour nursing support identified by six percent of GPs and 14 percent of district nurses (p=0.003) (Figure 22). GPs were able to identify global reasons e.g. lack of generalised palliative home care. The district nurses were able to identify individualised services e.g. lack of 24 hour nursing support.

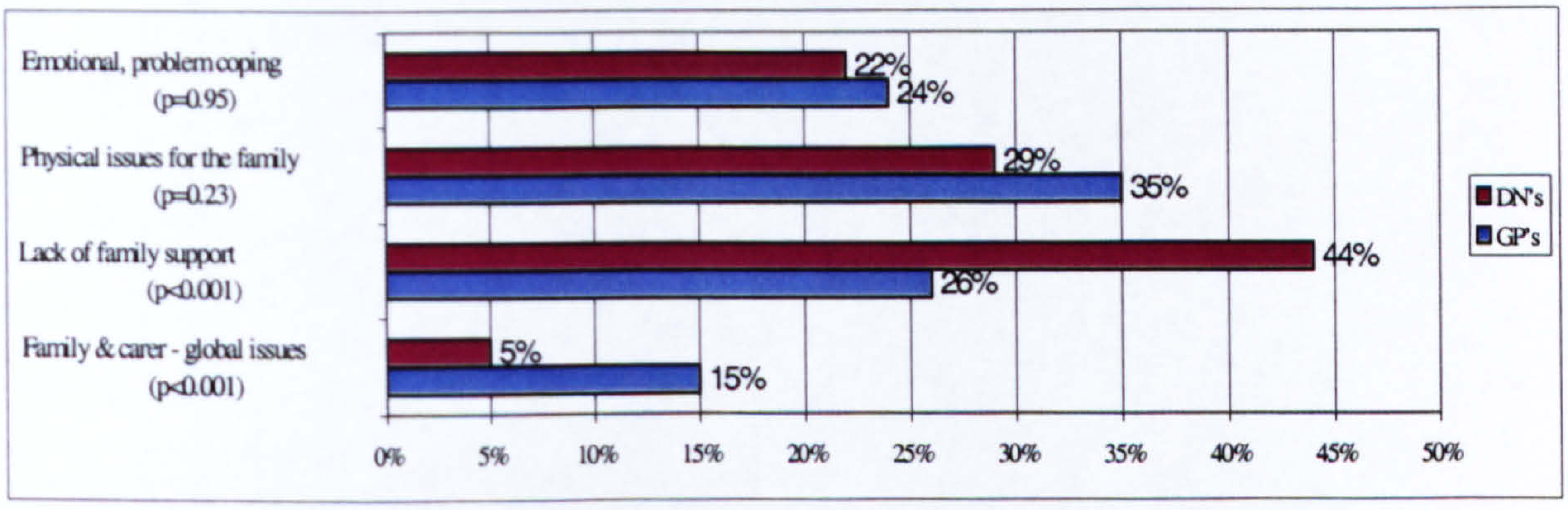
Figure 20 Service provision obstacles mentioned by district nurses



Lack of resources in general was highlighted by 12 percent of GPs and 29 percent of district nurses (p=0.000) (Figure 19, 20 and 22). The sub-groups were home environment/facilities (one percent of GPs and five percent of district nurses) and lack of equipment (four percent of GPs and ten percent of district nurses). Regarding resources, the district nurses not only highlighted them, but were also able to identify the different types of resources that were lacking.

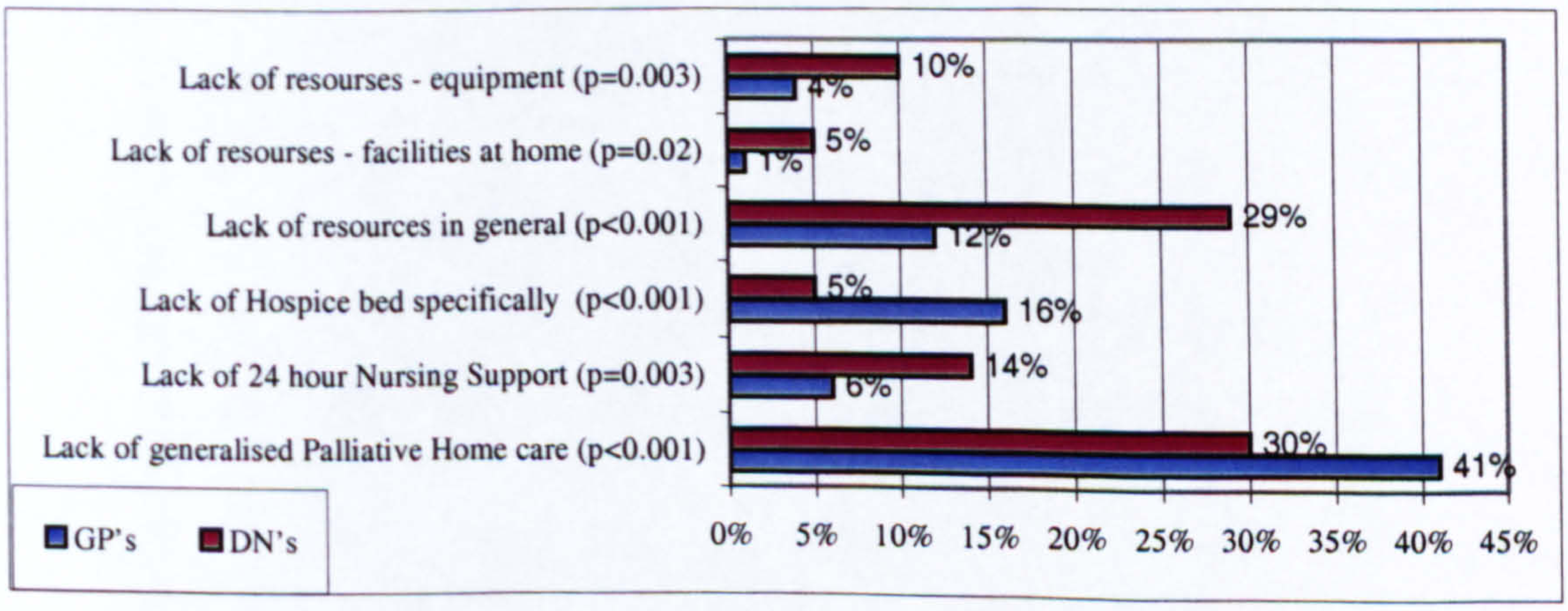
The final question asked if the respondents would like feedback on the findings from the questionnaire and 92 percent (276) of district nurses and 84 percent (224) of GPs requested for a copy of the findings from the questionnaire.

Figure 21 Obstacles concerning family issues



percentages quoted are of total obstacles mentioned [768 for GPs and 911 for DNs] rather than percentages of respondents

Figure 22 Service provision obstacles where there were significant differences



percentages quoted are of total obstacles mentioned [768 for GPs and 911 for DNs] rather than percentages of respondents

4. Discussion

4.1. Education

The results showed that only half of the respondents had attended palliative courses and only a quarter of the respondents had attended seminars (see Table 22). *Cancer Pain Relief and Palliative Care* was first published in 1990 and updated it in 2002 by the WHO and called on governments to ensure that healthcare workers are adequately trained in palliative care and the relief of pain and recommended that palliative care courses be an obligatory part of the basic training and certification of healthcare workers.[1] Recognition and knowledge of symptoms and treatment should be included in programmes of training for members of the primary health care team.[149] In the new medical curriculum of Glasgow University the students are introduced to palliative care issues early in their training and experience working in hospices and with patients requiring palliative care. The first batch of doctors who have undergone the new problem based learning technique of medical education qualified in 2002.

In this current study there were four training options (seminar, tutorials, hospice attachments and written information) in the questionnaire and average of the responses to the four options showed that 93 percent of the district nurses who responded were in favour of more training opportunities in palliative care compared to 76 percent of the GPs (see Table 22). Donald and MacPherson reported similar results in their report where 69 percent of GPs and 100 percent of district nurses were in favour of education/training in palliative care.[209] There is a need for increase in the educational opportunities for the GPs and district nurses so as to keep up with new advances and concepts in palliative care that have occurred over the past decade and will be occurring in the future. Addington-Hall and McCarthy (1995) in their study on *Dying from cancer: results of a national population-*

based investigation reported that education in the principles of palliative care is needed at all levels of the NHS.[74]

> *"Training on palliative issues is necessary for generic workers, not only specialist workers. Ranging from trained nurses and home helps. Again, understanding benefits the level of care given". – quote by a DN taken from the responses to the questionnaire survey of GPs and district nurses in part II of this current study.*

Millar (1996) in his article titled *Palliative care experience and training of Scottish General Practitioner trainees* and concluded that although trainees are being given clinical experience in dealing with patients requiring palliative care, training in the subject is virtually absent during their hospital years and inadequate during their general practice year.[135] He recommends that regional advisers must address this in training as tomorrow's GPs are acknowledging that there will be a significant increase in home based palliative care.[135]

> *"I recently attended an excellent and eye opening lecture of palliative care in cardiac failure". – quote by a GP taken from the responses to the questionnaire survey of GPs and district nurses in part II of this current study.*

Barclay (1997) reported from a postal survey with GPs that there was a continuing need for medical education in palliative care especially in basic medical education and during the clinical periods.[210] This should continue as they are junior doctors, and is especially important for communication skills and bereavement care.[210]

Education in any medical field is a continuous process and the GPs and district nurses, who are the main palliative care service providers in the community, need to keep up with the rapidly progressing field of palliative care. They need to keep abreast with palliative care developments and to be allocated time and resources to be able to provide the best possible palliative care service for their patients. Hillier (2001) assessed palliative medicine education in the UK and reported that palliative care training is important because it improves quality of life and relieves suffering for patients and families. These skills in palliative care (e.g. empathy, listening, communication, identification of problems and goals, developing priorities fast, and most importantly developing inter-professional teams so that patients get the right care at the right time) are useful in all health settings.[211] Hillier concludes by saying that palliative care education needs to start in the cradle and needs to continue to the grave. This need has to compete with the other fields of medical education which will have their own priorities.[211] Hillier's final word of caution to all is that none of us should be so arrogant that we consider only ourselves, our speciality or indeed our profession to have the monopoly for compassion and care.[211]

Multiple logistic regression tests found that in this current study the respondents who had attended conferences were significantly more likely to support all future palliative medicine specialist services (Table 29), future palliative home care by district nurses and occupational therapy from Social Services Department for non-cancer patients (Table 29). Whether the GPs and district nurses attended courses was found to be significant for the differences (hospital or nursing home) that were found in answers to the question on where the health care professionals thought their patients would prefer to die. Those who attended a conference (where the latest evidence is discussed and findings of various participants are presented as presentations or as posters) were more in favour of referring patients to the specialist palliative care team at diagnosis but those who had attended a course (where there are fixed syllabus and it is not possible to have a wider discussion) were more in favour of referring when death was imminent. These findings could be because in palliative care courses there are few topics about palliative care for non-cancer patients whereas in conferences there are more likely to be discussions around current views and new initiatives about palliative care for non-cancer patients.

The other covariant identified from multiple logistic regression where there was a significant difference was those who found it useful to have more information on palliative care. These were for future services, two for cancer patients and one for non-cancer patients. The other question where this covariant was also significant was for the responses to statements on palliative care issues. It was significant in two out of the 13 statements that the GPs and district nurses were requested to comment upon. This further supports the need for continuous education programmes for health care professionals and inclusion of conferences on palliative care issues concerning cancer and non-cancer patients. Information and knowledge on the latest palliative care issues will help the GPs and district nurses provide a better palliative care service for both cancer and especially non-cancer patients.

Bertero (2002) found that challenge, control, frustration and relationships were core for the caring philosophy of district nurses in Sweden involved in a qualitative study on their perception of palliative care in the home. His recommendation was that district nurses must be offered resources and education in order to be able to fulfil their commitment of providing good palliative care.[212]

Notcutt (2003) wrote in response to an article on *Care of the dying* by Ellershaw[75] and said Ellershaw's article should be a wake up call to the deans of medical and nursing schools and to the royal colleges.

> *"No longer is it acceptable to teach surgery and medicine and not include palliative care in the curriculum. The wards of our hospitals are full not only of curablly sick people who need care but also of dying people".*[76]

As this current study was being finalised a report was published in the latest RCN bulletin (17-30 September 2003) on the front page titled *Education fails cancer patients* and the RCN was urging for better training and issued its strongest warning of this need in their framework for training.[213] Commenting on the framework James Kennedy, RCN Scotland Secretary said: "Two out of five people in Scotland will be affected by cancer during their lifetime yet only 1% of nurses in Scotland have a specialist qualification in cancer care. This framework recommends that the Scottish Executive commits to better cancer training not only for nurse specialists but also for nursing students in order to improve the care given to cancer patients and their families. We are calling on the Scottish Executive to adopt these recommendations and to follow our lead by drawing up a framework for cancer nursing".

4.2. Current and future palliative care services in Glasgow

Patients requiring palliative care regardless of diagnosis spend most of their lifetime in the community. The GPs and district nurses acknowledged the importance of specialist palliative care services. This highlighted the lack of social services, particularly occupational therapy input and lack of equipment both from social services and the health board.

> *"Nursing patients in the community requiring palliative care requires time - care and sensitivity - this is a time when we should be able to spend Time with these patients and their families which is not always the case". – quote by a DN taken from the responses to the questionnaire survey of GPs and district nurses in part II of this current study.*

> *"Also feel, services for cancer patients can be started quicker than for non-cancer i.e. wheelchair order - 7 months waiting list - only cancer patients have priority". – quote by a DN taken from the responses to the questionnaire survey of GPs and district nurses in part II of this current study.*

In this current study there were significant differences between the views of GPs and district nurses and these differences were found to be still significant (more for non-cancer patients) after adjusting for all the covariates (Table 29).

Barclay et al in 1999 found significant differences in the views of GPs and district nurses regarding service adequacy and priorities for future development.[152] His study found that the district nurses had a better insight into the needs of patients requiring palliative care.

There were three services where both the GPs and district nurses agreed on and identified gaps in the palliative care services. Less than 50% of GPs and district nurses felt that the social workers, occupational therapist and access to equipment from the social services department for both cancer and non-cancer patients were adequate (Tables 23 and 24).

The usage of telephone advice for palliative care in the current study showed that very few had used the service (GP = 25% and 9% and for district nurses = 24% and 14% for cancer and non-cancer patients respectively). Most of those who had used it felt that it was adequate (>80%). When asked about the priority of telephone advice in palliative care in the future the response was 34% and 26% by GPs and 68% and 56% by district nurses for cancer and non-cancer patients respectively. This contrasts with the findings of a recent public survey (2003) report published by the Scottish Partnership for Palliative Care which found that 79% of the respondents were supportive of a telephone advice line. [214]

4.2.1. For cancer patients

Overall the GPs and district nurses recognised/identified the cancer patients' needs and were in favour of better cancer services in the future. The greatest positive shift by district nurses in the ranking from current to future services was for access to equipment from both Health Board (+11) and Social Services (+10 [see Table 27]). The greatest negative shift (-5) was for 24-hour telephone advice for palliative care issues (by GPs) and palliative day care in the hospice (by district nurses). The district nurses placed lesser importance (negative shift of 4) on Macmillan services for the future than the GP (positive shift of 3) and this concurs with the findings of Barclay.[152]

> *Any competent SP/district nurse team should be able to provide reasonable quality palliative care if backup from accessible hospice/hospital specialist team easily available in time of difficulty. I do not think further sub/local specialising is the way forward e.g. I do not find Macmillan nursing services adds more. Sorry is this hearsay". – quote by a GP Principal taken from the responses to the questionnaire survey of GPs and DNs in part II of this current study.*

Dyer's study on GP's perspectives on service provision in Forth Valley found that the GPs used the two local hospitals equally with a high percentage of GPs indicating use of the local hospice unit mainly for in-patient symptom control, consultant advice, Macmillan nursing, respite and day care services.[139] Hunter found that in palliative care district nursing 50 percent of the workload was for cancer patients and only seven percent was for multiple sclerosis and one percent was for motor neurone disease.[140] Elfrink et al (2002) looked at the use of a telephone consultation palliative care service by GPs and district nurses but it was only for cancer patients.[215] Over a three year period they found that the frequency of calls from the GPs did not change but the calls from the district nurses rose from 12 % to 35% and 48% over this period[215]. These findings are similar to the current study where the district nurses were more in tune with changes in palliative care services and were willing to use them.

4.2.2. For non-cancer patients

There is great current interest amongst specialist palliative care practitioners to increase palliative care services to include more non-cancer patients. This should also be discussed and encouraged among the GPs and district nurses as they provide care in the community. More than 70% of GPs and district nurses gave high priority for palliative outpatient services in hospices for cancer patients but less than 45% said it was of high priority for non-cancer patients (Table 25 and 26). This highlights the lack of recognition of health professionals for need for palliative care for non-cancer patients.

The district nurses gave the lowest ranking for future Macmillan services for non-cancer patients (shift of –12 from adequacy of current services [Table 28]) and the GPs gave it the third lowest rank (shift of –7). This might be due to the fact that Macmillan services are not provided for non-cancer patients. There were significant differences in responses of GPs and district nurses to all identified palliative care services (Table 29). The district nurses views and perceptions were for more palliative care services to meet the needs of non-cancer patients. This could be explained by the fact that the district nurses had more exposure to the non-cancer patients than the GPs (Figure 16).

"Young disabled adult's attendance at hospice for respite – is this appropriate? Are the alternatives appropriate? i.e. nursing home or Young Disabled Unit at Southern general. This is certainly an area for further discussions. The skills of a palliative care consultant in linking with rehabilitation consultant would greatly benefit our client group in management of pain/spasm". – quote by a physical disability team nurse dealing with multiple sclerosis taken from the responses to the questionnaire survey of GPs and district nurses in part II of this current study.

At the moment, I feel that non-cancer patients would benefit from the wonderful work that the hospice staff do – but I wouldn't dream of referring this patient because I know that they cannot cope with our cancer patients". – quote by a DN Sister taken from the responses to the questionnaire survey of GPs and district nurses in part II of this current study..

"Only problem has been access to services for non-cancer disease e.g. heart failure, Motor Neurone disease (over past 5 years or so)". – quote by a GP taken from the responses to the questionnaire survey of GPs and district nurses in part II of this current study.

4.3. Statements on palliative care issues

There were significant differences, in nine out of the 13 statements, between the GPs and district nurses even after adjusting for the covariates. In these nine statements there were two other covariates that were significant in three statements (see Appendix 13). *Age* and *useful to have more information* showed significant differences for: a) developing palliative care services for young adults; b) for those with learning disabilities; c) to encourage, in health centres/localities, a nurse trained in palliative care to develop this as a special interest. Age also showed significant differences for statements concerning bereaved carers services/access and pharmacist role in advising patients and these issues might be acceptable for the younger GPs and nurses.

4.4. Hospice and hospital beds

This current study showed that GPs sent their urgent palliative care patients to hospital because of ease of access and difficulties in procuring early admission to a hospice bed unless the patient was already known to the hospice. GPs acknowledged that hospital was not an appropriate place for palliative care due to the hospitals acute care nature, the lack of privacy and lack of individual nursing care. Mills (1994) studied the *care of dying patients in hospital* and concluded "care for many of the dying patients observed in these hospitals was poor".[216] A letter by Bennett questioned Mill's findings and postulated that since the study was carried out the palliative care movement has been developing.[217] The problem with Mills's study was that it was conducted in 1983 but only published in 1994. In the last 10 years hospital specialist palliative care services have further developed and hospitals have been increasingly involved with care of the dying. This is because of increased awareness of palliative care philosophies in statutory sectors and public expectations.

Low et al (2001) demonstrated that GPs in Eastern Sydney were tending to over-hospitalise their complex palliative care patients in the community.[218] Todd's (2002) study found that hospital at home care was worse than NHS services in terms of availability and limits on duration of care[130]. So four years after this study we still find that GPs and district nurses have to refer their palliative care patients to hospitals rather than to hospices or home care. Shipman (2002) found that previous experience with, and easy access to, specialist palliative care services were important factors in decision making about placement as was shown in this current study.

The GPs and district nurses had no choice but to send many of their patients requiring palliative care to hospital as shown by the current study. Hockley (1989) found that hospital nurses generally found caring for the terminally ill rewarding but the younger nurses found it difficult to cope with the emotional aspects.[219] In this current study the district nurses preferred a nursing home to a hospital for their palliative care patients and this could be because they knew that the hospital setting was generally inappropriate for patients requiring palliative care. Herd's study (1990) on *Terminal care in a semi-rural area* concluded that the commonest reasons for hospital admission for these patients was the lack of care at home and that nearly half the patients dying in hospital were in acute wards. Acute wards are frequently criticised by nurses and relatives as being unsuitable for dying patients.[70] A decade later we are facing similar situations. Herd concluded that a need for expert advice on palliative care was revealed.

Differences between the GPs and district nurses responses to bed availability were still significant for hospice beds but disappeared for hospital beds after adjusting for the covariates. The hospice beds in the GGNHSB area have reduced by three in the largest hospice over the two years of this current study but other palliative care services (including day-care, out-patient and home care) have remained the same or increased across all the hospices (see Appendix 8). Dyer's study also found that of the patients who died in hospital GPs views were that this setting was not appropriate.[139]

"Through past experience have found that I have spent a lot of time convincing patients/carers that it would be beneficial to patient to be admitted to hospice and then find it soul destroying to be told there is no bed". *quote by a DN Sister taken from the responses to the questionnaire survey of GPs and district nurses in part II of this current study.*

"I have experienced situations where my patient has much preferred hospice admission and I have had to admit to hospital because of lack of bed. I did feel the patient has been let down by the services". *quote by a GP Principal taken from the responses to the questionnaire survey of GPs and district nurses in part II of this current study .*

4.5. Preferred place of death for the patients

There was unanimous agreement among the GPs and district nurses that the preferred place of death was in the patient's home (93 percent) and the next best place was the hospice. There is evidence to support the case that most patients would prefer to die at home.[9] However, the statistical evidence on actual place of death does not reflect this preference.[10] The paradox of terminal care (where patients would prefer to die at home but statistical evidence showing different results) is seen in Glasgow where, despite it being known that many patients with cancer wish to die at home, only 27 percent of all cancer patients do so.[148] About 52 percent of cancer patients die in NHS general hospitals and 19 percent in a hospice (Table 37). Sims et al (1997) showed in their study that there was statistically significant evidence that place of death was associated with social class.[77] Grande et al (1998) showed in their study that cancer patients in higher socio-economic groups were both more likely to die at home and to access home care.[78]

Table 37 Deaths from cancer by place of death - GGNHSB residents 1989-91

	All Cancers 1991* (ICD9 140-208)
NHS Hospital	1709 (52)
Hospice	629 (19)
Own home	867 (27)
Other**	66 (2)
Total	3271

Source: Registrar Generals Quarterly lists ** Private hospital, private nursing home, home for elderly elsewhere

All the numbers within brackets () are percentages (%)

The GPs preferred nursing home to hospital while the nurses preferred hospital to nursing home as third and fourth choices and this difference was significant (p<0.001). These differences remained significant after adjusting for the covariates. The GPs have access to nursing homes and see these patients there whereas district nurses have no access to nursing home patients as the nursing homes have their own nursing staff. The district nurses have more contact/experience with hospital services as patients discharged to the community from hospitals are discharged to the care of the primary healthcare team and any nursing care/follow-up care is continued by the district nurses in consultation from the GPs. The only other significant factor to this question was attendance of a palliative care course by the respondents and this might be because those who had attended a course on palliative care would understand the need for the patient to have a choice in the place of death (see Appendix 13).

Higginson's (1998) study on ten year trends in place of death of cancer patients in England found that hospitals were still the most common site (though it is reducing) followed by hospices and nursing/residential homes (showing largest increases).[73] This current study shows that GPs prefer nursing homes to hospitals and they might be using the residential/nursing homes in preference to the hospitals.

4.6. Obstacles to patients preferred place of death

The obstacles identified by the GPs and district nurses in this current study were: i) patient, ii) family and carer issues [lack of support, physical and emotional, problem coping], iii) symptom control, and iv) service provision [lack of home help (social work), lack of hospice and hospital beds, lack of palliative home-care e.g. night support and 24 hour nursing support, lack of communication among providers, lack of information to make choice, GPs difficulties, and resources e.g. facilities at home and equipment]. These identified obstacles should be taken into account when planning future services and if addressed would help many patients to fulfil their wish and stay at home.

The main obstacles identified by the GPs and district nurses were lack of service provision, family and carer issues and symptom control. When these main obstacles were further divided into sub-groups there was a tendency for the district nurses to be more specific than GPs. This could be because the district nurses had a higher caseload of patients requiring palliative care compared to GPs as shown in Figure 15 (for cancer patients) and Figure 16 (for non-cancer patients) and as such might have increased contact with the patients and their views. Donald and MacPherson reported similar caseload differences between GPs and district nurses in their report on palliative care in Scotland.[209]

GPs were able to identify global reasons and district nurses were able to identify individualised services (see Figures 19 to Figure 22). In 1986 a needs assessment of services for terminal patients in Glasgow and use of services by GPs, was carried out by interviewing 64 GPs (10 percent of GGNHSB total)[147]. The study concluded that many (40%) GPs were unaware of the existence of important services and that a majority (60%) thought the home help and night-nursing services were inadequate. Donald and MacPherson reported that only 29 percent (182) of their total respondents (617) were able to identify links between service providers in relation to palliative care. Their respondents consisted of GPs, district nurses, Marie Curie employees, Macmillan employees, nursing home employees, specialist palliative care unit staff, social workers and hospital consultants. From the GPs only 11 percent of the respondents were able to identify links between service providers in relation to palliative care compared to 33 percent of the district nurses who responded. The findings from the above mentioned two studies[147;209] which might explain the reason the district nurses are more specific about these obstacles.

Thorpe's[72] study (1993) summarised the points that would enable dying people to remain at home. They were adequate nursing care, a night sitting service, good symptom control, confident and committed GPs, access to specialist palliative care, effective co-ordinated care, financial support and terminal care education. In this current study all of these have been identified as obstacles that prevent dying people remaining at home. Seven years later there has not been much progress to remedy this.

Thorpe's[72] study confirmed the following two paradoxes i) most dying people would prefer to remain at home but most of them die in institutions ii) that most of their final year was spent at home but most people are admitted to hospital to die. His plan for government action was to expand the patient charter, invest in primary care, implement *The Principles and Provision of Palliative Care*[15] and to provide adequate funding for community care. There have been patchy improvements in palliative care services and patients were enabled to die in their home due to pilot/research projects where selected areas/patients have been cared for at home in *hospice at home* initiatives. These are not the norm but they should be. Most of the changes have been for cancer patients and changes for neurodegenerative patients have a long way to go.

In 2001 there was a case in court where a patient with multiple sclerosis took his health authority to court in order to receive terminal care at home.[220] The court found in his favour. This was a single case and has not prompted the government to introduce any new changes for all multiple sclerosis patients. Another patient who took legal action in 2001 had motor neurone disease and wanted the public prosecutor not to take any legal action if her husband helped to end her life due to her suffering.[221] The court rejected her request, as it would have re-opened the whole debate about euthanasia. They even took the case to the House of Lords in London where it was rejected also. Whether this patient and her family had received *holistic* palliative care or not is uncertain and this might have influenced their decision to go to court. At the same time in 2001 a professor of medical ethics wrote that it was morally wrong for the courts to reject the case of the motor neurone disease patient in an article titled *Why active euthanasia and physician assisted suicide should be legalised* and has provoked people to further debate the euthanasia issue[222]. Scott (2003) wrote that "high quality palliative care is not available to everyone in the UK; therefore, many people, when faced with the symptoms and fear associated with terminal conditions, do not feel that there is a credible alternative to assisted death".[223] When a person requests euthanasia the first step for health professionals must always be to consider the services that were made available to that person and his/her family and to examine why the health service failed.[223]

4.7. When to refer to Specialist Palliative Care

The Palliative Cancer Care Guidelines[6] on time of referral to specialist palliative care services are as follows:

On discharge from Hospital – Care at Home – When illness recurs:

> *"identification of the patients needs and of the appropriate resources to meet these needs may require advice and input from specialist palliative care services. Referral to a palliative care unit or services should be considered wherever possible before critical events occur".*

During the Illness – Terminal stage – Bereavement:

> *"throughout this time the effectiveness of pain and symptom management should be kept under constant review along within the level of psycho-social, spiritual and family support. The primary health care team and relatives will normally do this. Later they may need to refer to specialist palliative care staff or services for advice or support".*

Early referral should ensure better symptom control and prevent other problems developing. In this current study the district nurses recommended referring at diagnosis and this might reduce the number of urgent referrals. GPs (91 percent) and district nurses (79 percent) gave the highest score to *future problems anticipated* as a factor in deciding when to refer to specialist palliative care. This indicated that both (especially the GPs) would prefer to be prepared for problems before they happen. About 80 percent of the GPs and district nurses prefer early specialist palliative care involvement for anticipated problems and symptom control. This has implications for resources which will increase when non-cancer patients requiring palliative care are included. These views will be very useful in any forward planning of services.

> *"We like to provide palliative care ourselves within the practice. While some specialist liase well with us, others tend to take over management and make changes/decisions without consulting us. This makes me cautious about referring to the specialist services unless I feel my expertise is insufficient for a particular problem". quote by a GP taken from the responses to the questionnaire survey of GPs and district nurses in part II of this current study*

Combining the views of GPs and district nurses, the most common referral time was when further problems were anticipated (85 percent) followed by difficult symptom control (80 percent), at diagnosis (58 percent), when family can no longer cope (55 percent) and lastly when death is imminent (23 percent). The differences between GPs and district nurses on the times of referral at diagnosis and imminent death remained significant even after adjusting for the covariates. In both instances there were more district nurses in favour of referring to the specialist palliative care team. Specialist palliative care encourages early referral to its service and overall district nurses views are more inclined towards early referrals.

The district nurses have more contact with patients in their homes and this may allow them a greater understanding of patients' needs. These views on care should be considered in future planning. Todd (2002) found similar numbers in his study which was nearly four years after the current study.[130] In Todd's study district nurses (93%) and GPs (57%) referred patients to specialist palliative care services and the district nurses (90%) and GPs (42%) admitted their patients requiring palliative care to the hospital at home care. In both instances the percentage of district nurses referring or admitting their patients to the hospital at home was higher than that for the GPs.[130]

5. Conclusion

Overall in this current study the district nurses (rather than GPs) were more supportive of the palliative care needs of non-cancer patients, able to identify sub-groups within global issues in palliative care and were more inclined to want information, training and attachments in palliative care. Hatcliffe in 1996 published his findings on *district nurses perception of palliative care at home* and identified high levels of satisfaction with the palliative care team and a need for further education and improved communication.[138] The district nurses in the GGNHSB area also cared for a higher number of cancer and non-cancer cases compared to doctors. Asch et al (1997) in their article *The limits of suffering: critical care nurses views of hospital care at the end of life* found that some nurses were frustrated about their limited role in the management of patients at the end of life, given their special understanding of these patients experiences and wishes[224]. Similar feelings were expressed by district nurses in the current study.

Christakis and Lamont (2000) found that doctors tend to be inaccurate in their prognosis for terminally ill patients.[225] Only 20 percent of the doctors' predictions were accurate. The majority, 63 percent were over-optimistic and 17 percent were over-pessimistic. The stronger the doctor patient relationship the lower the prognostic accuracy.[225] This has implications in palliative care in the community where the doctor should know when to stop active treatment/resuscitation in terminally ill patients.

Wilkes (2001) found that nurses providing palliative care at home were more prone to stress than nurses not providing this service, and suggested that some form of debriefing for nurses would help and that this could be enhanced by educational and support sessions.[226]

In spite of all this the patients' perceptions must be taken into account as has been demonstrated by a study by Krishnasamy (2001) which found that lung cancer patients reported that they found the hospital doctors (76%) and their GPs (65%) were their key source of support and were identified as being particularly helpful when compared to hospital nurses (48%) and district nurses (20%).[155]

In the current study the GPs and district nurses stated that patients who had previously been seen by the palliative care specialist or the hospice team were more likely to be admitted to the hospice than those who were not known. A study on cancer patients by Grande et al (2002) reported that referral to palliative home care is more likely among patients who have had prior contact with cancer services.[227] They also found patients referred to the hospital at home service were younger and lived in less deprived areas.[227] Not much has changed since the current study.

Hanratty's study (2002) on doctors' perception of palliative care for heart failure patients highlighted that the GPs feel that they should be the main carer in the community for palliative care for non-cancer conditions.[137] For this to happen the GPs have to acknowledge that non-cancer patients need palliative care and the current study shows that the district nurses are more inclined to accept this than the GPs. The positive aspect of Hanratty's study was that doctors were in agreement that the role of the district nurses in palliative care should be developed.[137]

The objectives on the palliative care views of the GPs and district nurses were assessed in this chapter. There were significant differences between the views of the GPs and district nurses in the following null hypothesis, which are rejected:

There is no difference between the views of GPs and district nurses concerning:

- current palliative care services for cancer patients,
- current palliative care services for non-cancer patients,
- future palliative care services for cancer patients,
- future palliative care services for non-cancer patients,
- hospice bed availability for palliative care patients,
- hospital bed availability for palliative care patients,
- place of death for their terminally ill patients (for 3rd and 4th choice),
- obstacles preventing their terminally ill patients from dying in the place of their choice,
- when first to refer their patients with incurable disease to the specialist palliative care team.

Chapter 7

Palliative care service users - cancer *(lung, breast and colo-rectal)* and non-cancer *(neurodegenerative diseases)* in the GGNHSB area

Objectives:

i) *to undertake a health status assessment and measure the outcome of care for:*

- cancer patients (lung, breast and colo-rectal),
- non-cancer patients (neurodegenerative diseases - motor neurone disease, Huntington's disease and multiple sclerosis),

ii) to determine the patients knowledge of available palliative care services in GGNHSB area.

Null hypothesis:

- *There are no differences between the perceived health problems of patients with cancer (lung, breast and colo-rectal) and non-cancer diseases (neurodegenerative diseases - multiple sclerosis, motor neurone disease and Huntington's disease).*
- *There are no differences between the outcome of the care of patients with cancer (lung, breast and colo-rectal) and non-cancer diseases (neurodegenerative diseases - multiple sclerosis, motor neurone disease and Huntington's disease).*
- *The patients needing palliative care are aware of the palliative care services available in GGNHSB area.*

1. Methods used in the preparatory stage

The third part of the current study (Figure 4) dealt with the needs of patients from the perspective of patients themselves. The interviews involved two groups of patients (cancer and non-cancer). The data collection with patients involved quantitative methods using validated tools and summary qualitative data recorded from patients willing to provide comments on personal experiences. The perceived health problems of the patients were measured and the outcome of palliative care input was assessed. This was achieved using validated tools.

1.1. Tools used for patient interviews

In 1997 when the initial proposal was submitted to the ethics committee the European Organisation for Research on Cancer Treatment Quality of Life Questionnaire (EORTC QLQ-C30) was the tool selected for patient interviews. No interviews were conducted in 1998 and it was decided to change the tool for the interviews from the original EORTC QLQ-C30 to the Nottingham Health Profile (NHP) and the Palliative Care Outcome Scale (POS). The reason for this change was the EORTC QLQ-C30 was developed for lung cancer patients to evaluate their quality of life in patients participating in international clinical trials. It was validated in 1993.[228] It contains a generic core with "cancer-specific" modules and work is being carried out to extend the questionnaire for patients with more advanced cancer.[229;230] Hearn and Higginson in their review of outcome measures stated that some questions in the EORTC QLQ-C30 were thought to been inappropriate and have caused distress in patients with advanced disease in a French community setting.[231]

Siegrist's study (1990) measuring the social aspect of subjective health in chronic illness found that the EORTC was far too limited and ignored much of the impact of cancer on social life.[232] Siegrist (1989) commented that the NHP measured along six different dimensions and was capable of discriminating between elderly patients with different degrees of disability.[233]Montazeri used the EORTC questionnaire for a PhD study on the quality of life in lung cancer patients in the North-East sector of Glasgow and it was found that some questions did not make sense for patients in the UK.[143] Montazeri found that the EORTC questionnaire was limited in identifying patient's needs with regards to financial difficulties, or even issues relating to the patient's family and social life and that the wording of the questions was inadequate and that they were unlikely to identify patients' needs.[143] In this current study the sample included both cancer and non-cancer patients who require palliative care. This current study was assessing patients' needs and therefore tools capable of measuring outcome, one for general health status and one for palliative care were chosen. The NHP and the POS fulfilled these criteria.

1.1.1. Nottingham Health Profile

The NHP (Appendix 14) is a generic instrument[234] used to measure physical, social and psychological distress and it evolved from the Nottingham Health Index, which was tested in studies between 1976-78.[235] The Nottingham Health Index originally had 136 statements that were reduced to 82 after these studies. The NHP originated as a "population screening tool" and was to be a measure of subjective health status. However the authors believe that it is more helpful to regard the NHP as a measure of perceived distress in the physical, emotional and social domains. It has been translated and validated for use in Spanish, Catalan, French, Italian, German, Dutch, Danish, Swedish and Finnish with consideration to the linguistic and conceptual differences of various cultures.[236] It is also available for use in North America. The NHP consists of two parts and the second part is recommended only where it is relevant for the group under study.

The NHP was first developed in September 1975 by Martini and McDowell and was completed by Hunt, McKenna and McEwen, in December 1981. Part I of the NHP contains 38 statements in six categories covering issues concerning sleep (TSL = five items), energy (TEN = three items), emotional reactions (TEM = nine items), social isolation (TSO = five items), physical mobility (TPM = eight items) and pain (TP = eight items). The respondent only has to answer "YES" or "NO" to each statement depending on his or her condition at the moment of completing the questionnaire. The "YES" answers have a score of "1" and the "NO" answers are scored "0". The `YES answers have been weighted and authors recommend that UK based studies use the weighting system so as to allow comparison with previously published norms. For analysis of Part I, when comparing two independent groups, a Mann-Whitney U-test is recommended.

Part II consists of seven statements to assess various aspects of daily life, which are being affected by the respondents perceived state of health. The areas covered are employment, jobs around the home, social life, personal relationships at home, sex life, hobbies and holidays. According to the authors Part II is best used with specific groups for example the chronically ill. For comparing independent groups, for Part II, a Chi-square test is recommended.

The NHP was validated and found to be suitable for use with a wide range of people in studies[237-244] carried out between 1978-81.[245] The reliability tests were carried out in two major studies involving 58 patients with osteoarthrosis who were waiting for hip replacement operations and 93 patients with peripheral vascular diseases. These studies demonstrated a high satisfaction in patients suffering from chronic problems and were less satisfactory in patients who do not suffer from persistent problems. For non-chronic problems there was difficulty in the relationship between sensitivity of the instrument to change and its ability to elicit consistent scores. This was not a problem in the current study, which was for patients with chronic, progressive and incurable diseases, and the patients were only interviewed once and so the NHP questionnaire was only used once. One of the ways of using NHP appropriately is to use it as an outcome measure for group comparisons and that was one of the aims of the current study.

The NHP is a self-administered questionnaire and can be used in one to one interviews or as a postal questionnaire. In this current study the NHP was used in one to one interviews in the patient's home along with another outcome measure the POS. The authors of NHP recommended that the questionnaire should not be read out, nor the statements put in the form of questions. In the current study there were a few patients (motor neurone disease, Huntington's disease and cancer patients) who could not hold a pen but were capable of reading. For these patients the interviewer marked their responses. Consistency in the mode of administration of NHP was maintained for all the patients.

The current study used both Part I and II of the NHP, as it was relevant for the two groups involved because the patients were chronically ill and were from all adult age groups. The NHP scores were found to vary by age, sex and social class by the authors of NHP and in this current study these variables were noted for all the patients and as part of this current study will be descriptive these variables will be taken into account.

Advantages of NHP in this study:

The time to complete the questionnaire was crucial as all the patients in this current study had a chronic, progressive and incurable illness and the patients preferred short interviews. (NHP takes five to fifteen minutes to complete). NHP has high reliability and validity and is cheap and easy to administer and these factors were paramount in this current study. This current study was about *palliative care* but did not use this word in any of the patient information notes and the word used was *chronic illness*. The NHP does not ask directly about health problems and can, therefore, be used with people who do not consider themselves to be ill. In this current study it was the *degree of illness* that was omitted along with the word *palliative*. NHP is easy to score and to compute using SPSS.

The NHP scores provide profiles, which differ, for different medical diseases and in the current study the patients involved had cancer and non-cancer diseases. Jenkinson et al[246] argue in their study that NHP was designed specifically to uncover the chronically ill in populations and their research indicated that the instrument was sufficiently sensitive to be successful in permitting variations within and between illness groups to be determined. However their study found the domains of mobility and pain to be confounded. The NHP Manual provides age, sex and social class "norms" for comparison and this was essential in this current study.

One of the limitations of NHP is that it does not cover areas specific to palliative care and this limitation was overcome by using POS, a specific outcome measure for palliative care. The advice by the authors of NHP was followed on the order in which the instruments are completed, when two instruments are used. The NHP was completed first followed by POS so as to avoid sensitising the individual by the statements in POS. Another limitation of NHP is that it is not possible to extract portions (emotional, physical, social, pain and energy) to be used independently but this was an advantage in this current study as palliative care is holistic and covers all the areas covered by NHP. In the introduction of a study by Kind et al, they included the NHP as one of the eight generic measures developed over the past 25 years that generated information which was useful for establishing the degree of morbidity in the community, enabling different population subgroups to be compared.[247] This would help in assessing health needs or in informing those responsible for allocating health resources. NHP is copyrighted to the authors and permission was obtained from Professor J McEwen.

Comments by Bowling[248] on others who have used NHP:

- several of the popular generic health related quality of life scales have been used to assess outcome in rheumatology. Among the most popular have been the Sickness Impact Profile and the NHP.
- In Europe, the NHP has been a popular measure of health status outcome in relation to health-related quality of life. It has been used to supplement disease-specific questions in outcome studies across many medical specialities.
- Wright et al reviewed the literature on quality of life in end stage renal failure and reported that generic life satisfaction measures, dialysis-specific health-related quality of life scales, function ability and health status measures (the NHP) were the most commonly used broader outcome indicators with renal patients.

1.1.2. Palliative care outcome scale

A review of the current outcome measures in palliative care by Hearn and Higginson saw the beginning of the development of a national tool to be used in the audit of palliative care.[231] The review initially identified 41 measures (the criteria for inclusion and assessment of outcomes was a measure assessing more than one domain and a target population of advanced disease or palliative care) and highlighted the problems of these tools which were:

- Only 12 of the 41 measures satisfied the inclusion criteria. They contained from five to 56 items and covered aspects of physical, psychological and spiritual domains.
- The measures met some but not all of the objectives of measurement in palliative care[15] (emphasis is not only on the relief of pain and symptoms but also on the resolution of emotional, social, psychological and spiritual problems; the provision of information; good communication; and support for the family)
- They were constantly being amended and updated and were not consistently revalidated for individual settings.

The Palliative Care Outcome Scale (Appendix 15) was designed to be a generic tool input assessing the outcome (including quality of life and care of patients and families) of palliative care, as there was no such tool available. It was developed using data from the above-mentioned review of outcome measures. Patients in the palliative stage are often unable to complete long complicated questionnaires. According to Kind et al patient involvement in recording and assessing their own state of health is a major element in the process of evaluating the impact of health care.[247]

The validity and reliability tests of POS were carried out by a purposive sample (all new referrals) in 8 services providing specialist palliative care[249] and included:

- St Christopher's Hospice (two of four inpatient wards and all the home care teams);
- King's College Hospital (specialist palliative care team, inpatient hospital service);
- Leicestershire Hospice (home care team);
- Liverpool Marie Curie Centre (inpatient and outpatient services);
- Watford Peace Hospice (day care service);
- James Paget Hospital (specialist palliative care team, inpatient, outpatient, and community services);
- Highland hospice in Scotland (inpatient service);
- Suffolk Community (specialist palliative care service).

In conclusion the authors reported that this multi-centre study provided comprehensive data on the validity and reliability of a new core outcome measure for palliative care.

POS consists of ten questions based on those reliable and valid questions used in other quality of life measures that covered the physical, psychological and spiritual domains of life within the remit of palliative care. In addition a space is provided to list "main problems" at the end of the questionnaire. There is a staff completed version and a patient completed version. In this current study only the patient completed version was used as all the interviews were carried out in the patient's home and all the patients were able to complete the questionnaire on their own or with help to mark the responses after they had read the questions themselves.

POS is being used in various settings such as hospice, day care centres, hospitals, general practice, research projects, nursing homes, oncology units and community nursing. It is also being used in the UK, USA, Belgium, Canada and Hong Kong and the total number of registered users at 1997 was 96. POS also provides a core measure for the use in palliative care to which additional, validated items could be added in the future. POS is copyrighted to Professor Irene Higginson and written permission was obtained for its use in this current study.

1.1.3. Performance score

The performance score or status is a "tool" utilised to describe how well a patient perform daily activities. The original "tool" was the Karnofsky performance score (KPS) and was a stratified scale at intervals of 10 percent starting from zero percent (dead) to 100 percent (no complaints and without evidence of disease).[250] It was originally designed for use with lung cancer patients in relation to assessing palliative treatments. The WHO Functional scale is a five-point performance scale but is a narrow physician-completed scale. The Eastern Co-operative Oncology Group (ECOG) performance scale (Zubrod Scale) is a condensed version of the KPS from which it was developed. All of these performance-measuring tools are limited in that they do not encompass any psychosocial indices of quality of life.

Eastern Co-operative Oncology Group

The ECOG, established in 1955, is one of the largest clinical research organisation in the US conducting clinical trials in adult cancers. It was founded in the East Coast of the US but is now an international group. They are involved in research and dissemination of their findings worldwide. The ECOG performance status was created in 1982.[251] These scales and criteria are used by doctors and researchers to assess how patient's disease is progressing, assess how the disease affects the daily living abilities of the patient, and determine appropriate treatment and prognosis. The original scores had six grades from zero (normal activity) through to four (unable to get out of bed) and finally grade 5 for dead. In this current study the sixth grade was excluded from the table used during the interviews (See Table 38 for the full scores). The ECOG is probably the most widely used performance measure in oncology.[248]

1.1.4. Conclusion on tools

Bowling in her book on measuring disease says that

> *"while measures of physical functioning and limitations on activity are of obvious value in measuring the outcome of joint disorders, they do not necessarily provide a sufficiently detailed assessment of functioning in everyday social roles. The inclusion of health status and health-related quality of life items is now seen as desirable in outcome research. However, generic scales always require supplementation with disease-specific items."*[248]

The same view could be taken for palliative care. Three items were used in this current study of comparison of palliative care between cancer and neurodegenerative diseases. The ECOG score to measure the physical function and limitation on daily activity, the NHP to measure health status and health-related quality of life and finally the POS was the disease specific item.

Muldoon et al (1998) looked at quality of life measurements and concluded that

> *"Assessment of patient's experience of disease and treatment is now acknowledged as a central component of health care and health care research. Self reported information obtained from quality of life questionnaires is and will continue to be essential in this endeavour"*[252]

The most widely accepted definition of pain is from the International association for the Study of Pain (IASP) and the American Pain Society (APS):

> *"an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage".*[253]

But pain is not determined only by tissue damage and is highly personal and subjective. A more appropriate definition for clinical practice is the following quote as it places the emphasis on the patient's self-report of pain as its single most reliable indicator.[254]

> *"pain is whatever the experiencing person says it is, existing whenever he/she says it does".*[255]

All the tools used in this current study measure the patient's pain as he/she perceives it.

2. Methods used for the main study

2.1. Patient interview

The NHP and POS questionnaire were used for the interviews with the patients and the time taken for completing both questionnaires was around 30 minutes. Before using these tools, an initial basic demographic data of the patients was recorded and an observer rating of physical ability (score developed by the ECOG) was recorded.

2.1.1. Sampling

Jordhoy et al in their study looked at the challenges in palliative care research and identified recruitment, attrition and compliance as the major obstacles in trying to carry out a randomised controlled trial in palliative care.[256] These obstacles are encountered in most palliative care research for recruitment of patients. There is a high dropout rate and withdrawal due to deterioration in the patient's condition. Few direct referrals for possible participants from fellow physicians and excessive workload were cited as other reasons for not entering patients into research.[256] Finally recruitment in a palliative care setting calls for careful ethical consideration and the dangers of coercing the patients should always be considered. All of these points were constantly kept in mind while recruiting the sample for the current study.

This current study used a non-probability sampling method and a convenience sampling method was used where available individuals were entered for the current study.[257] This was achieved with the help of various organisations (for 48 non-cancer patients), hospitals and hospices (for 34 cancer patients). Figure 23 shows the sampling frame used for this current study.

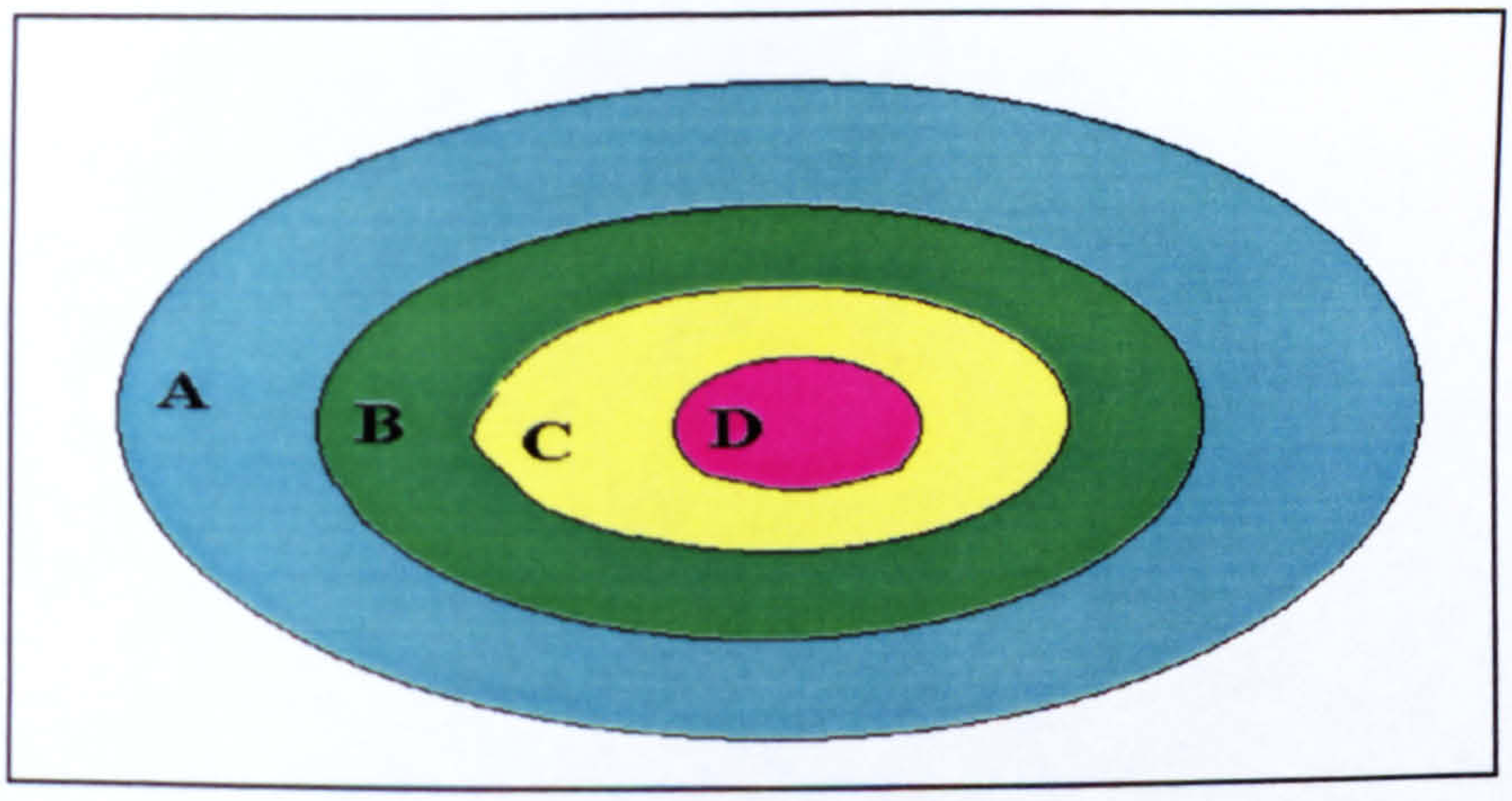
Cancer patients sample

The cancer group was made up of patients with lung, breast or colorectal primaries. They were in the palliative stage of illness and had no chemotherapy, radiotherapy or surgery in the two weeks prior to the interview. This was to avoid side effects of the active treatment masking the perceived health problems of the patients. The initial identification of the patients was conducted using two sources. The first was from the specialist clinics in Stobhill hospital (lung and breast cases) and the Western Infirmary (colorectal cases). Patients were also identified from the home care services of the three hospices in GGNHSB area.

Non-cancer patient sample

The non-cancer group was made up of patients suffering from neurodegenerative diseases namely multiple sclerosis, motor neurone disease or Huntington's disease. They were identified from their respective local organisations. The initial identification of the patients was accomplished from three sources. The Multiple Sclerosis Therapy Centre in Glasgow has a register of 1,000 + names and they identified patients with their corresponding GPs. The Scottish Motor Neurone Disease Association identified patients, with the names of the respective GPs, from their register. The Scottish Huntington's Association identified patients (they had to obtain permission from their patients due to the genetic component of Huntington's disease) and their GPs.

Figure 23 Sampling frame



A = Total Population (GGNHSB area)

B = Target Population (Cancer and Non-cancer cases)

C = Sampling frame (those requiring palliative care)

D = Sample (Lung, Breast, Colorectal cases and multiple sclerosis, motor neurone disease, Huntington's disease cases)

2.1.2. General Practitioners approval to contact patient

The patients and their respective GPs were identified as mentioned above using various sources. Once the patients were identified then their GPs were contacted to obtain permission to write to their patients giving them the option to take part in the current study. Initially the GPs were sent letters containing information about the current study and the name of their patient who had been identified as suitable for the current study (Appendix 16). In order to minimise the time interval between letters and to reduce the paper work for the GPs it was decided to contact the GPs by phone at a convenient time such as during breaks from their surgeries.

2.1.3. Initial contact with the patients

After obtaining the GP's permission, the patient was sent a letter outlining the current study along with a consent form (if they consented to the interview they were asked to furnish a contact phone number) with a reply paid envelope (Appendix 17). When the patient replied giving their consent they were contacted to make an appointment to visit them at home to further discuss the current study, obtain written informed consent and then if appropriate to conduct the interview.

2.1.4. Interviews

After a preliminary introduction the patients were again informed about the current study, its purpose and what was expected of them. Each patient was allocated an identification number. Their names, age, gender, marital status and address with post-codes were noted. Their illness, length of illness, date of diagnosis and their carer were also recorded. The initial data collection also included recording of date, time and length of interview.

The patients were shown the ECOG table (Table 38) and asked to mark the statement that they felt was their own assessment of their daily performance scale. After completing this, the NHP questionnaire was given to the patients and they were asked to read the instructions carefully before answering all the questions. The patients were requested to complete both part I and part II of the NHP. After the NHP was completed by the patient, it was checked to confirm that all the pages/questions were answered. The patients were then given the POS questionnaire to complete. Queries about the questions by the patient were clarified. After completion of the two questionnaires, a list of known service providers was introduced to assess the patient's awareness of these services (Appendix 18).

Table 38 ECOG scores used in patient interviews.

SCORE	DEFINITION
0	ABLE TO CARRY OUT NORMAL ACTIVITIES WITHOUT RESTRICTION
1	RESTRICTED IN PHYSICALLY STRENUOUS ACTIVITY BUT AMBULATORY AND ABLE TO CARRY OUT LIGHT WORK.
2	AMBULATORY AND CAPABLE OF ALL SELF-CARE BUT UNABLE TO CARRY OUT ANY WORK, UP AND ABOUT MORE THAN 50 PERCENT OF WAKING HOURS.
3	CAPABLE OF ONLY LIMITED SELF-CARE, CONFINED TO BED OR CHAIR MORE THAN 50 PERCENT OF WAKING HOURS.
4	COMPLETELY DISABLED, CANNOT CARRY ON SELF-CARE; TOTALLY CONFINED TO BED OR CHAIR.

Once both these questionnaires were completed, the patients were informed that during the initial part of the current study a list was produced of the various service providers in GGNHSB area and that this list was updated recently. They were also informed that this list consisted of all the service providers for chronic illness including those outwith their illness. There were three columns for each of the service providers. The first column was for *"if they knew about the service"*, the next column was for *"if they had used the service"* and the third column was for *"if they had no knowledge of the service"*. They were then asked to tick one of the three columns in the list (Appendix 18). After completion of the questionnaires the patients were asked if they wanted to comment on any matter regarding the care that they had received. They were also asked if they had any needs that they felt were not met during their present illness.

All the patients interviewed were very co-operative and willing to complete the questionnaires. They all had positive and negative experiences in the various stages of their palliative care journey and were happy to be able to talk about them. I was a researcher who only contacted them once and had no bearing on their treatment/care and they felt relaxed and this enabled me to be at ease during our interviews. My predicament, as is the dilemma of most researchers, was when patients volunteered information about their care and well being and the problems that they were having regarding accessing the various services. This was compounded by the nature of the illness of the patients that were being interviewed. An impartial researcher listens in confidence and retains the information in an anonymous document and keeps it safely. There were occasions when I felt it was appropriate in the end of my interview to volunteer impartial information about the various palliative care services, that I had identified previously for the current study, if it was lack of knowledge that was denying the patient access to these services. Empowerment of the service users will only occur if they have access to information and increasing one person's power requires that someone else's power must be diminished and those in positions of power are traditionally reluctant to let any of it slip away.[31]

The current study had the collaboration of the GGNHSB, Glasgow University, primary care services (GPs and district nurses), the service providers and the service users. It has also been a process over three years with pilot studies carried out and changes made to the questionnaires, with quantitative and qualitative methods and it is not an aggregate needs assessment but focuses on the palliative care needs of cancer and non-cancer patients within Greater Glasgow. It has used not just an epidemiological or demographic method but has been adapted to take in the local context and needs and has adapted methods to serve its purpose. From the beginning GGNHSB has been closely involved and has received regular updates. Hopefully the Health Board will use the final findings from the current study in the implementation of its future palliative care strategy for the residents of Greater Glasgow. All of the above were the criteria mentioned by Ingleton (2001) that were necessary for palliative care needs assessment to improve practice in a challenging health service research.[154]

2.2. Strength of the methods used

- Patients were in their own homes and felt comfortable in expressing their views.
- There were no time restrictions and the patients were in control of the process.
- At the end of the interviews the patients were given the opportunity to comment on any aspect of their care (positive and negative experiences). They were informed that any information they gave would be confidential and anonymous (see Appendix 17) and would help to identify areas of good practice and areas where improvements were needed. Note taking was kept to a minimum during these interviews. On returning from the interviews, notes were kept of information provided by the patients.
- Initial identification of non-cancer patients was through their community based support organisations and this helped to overcome patient identification in hospitals. This was a community-based study and mainly involved the GPs as the gatekeepers for the patients.
- The GPs were contacted first before contacting the patients. This safeguarded the interest of the patient and did not violate the data protection guidelines.

2.3. Research realities of the methods used

- Delay in process as the GPs were the gatekeepers and as such the patients did not have the first choice of refusal and this also delayed the process as the GPs were busy and were late in replying.
- Initial identification of the cancer patients was through the specialist services in the hospitals and then the patients' GPs were contacted for final approval to contact the patients.
- The patients were not selected for this current study randomly due to the difficulties mentioned earlier in the chapter. A convenience sampling method was used so that available individuals were entered for the current study.

2.4. Data analysis

The full coding for the data collected from NHP and POS questionnaires is in Appendix 19. Re-coding of the following data was carried out so as to facilitate analysis:

Age was coded as 1 = 20-39 years; 2 = 40-59 years; 3 = 60+ years

Depcat was coded as 1 = Carstairs 1 and 2; 2 = Carstairs 3-5; 3 = Carstairs 6 and 7

Health Sector was coded as 1 = North-East; 2 = West; 3 = South

Carer was coded as 0 = Self; 1 = Partner; 2 = Children; 3 = Friends
4 = Services; 5 = Others; 6 = Parent

The "YES" responses in the NHP were weighted according to the authors' guidelines. The basis analysis carried out with the data were:

- frequencies
- cross-tabulation
- histograms were created to visualise the results.

The data was also analysed using the following statistics tests:

- chi square test for significance
- bivariate correlation (one for NHP and one for POS)

The data for the patients was collected from two independent groups who were compared because they both required palliative care. The advantages of using distribution-free tests[258] are:

- they do not rely on any very serious restrictive assumptions concerning the shape of the sampled population
- they are more sensitive to medians than to means
- simplicity of their calculation
- they rank the raw scores and operate on those ranks and offer a test of differences in central tendency and are not affected by one or a few very extreme scores (outliers).

The major disadvantage is their lower power relative to the corresponding parametric tests.

The Mann-Whitney U test was used to compare the median scores from the patients' data.

2.4.1. Multiple logistic regression

The covariates (demographic data) used in regression analysis were:

- The illness of the patient (cancer or non-cancer)
- Age groups of patients (20-39, 40-59 and 60+ years)
- Sex of the patients
- Carer of the patients (grouped as self, partner and others)
- ECOG scores of the patients were re-coded as the number of patients who were completely disabled were only three (all non-cancer patients) and those reporting as normal were seven (three cancer and four non-cancer). These ten patients were considered as missing and excluded from the regression calculations.
- Health sector in which the patients resided (north-east, west or south).

The covariates (demographic data) not used in regression analysis was:

Length of illness of the patients was not used, as there were too many categories.

3. Results

3.1. Introduction

GPs were the gatekeepers for the patients involved in this current study. Permission to contact the patients was first obtained from 209 GPs (111 for neurodegenerative disease and 98 for cancer patients). A total of 176 GPs (83 for neurodegenerative disease and 93 for cancer) responded within a couple of weeks. Of these, 12 GPs (3 for neurodegenerative disease and 9 for cancer) refused permission to contact the patient due to the condition of the patient and nine GPs (2 for neurodegenerative disease and 7 for cancer) replied to inform that the patient had died. A total of 33 GPs (28 for neurodegenerative disease and 5 for cancer) did not reply to the letters (see Appendix 20 for full details). In nine cases the patient died because of delays and no response may have been because of the workload of the GPs and the weight of daily correspondence.[203] (Table 39 for full details)

When initial contact with GPs by post did not produce any response, the GPs were contacted by phone in their surgery during their breaks. This proved to be very effective as all the GPs were very helpful and were able to immediately approve or with-hold contact with their patients if they felt that the patient was not suitable for the current study. Access to a few patients was denied and the GPs gave their reason for this (see Appendix 20 for details).

A total of 154 patients (78 for neurodegenerative disease and 76 for cancer) were contacted and 103 (50 for neurodegenerative disease and 53 for cancer) of them responded. Of those who responded, 82 patients (48 for neurodegenerative disease and 34 for cancer) agreed to be interviewed and only 15 (2 for neurodegenerative disease and 13 for cancer) refused while 6 cancer patients died. There was no response to the letter from 52 patients (28 for neurodegenerative disease and 24 for cancer) and after one reminder these patients were not contacted again. The 15 patients who replied that they were not willing to take part in the current study were excluded from the list. (Table 39 for full details)

All but the following interviews were conducted in the patients' home at their convenience. At their request three of the patients with multiple sclerosis were interviewed in the Multiple Sclerosis Therapy Centre in Glasgow on the day they were coming for treatment. One patient with colo-rectal cancer was interviewed in an outpatient setting on the day of their follow-up, also at the request of the patient.

3.2. Demographic data

The total number of patients interviewed for this current study was 82, made up of 48 patients with neurodegenerative diseases and 34 cancer patients. The 48 patients with neurodegenerative diseases consisted of nine motor neurone disease patients, nine patients with Huntington's disease and 30 multiple sclerosis patients. The 34 patients with cancers included 14 patients with lung cancers, 12 patients with breast cancers and eight colo-rectal cancer patients.

This sample size gives 80 percent power to detect a difference in means of 0.65σ (σ = standard deviation) between the responses of cancer and neurodegenerative patients at the five-percent significance level.

3.2.1. Age and sex

The age group data (Figure 24) demonstrated higher numbers of patients in the 60+ age group for the cancer patients. The neurodegenerative group had 25 percent of their patients in both the below 40 and 60+ age groups with 50 percent in the 40-60 age group. Table 40 illustrates significant differences in age groups between cancer and neurodegenerative patients with a p value of 0.004.

Table 39 Summary of breakdown of the patient sampling process

	Pt. Identified	GP Contacted	GP said Yes	GP said No	Pt. Died	No Response	Pt. Contacted	Pt. Said Yes	Pt. said No	Pt. Died	No Response
MS	70	70	49	1		20	49	30	1		18
MND	26	26	16	2	2	6	16	9	1		6
HD	15	15	13	0		2	13	9			4
LUNG	51	51	42	5	4		41	14	10	2	16
BREAST	29	29	26	3			26	12	3	3	8
COLO-REC	18	18	9	1	3	5	9	8		1	
TOTAL	209	209	155	12	9	33	154	82	15	6	52

	Pt. Identified	GP Contacted	GP said Yes	GP said No	Pt. Died	No Response	Pt. Contacted	Pt. Said Yes	Pt. said No	Pt. Died	No Response
Neurodegenerative disease	111	111	78	3	2	28	78	48	2		28
CANCER	98	98	77	9	7	5	76	34	13	6	24
TOTAL	209	209	155	12	9	33	154	82	15	6	52

Figure 24 Sample by age groups

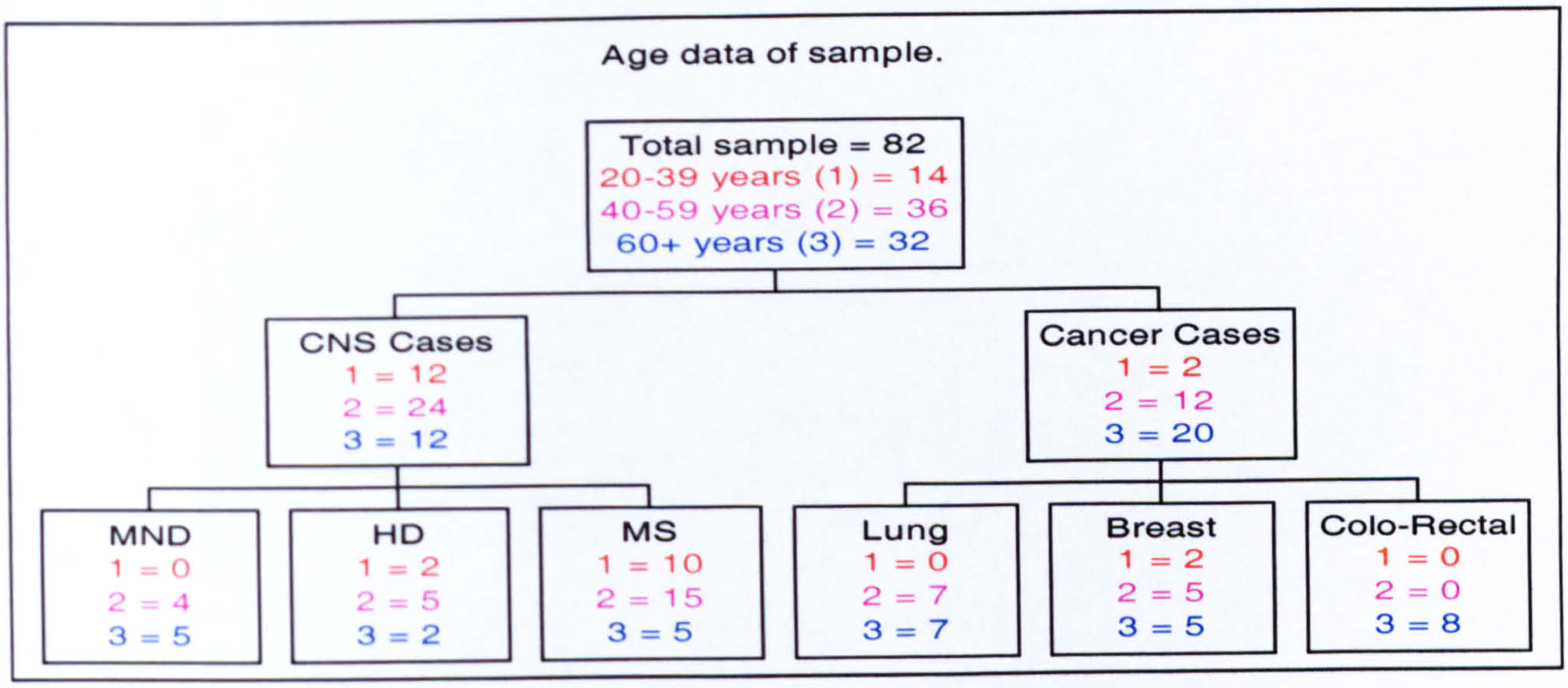


Table 40 Sample by age showing p value.

Age	Neurodegenerative disease	Cancer	P value
20-39 years	**12 (25)**	**2 (6)**	**p value = 0.004**
40-59 years	**24 (50)**	**12 (35)**	
60 + years	**12 (25)**	**20 (59)**	
Total	**48**	**34**	

(all numbers in brackets are percentages)

The sex group data (Figure 25) showed a higher number of females in the cancer group, which can be explained by the 12 patients with breast cancer. There were more males in the motor neurone disease and lung cancer groups and more females in the Huntington's disease and multiple sclerosis groups.

The Carstairs depcat[171] areas of the patients illustrated higher numbers of neurodegenerative patients in depcat 1 and 2 while the numbers were higher for cancer patients in depcat 6 and 7 (Figure 26).

Figure 25 Sample by sex

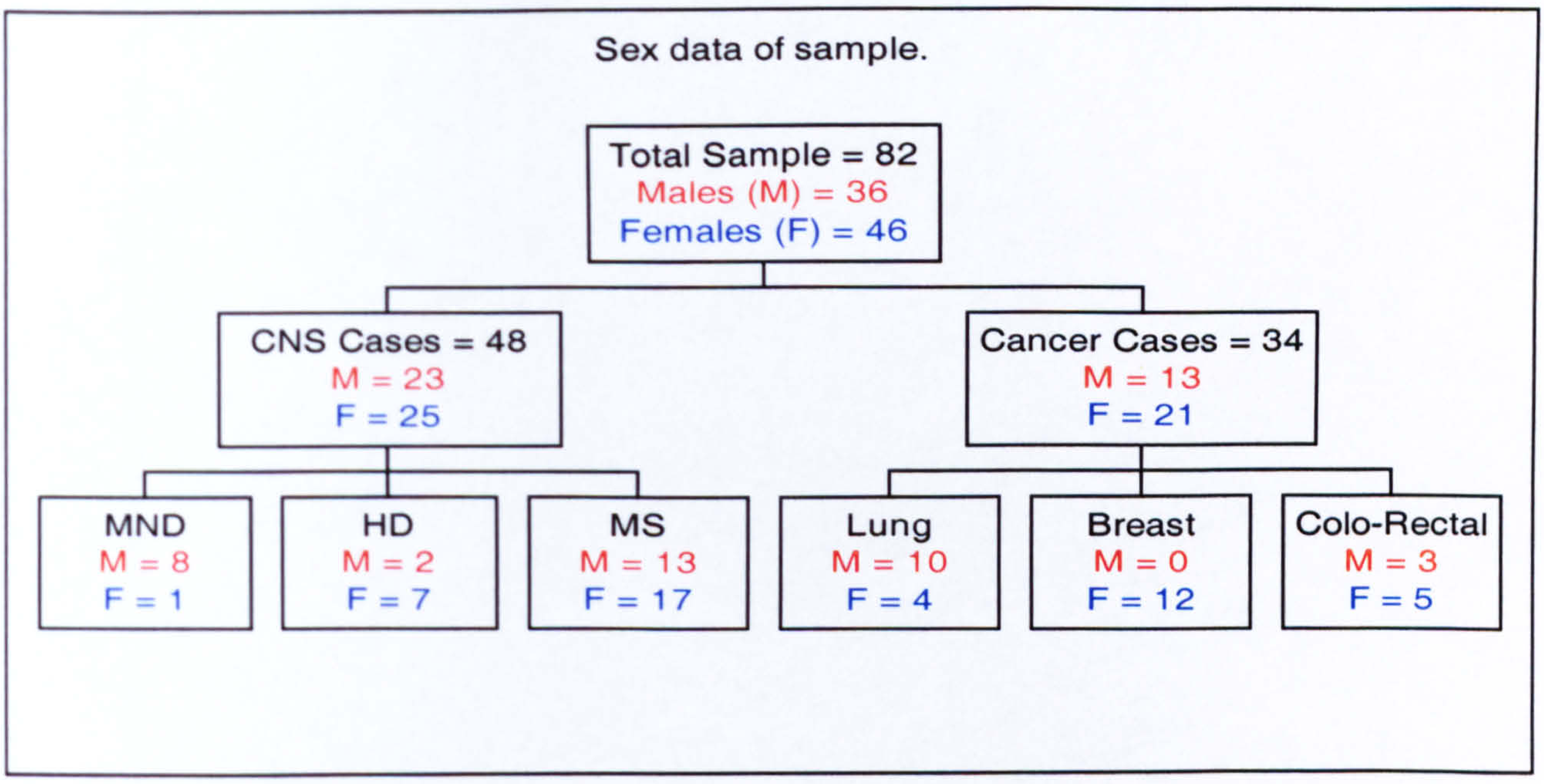
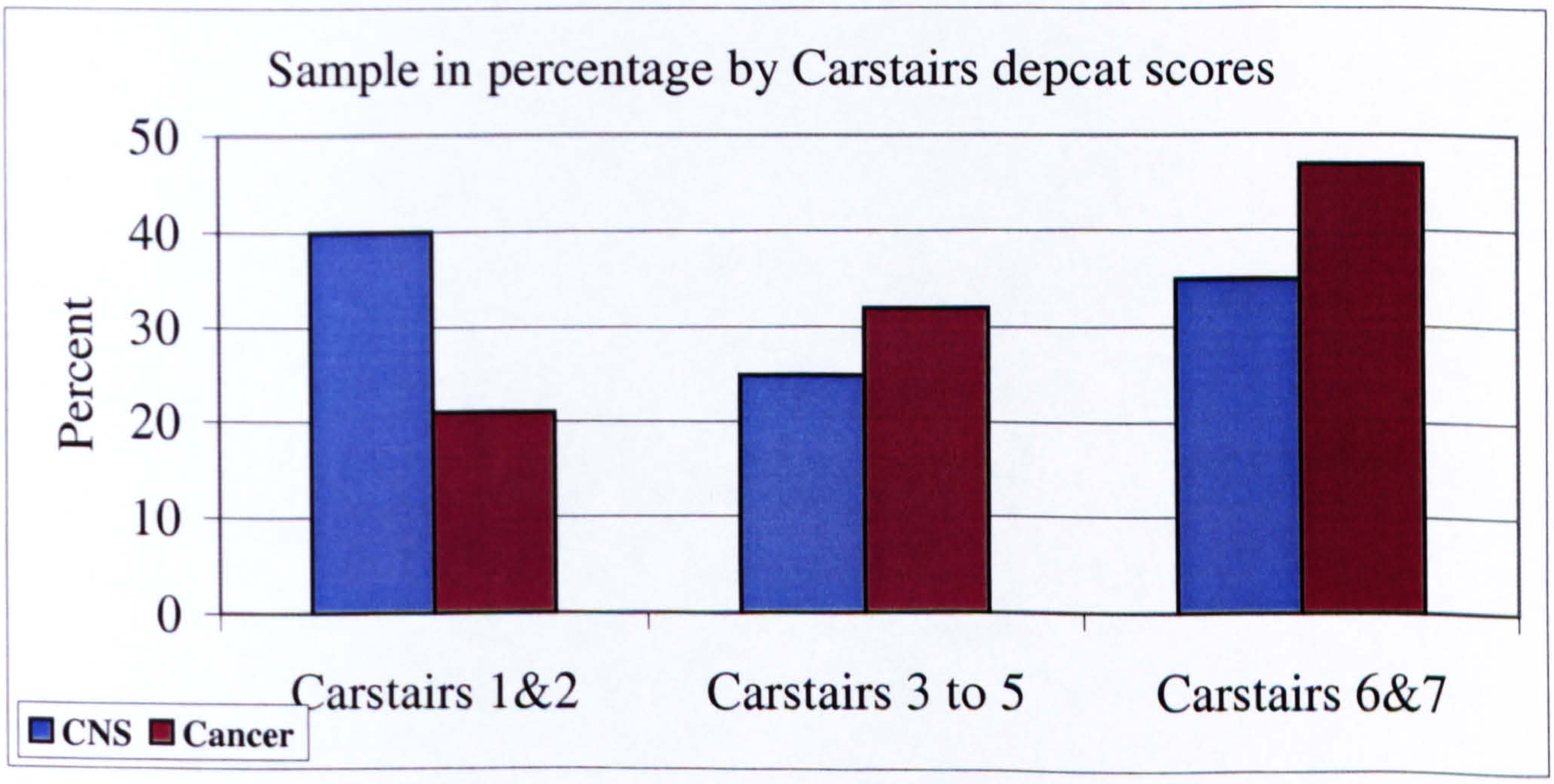


Figure 26 Sample by depcat



3.2.2. Carers and ECOG

Over 40 percent of both groups mentioned their partners as the main carer while over 30 percent of both groups looked after themselves with no specific person as their carer (Figure 27). More cancer patients (28%) than neurodegenerative patients (10%) mentioned children and service providers as carers. Only neurodegenerative patients (especially Huntington's disease) mentioned their parents as carers. The ECOG scores of the sample illustrated that a higher percentage of patients in the cancer group were able to continue their daily activities without help and this was reversed for neurodegenerative patients. A higher percent of neurodegenerative patients needed help with their daily activities (Figure 28) and they were the only group to be in the completely disabled category. There were significant differences in the ECOG scores of cancer and neurodegenerative patients (p = 0.048).

Figure 27 Carers for the patients

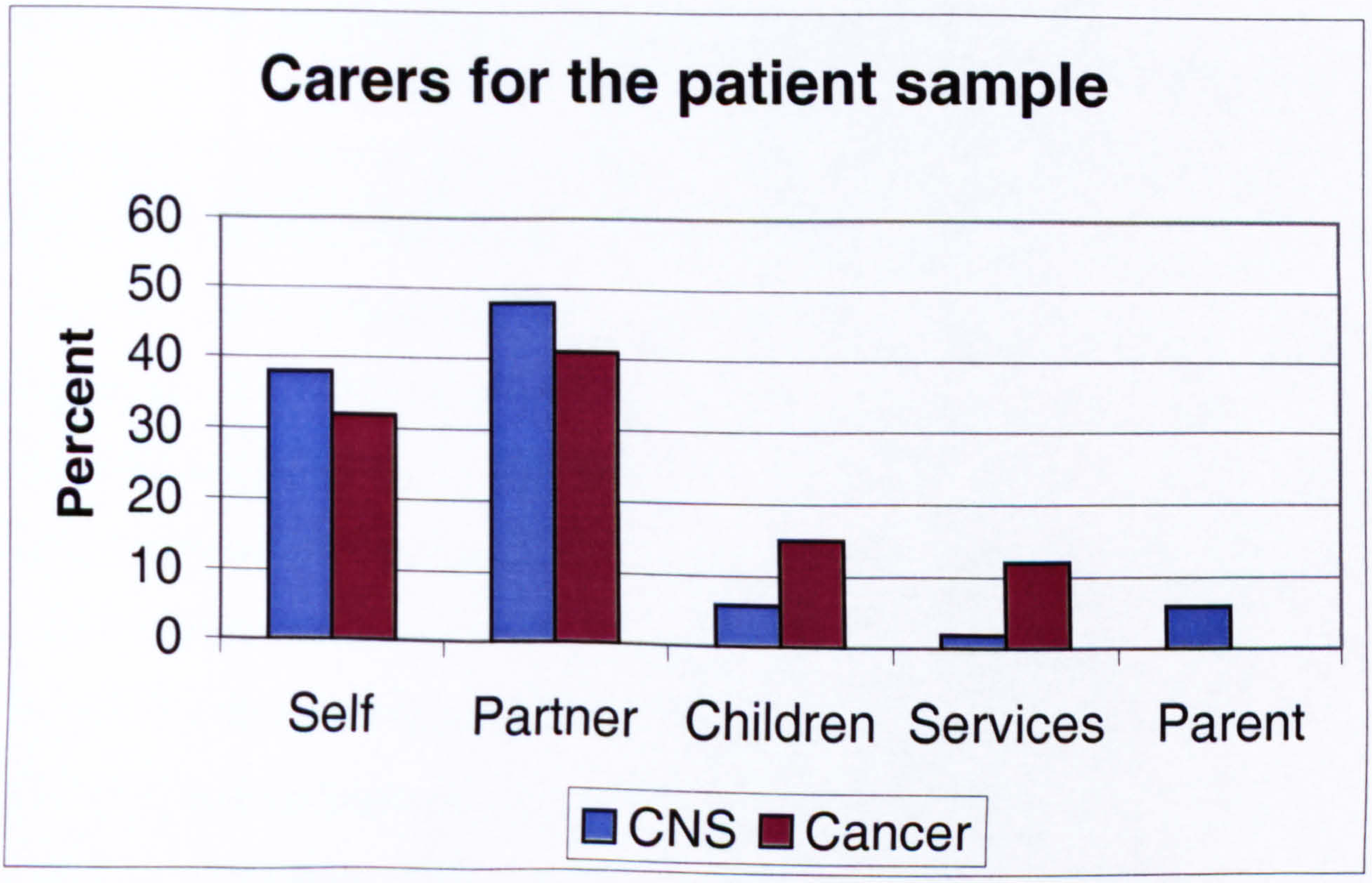
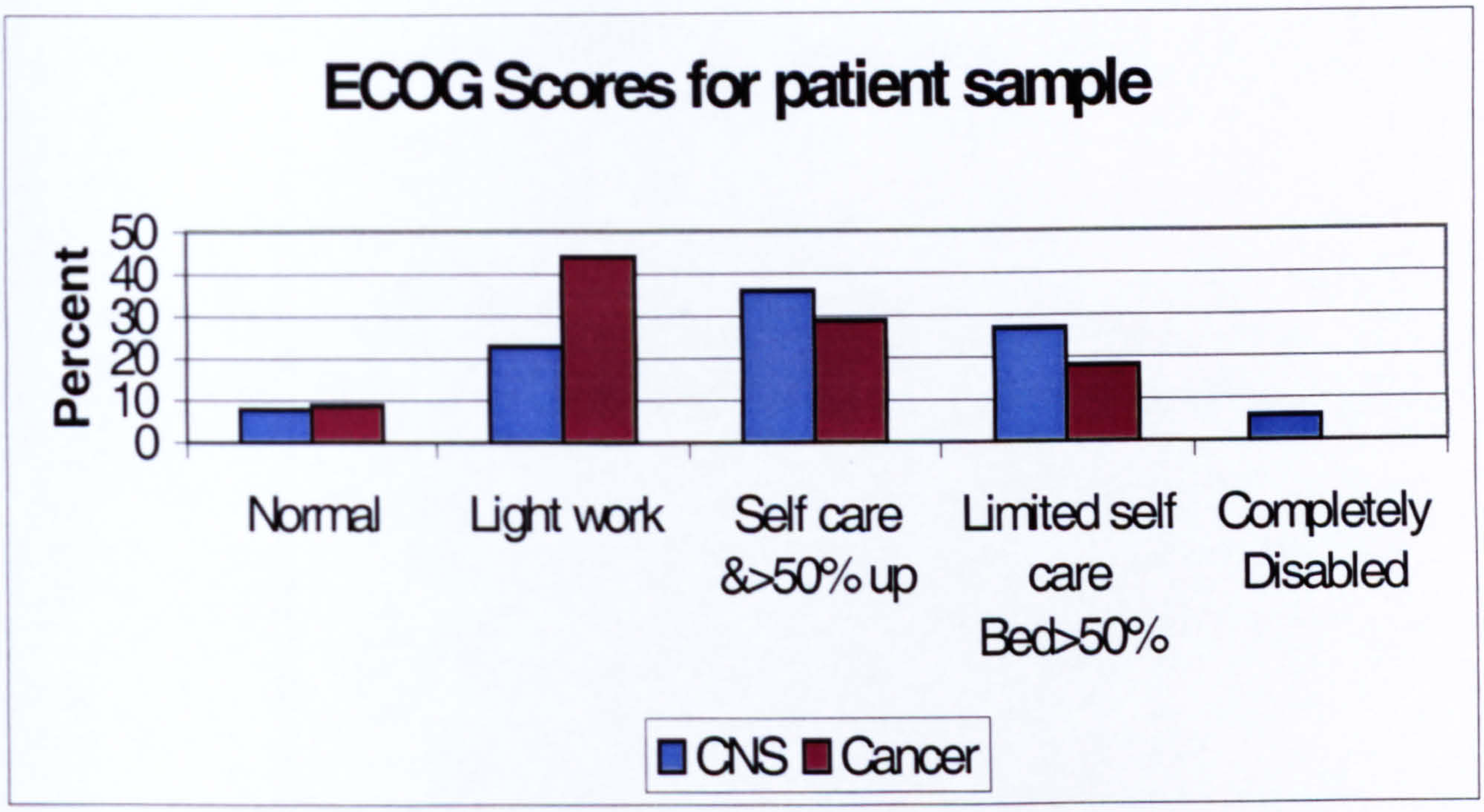


Figure 28 ECOG scores of the patients



3.2.3. Interval between first symptom and diagnosis

There were two questions (length of illness and date of diagnosis) in the initial demographic data collection sheet. This enabled calculation of the time interval between the start of symptoms (related to their illness) and the definitive diagnosis of their illness (Figure 29). Only in two diseases did the patients know their diagnosis months before the start of their symptoms *(minus 138 months for multiple sclerosis and minus 78 months for Huntington's disease).* The intervals between knowing their diagnosis and start of their symptoms for multiple sclerosis was *minus 138 to plus (after start of their symptoms) 306 months* and for Huntington's disease it was *minus 78 to plus 66 months*. In all the other diseases the patients had experienced symptoms related to their condition months before they were told about their diagnosis. The shortest intervals were for colo-rectal cancers (6-36 months) followed by breast cancers (6-42 months). Lung cancers ranged from 6-66 months followed by motor neurone disease that ranged from 18-114 months. There were significant differences between the cancer and neurodegenerative groups as shown in Table 41 (p = <0.001).

Figure 29 Months ill before diagnosis

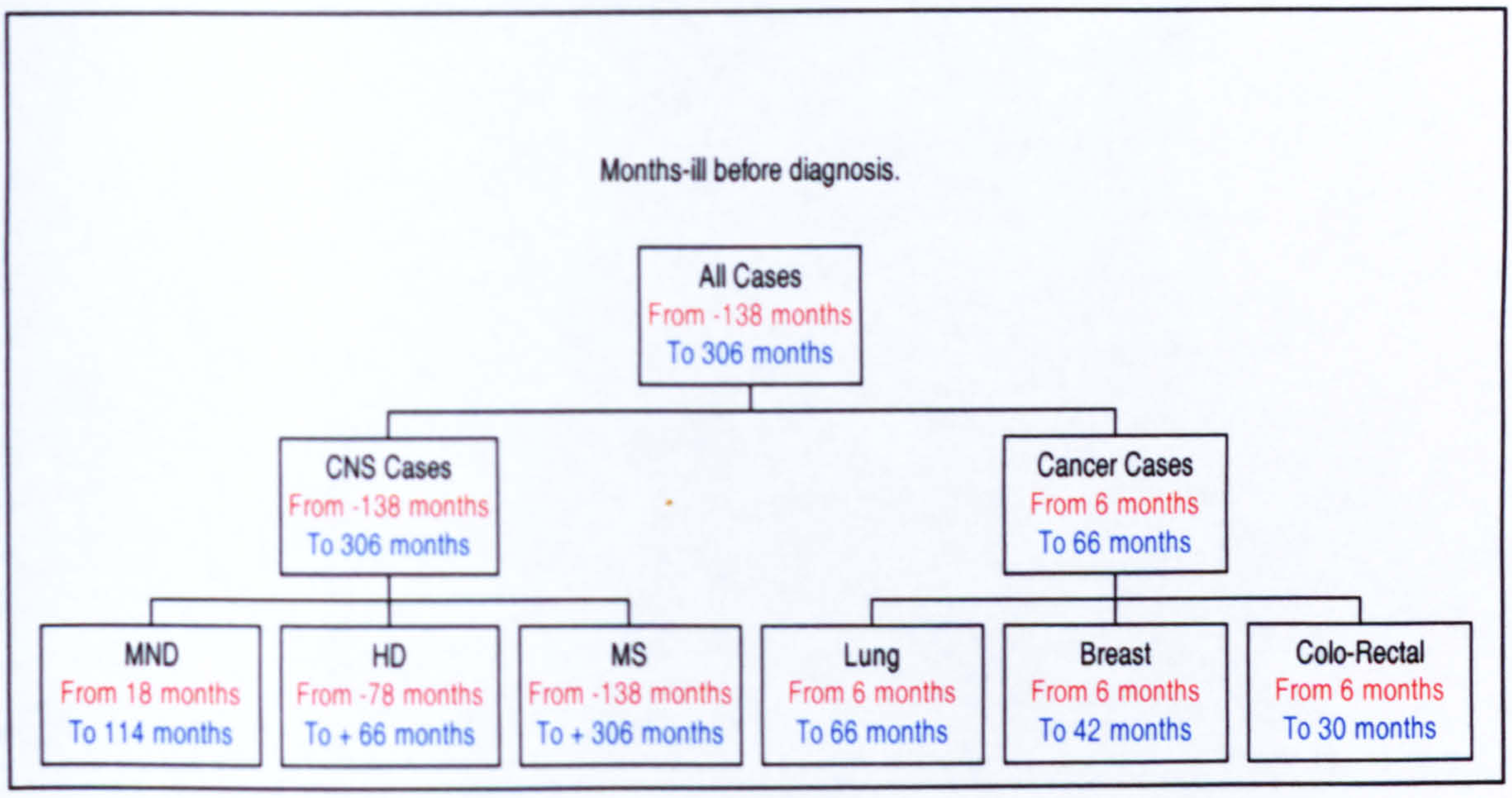


Table 41 Sample by months ill before diagnosis showing p value.

Months ill before diagnosis	Neurodegenerative disease	Cancer	P value
-18 to -138 months	**6 (12)**	**Nil**	**p value = < 0.001**
6 to 24 months	**15 (31)**	**30 (88)**	
30 to 60 months	**9 (19)**	**3 (9)**	
66 to 120 months	**10 (21)**	**1 (3)**	
More than 120 months	**8 (17)**	**Nil**	

(all numbers in brackets are percentages)

3.2.4. Relationship between the demographic data

Cross-tabulations between the demographic data collected from ALL patients showed the following significant differences (no significant differences between the demographic data of cancer and non-cancer patients were detected):

- Age and type of condition (cancer or non-cancer) p = 0.004
- Age and carer p = 0.01
- Sex and ECOG score p = 0.046
- Sex and carer p = 0.03

3.3. Nottingham Health Profile

Mean scores were calculated from the responses by cancer and neurodegenerative patients to Part I of the NHP questionnaire and are presented in Figure 30. In all categories except for sleep the neurodegenerative patients scored higher when compared to cancer patients. The biggest difference between the cancer and neurodegenerative patients was seen in Energy (TEN) and Mobility (TPM) where mean scores for the neurodegenerative patients were greater than mean scores of cancer patients. The sample size and 80 percent power for this current study detects difference for Energy (where Standard Deviation is 24) of 16, and for Mobility (where Standard Deviation is 23) detects a difference of 15 between the responses of cancer and neurodegenerative patients at the five percent significance level.

3.3.1. Relationship between NHP and demographic data

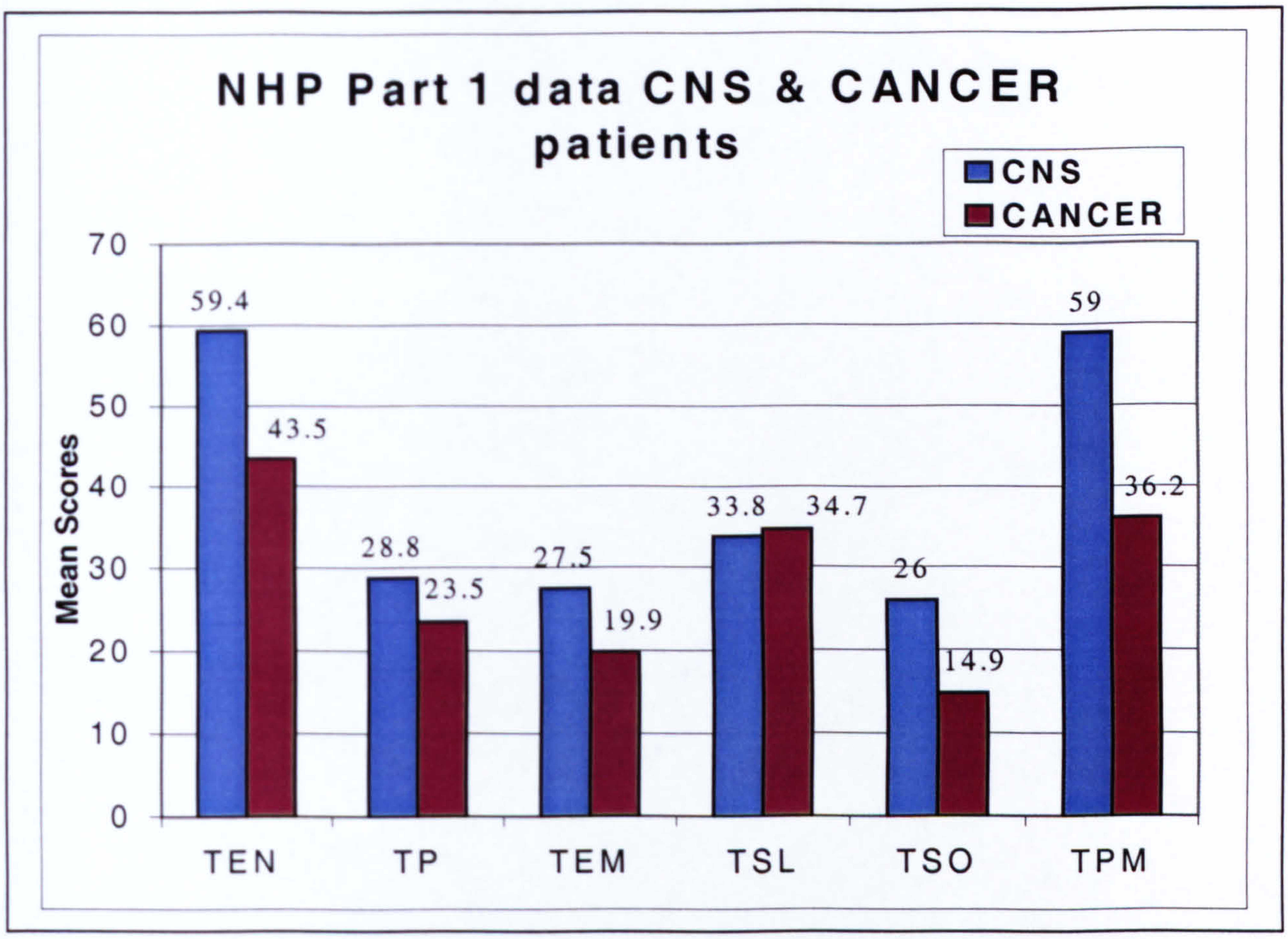
Cross-tabulation analysis were carried out with NHP data and demographic data that were collected. There were significant findings for NHP Part 1 but these were not included as fewer than 80 percent of the cells had an expected count less than 5. Only Part 2 of NHP had the following significant findings:

- ECOG with Part 2 the p value was 0.004
- Type of condition and Part 2 the p value was 0.008

Mann-Whitney tests

Mann-Whitney tests were performed on the data collected (Table 41) and there were significant differences between cancer and neurodegenerative patients for Energy (TEN: p value = 0.028), Mobility (TPM: p value = <0.001) and Social Isolation (TSO: p value = 0.013). Part II of the NHP also showed significant differences between the neurodegenerative and cancer patients as shown in Table 42 (p = 0.005).

Figure 30 Mean scores of neurodegenerative and Cancer patients for NHP Part 1



TEN = total of 3 items on energy; TP = total of 8 items on pain; TEM = total of 9 items on emotional reaction; TSL = total of 5 items on sleep; TSO = total of 5 items on social isolation; TPM = total of 8 items on physical mobility.

Table 42 Mann-Whitney tests on selected NHP data

	N	Mean Rank	Sum of Ranks	P value
TEN (energy)				
Neurodegenerative disease	48	46.22	2218.50	**p value = 0.028**
Cancer	34	34.84	1184.50	
TPM (physical mobility)				
Neurodegenerative disease	48	50.09	2404.50	**p value = <0.001**
Cancer	34	29.37	998.50	
TSO (social isolation)				
Neurodegenerative disease	48	46.75	2244.00	**p value = 0.013**
Cancer	34	34.09	1159.00	
Part II				
Neurodegenerative disease	48	47.59	2284.50	**p value = 0.005**
Cancer	34	32.90	1118.50	

A breakdown of the number of questions in Part II of the NHP that were mentioned as being a problem by the patients is shown in Table 43. This shows that eight percent of neurodegenerative and 32 percent of cancer patients mentioned none to two questions as being a problem while 31 percent of neurodegenerative and 12 percent of cancer patients mentioned six to seven questions as being a problem. There were similar percent of cancer (56%) and neurodegenerative (61%) patients who mentioned from three to five questions as being a problem

Table 43 Results from Part II of NHP questionnaire

Number of activities affected	Neurodegenerative disease	Cancer
None	1 (2)	7 (21)
One	1 (2)	3 (9)
Two	2 (4)	1 (3)
Three	9 (18)	8 (23)
Four	12 (25)	3 (9)
Five	8 (17)	8 (23)
Six	8 (17)	3 (9)
Seven	7 (15)	1 (3)
Total	48	34

(all numbers in brackets are percentages)

3.3.2. Multiple logistic regression

Multiple logistic regression tests were carried out with the individual questions in Part I and II of NHP and the covariates (demographic data of patients). No calculation was possible with the weighted scores in NHP Part I as there were too many possibilities in the dependent variables (TSO, TP, TSO, TSL, TPM, TEM and TEN). In the following questions of NHP Part I and II, there were differences for cancer or non-cancer patients (see Appendix 13a for full details) after adjusting for the covariates mentioned in the methodology section:

NHP Part I	**Covariate**	**p value**
HAS PAIN WHEN WALKS (TP)	ECOG (non-cancer)	0.03
HAS PAIN WHEN WALKS (TP)	SEX (non-cancer)	0.01
HAS PAIN WHEN STANDING (TP)	SEX (non-cancer)	0.03
HAS PAIN WHEN USING STAIRS OR STEPS (TP)	SEX (non-cancer)	0.01
LOSES TEMPER EASILY (TEM)	CARER (cancer)	0.05
FINDS IT HARD TO REACH FOR THINGS (TPM)	ECOG (non-cancer)	0.04
FINDS IT HARD TO DRESS (TPM)	ECOG (cancer)	0.05
FINDS IT HARD TO CONTACT PEOPLE (TSO)	CARER (non-cancer)	0.05
WAKES UP EARLY (TSL)	HS (non-cancer)	0.05
NHP Part II	**Covariate**	**p value**
JOB OF WORK	ECOG (cancer)	0.04
HOME LIFE	CARER (non-cancer)	0.02
LOOKING AFTER THE HOME	SEX (cancer)	0.01

In the following questions of NHP Part I and II, there were four significant differences between cancer and non-cancer patients (type) after adjusting for the covariates mentioned in the methodology section (significant differences are in bold).

NHP Part I	**Covariate**	**p value**
❖ **FINDS IT HARD TO CONTACT PEOPLE (TSO)**	**TYPE**	**0.004**
❖ **HARD TO BEND (TPM)**	**TYPE**	**0.001**
❖ FINDS STAIRS OR STEPS DIFFICULT (TPM)	TYPE	0.02
❖ **NEEDS HELP TO WALK OUTSIDE (TPM)**	**TYPE**	**0.003**
NHP Part II	**Covariate**	**p value**
❖ **JOB OF WORK**	**TYPE**	**<0.001**
❖ HOME LIFE	TYPE	0.04
❖ INTEREST & HOBBIES	TYPE	0.04

3.4. Palliative Care Outcome Scale

In the POS questionnaire there were greater mean scores in only three questions for cancer patients compared to neurodegenerative patients and they were for: i) other symptoms, ii) anxiety and iii) family anxiety (Figure 31). The mean scores were greater in six of the questions for neurodegenerative patients compared to cancer patients and they were for i) pain, ii) information, iii) support, iv) life worthwhile, v) self worth and vi) personal affairs. They both score equally for wasted time (Figure 31).

3.4.1. Relationship between POS and demographic data

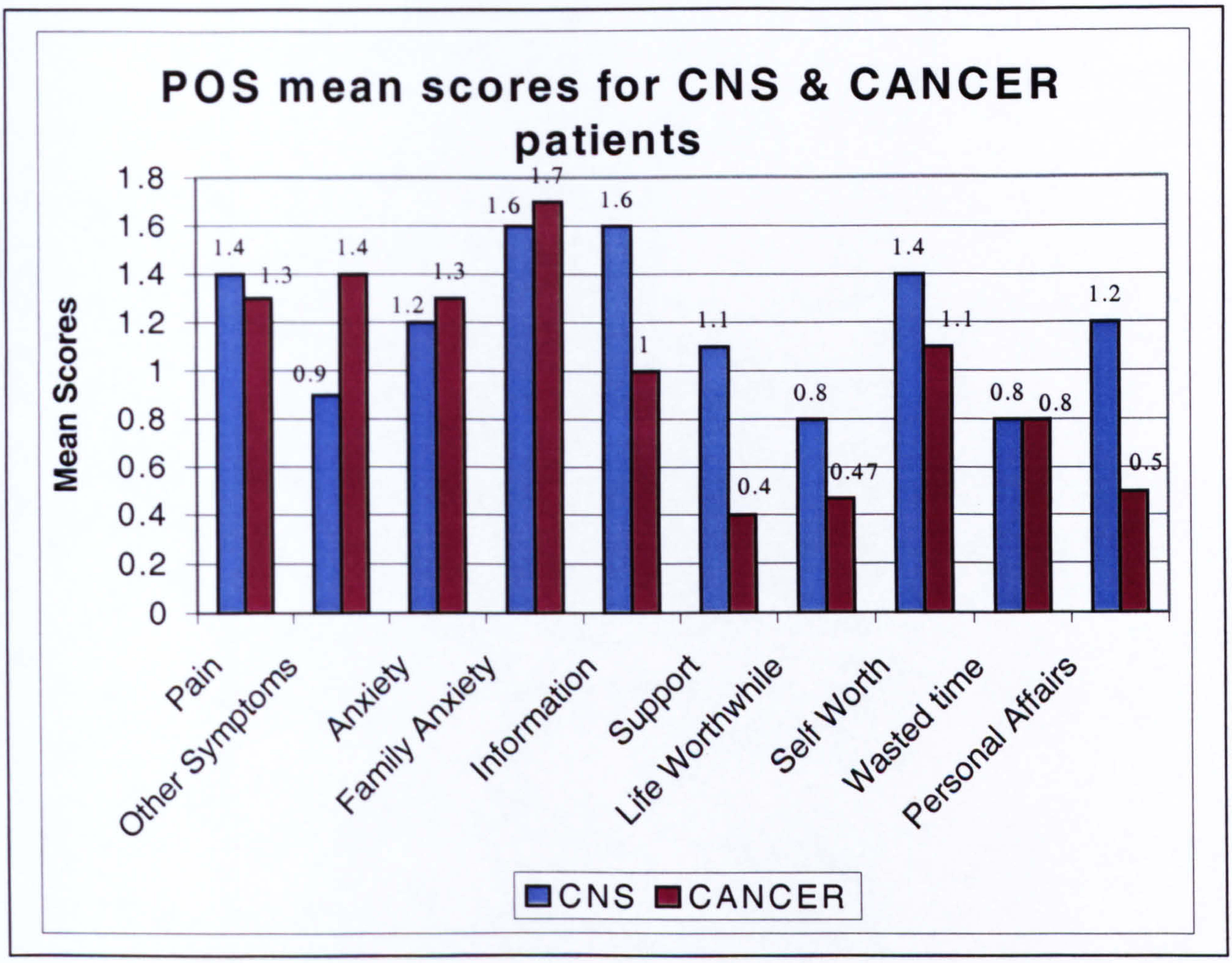
Cross-tabulation analysis were carried out with POS data and demographic data that were collected with ALL the patients and separately between cancer and non-cancer patients. The differences with ALL the patients are mentioned below:

- ECOG with Wasted time (POS 9) the p value was 0.02
- ECOG with Personal Affairs (POS 10) the p value was <0.001
- Type (cancer and non-cancer) with Other Symptoms (POS 2) the p value was 0.05
- Type (cancer and non-cancer) with Information (POS 5) the p value was 0.05
- Type (cancer and non-cancer) with Support (POS 6) the p value was 0.05
- Type (cancer and non-cancer) with Life Worthwhile (POS 7) the p value was 0.03
- Type (cancer and non-cancer) with Personal Affairs (POS 10) the p value was 0.01

The differences between cancer and non-cancer patients are mentioned below:

- Age with Self Worth (POS 8) the p value for cancer patients was 0.02
- Depcat with Self Worth (POS 8) the p value for cancer patients was 0.04
- Carer with Information (POS 5) the p value for cancer patients was 0.02
- Depcat with Self Worth (POS 8) the p value for non-cancer patients was 0.02
- ECOG with Anxiety (POS 3) the p value for non-cancer patients was 0.003
- ECOG with Personal Affairs (POS 10) the p value for non-cancer patients was 0.04

Figure 31 Mean scores of neurodegenerative and Cancer patients for POS



3.4.2. Mann-Whitney tests

Mann-Whitney tests were performed on the data collected and there were significant differences between cancer and neurodegenerative patients for Support (p = 0.003) and for Personal affairs (p = 0.014) (Table 44).

Table 44 Mann-Whitney tests on selected POS data

	N	Mean Rank	Sum of Ranks	P value
		Personal Affairs		
Neurodegenerative disease	48	46.07	2211.50	**p value = 0.014**
Cancer	34	34.04	1191.50	
		Support		
Neurodegenerative disease	48	47.49	2279.50	**p value = 0.003**
Cancer	34	33.04	1123.50	

Table 45 Results from POS questionnaire (6 – Support)

Support	Neurodegenerative disease	Cancer
Always	20 (42)	26 (76)
Mostly	12 (25)	3 (9)
Sometimes	8 (17)	4 (12)
Occasionally	5 (10)	0
None	3 (6)	1 (3)
Total	48	34

(all numbers in brackets are percentages)

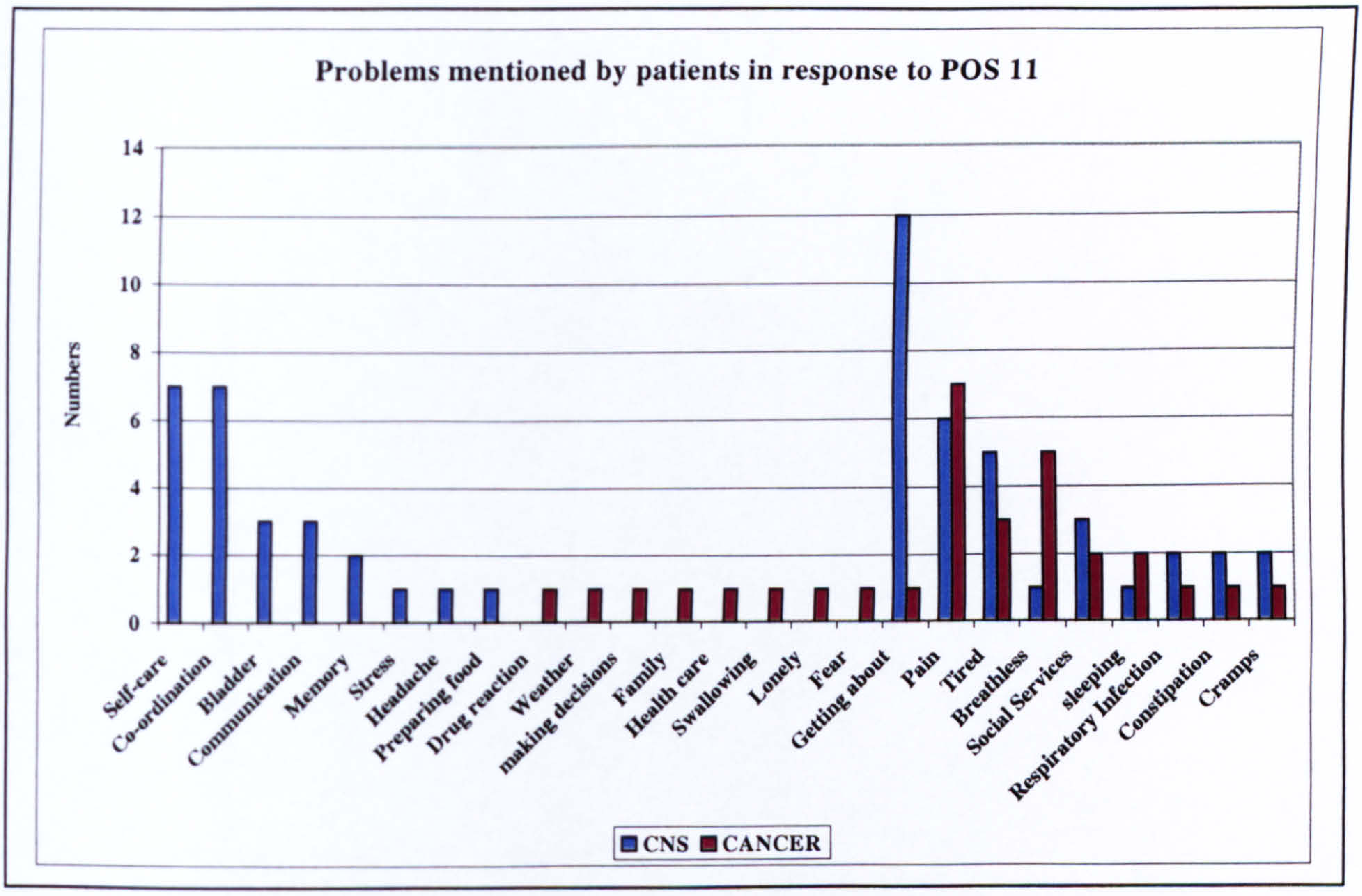
On the question of support, only 42 percent neurodegenerative patients had support "Always" while 76 percent cancer patients acknowledged that they had support "Always" (Table 45). With regards to their personal affairs, only 54 percent of neurodegenerative patients had "Sorted" them while 79 percent of cancer patients had it all "Sorted" at the time of the interview (Table 46).

Table 46 Results from POS questionnaire (10 - Personal Affairs)

Personal Affairs	Neurodegenerative disease	Cancer
Sorted	26 (54)	27 (79)
Being sorted	15 (31)	6 (18)
Not sorted	7 (15)	1 (3)
Total	48	34

(all numbers in brackets are percentages)

Figure 32 Problems mentioned by patients.



The problems mentioned by the patients in this current study in response to question 11 (if any, what have been your problems in the last three days?) in the POS questionnaire are highlighted in Figure 32. There were nine problems that were common to both cancer and neurodegenerative patients. There were more neurodegenerative patients compared to cancer patients who complained of the following problem: i) getting about, ii) tired, iii) social services, iv) respiratory infections, v) constipation and vi) cramps. There were more cancer patients compared to the neurodegenerative patients who complained of the following problem: i) pain, ii) breathless and iii) sleeping.

The problems mentioned only by the neurodegenerative patients were more related to effects on their nervous system e.g. i) self-care ii) co-ordination, iii) bladder, iv) communication, v) memory, vi) stress, vii) headache and viii) preparing food. The problems mentioned exclusively by the cancer patients were more concerning general health, e.g. i) weather, ii) drug reaction, iii) swallowing and iv) health care, or concerning psychological issues e.g. i) family, ii) lonely, fear and iii) making decisions.

Multiple logistic regression

After adjusting for all the covariates mentioned in methodology section there were differences for responses to POS 2 (other symptoms p = 0.03), POS 6 (support p = 0.02) and for POS 7 (life worthwhile p = 0.04) between the cancer and non-cancer patients (see Appendix 13a for details). The other covariates with significant differences are:

- Sex with POS 1 (pain p = 0.03)
- Sex with POS 1 for non-cancer patients (pain p = 0.04)
- Health sector with POS 6 (support p = 0.04)
- Age with POS 10 (personal affairs p = 0.03)
- ECOG with POS 10 (personal affairs p = 0.002)

3.5. Correlation non-parametric test

Correlation tests were performed, between NHP and POS responses by the patients, to determine the similarities in the answers to similar questions (Table 47). The most significant correlation was between the questions on pain in NHP and the one question on pain in POS (p = <0.001). The next highest correlation was between questions on emotion in NHP and anxiety in POS (p = <0.001).

Table 47 Showing the significant correlations between NHP and POS

POS	NHP	TP	TEM	TSL	TSO	TPM
PAIN	Pearson Correlation	.734				
	Sig. (2-tailed)	**.000**				
OTHER SYMPTOMS	Pearson Correlation	.390				
	Sig. (2-tailed)	**.006**				
ANXIETY	Pearson Correlation		.608	.325	.393	
	Sig. (2-tailed)		**.000**	**.024**	**.006**	
FAMILY ANXIETY	Pearson Correlation		.409		.421	
	Sig. (2-tailed)		**.004**		**.003**	
LIFE WORTHWHILE	Pearson Correlation		.328			
	Sig. (2-tailed)		**.023**			
SELF WORTH	Pearson Correlation	-.326	.470		.319	-.303
	Sig. (2-tailed)	**.024**	**.001**		**.027**	**.036**

There was significant correlation to a lesser degree for questions on the following:

- emotion in NHP and family anxiety and self worth in POS (p = 0.004) (p = 0.001) respectively
- social isolation in NHP and family anxiety in POS (p = 0.003).

3.6. Patients' knowledge of available palliative care services

Table 48 is a summary of the available palliative care services identified by the 6 patient groups (motor neurone disease, Huntington's disease, multiple sclerosis, Lung, Breast and Colo-rectal). The full tables for each of the groups is in Appendix 21. GGNHSB DN was known by all the groups of patients interviewed. Social services were known by all in the neurodegenerative group but in the cancer group, the breast cancer patients did not identify social services. All the cancer patients identified Marie Curie Hospice in Huntershill. Disease specific services were identified by the patients with the disease e.g. breast cancer patients identified Breast Cancer Care Association; patients with Huntington's disease, multiple sclerosis or motor neurone disease identified their own Associations. Breast, colo-rectal and multiple sclerosis patients were able to identify Macmillan nurses. Marie Curie nurses were known to lung and breast cancer patients and to a lesser extent to motor neurone disease patients.

Table 48 Patients knowledge of palliative care services available in GGNHSB area.

ORGANISATIONS	MND	HD	MS	LUNG	BREAST	Colo-rec.
Huntershill Marie Curie Centre	SOME	SOME	YES	YES	YES	YES
St. Margaret's Hospice	NO	NO	SOME	NO	SOME	SOME
The Prince and Princess of Wales Hospice	SOME	SOME	YES	SOME	SOME	YES
Macmillan Nurse	SOME	SOME	YES	SOME	YES	YES
Marie Curie Nurse	NO	SOME	SOME	YES	YES	SOME
Greater Glasgow NHS Board District Nurse	YES	YES	YES	YES	YES	YES
Social services - Community Care Services	YES	YES	YES	YES	SOME	YES
BACUP Scotland	NO	NO	NO	NO	SOME	NO
CRUSE Bereavement Care	NO	SOME	NO	NO	SOME	SOME
TAK TENT	NO	SOME	NO	NO	SOME	NO
Pain Association Scotland	NO	NO	NO	NO	NO	NO
Breast Cancer Care	SOME	SOME	SOME	SOME	YES	SOME
Body Positive	NO	NO	NO	NO	NO	NO
PHASE West	NO	NO	NO	NO	NO	NO
Positive Steps Partnership	NO	NO	NO	NO	NO	NO
Glasgow HIV-AIDS Support Group	NO	NO	NO	NO	SOME	SOME
Multiple sclerosis Therapy Centre	NO	SOME	YES	NO	NO	SOME
Crossroads (Scotland)	NO	SOME	NO	NO	SOME	SOME
Tom Allan Centre	NO	SOME	NO	NO	SOME	SOME
Rachel House Children's Hospice	NO	SOME	NO	NO	SOME	NO
Greater Glasgow Health Council	SOME	SOME	NO	NO	SOME	SOME
Scotland Huntington's Association	NO	YES	NO	NO	NO	NO
Scottish Motor Neurone Disease Association	YES	YES	NO	NO	NO	SOME
Alzheimer Scotland	NO	YES	NO	NO	NO	SOME

YES = > 2/3 know of the service; SOME = 1/3 to 2/3 know of the service; NO = < 1/3 know of the service.

3.7. Qualitative views expressed by patients about their care:

The qualitative views expressed by the patients were analysed by grouping them into five main areas. The themes that emerged were varied with both positive and negative comments about their care. There were more negative comments especially from patients with a neurodegenerative condition. In the cancer group the lung cancer patients commented most while in the neurodegenerative group the multiple sclerosis patients made more comments which were mostly negative. Overall the patients were glad to have the opportunity to say what they really felt about their care.

3.7.1.When first informed about diagnosis

The experiences of both cancer and non-cancer patients when they were informed of their diagnosis for the first time were not pleasant. Patients with multiple sclerosis had more negative comments on how they were informed about their diagnosis the first time. Their main complaint was about the lack of information offered about their future care/prognosis by the GPs and district nurses. Motor neurone disease and colo-rectal patients made no comments about this situation. The following are some examples from both cancer and neurodegenerative disease patients:

Patients gave examples of how they were unprepared when the diagnosis of cancer was told suddenly. There were instances when it took a long time for the diagnosis to be made after the patient saw the doctor. The other issue highlighted was that of support after they were told about the diagnosis. The following are some of the typical quotes:

> *"abrupt and as cold as that as if someone had cut me with an axe". "It was a new doctor and was told bluntly"* ***(Lung Ca)***
>
> *"It took 15 weeks to diagnose second tumour".* ***(Breast Ca)***
>
> *"The way they informed about diagnosis was dreadful". "Would like more information and explanation on diagnosis. No explanation given and hospital environment was not good".* ***(Multiple sclerosis)***
>
> *"No further information given on diagnosis and told not to get in touch with anyone or any association" by the consultant. When diagnosed after years, the patient was told: "go home" and no help was given.* ***(Multiple sclerosis)***
>
> *The way patient was informed about having multiple sclerosis was* dreadful. *No explanation was given by consultant and no advice or information about any support group.* ***(Multiple sclerosis)***
>
> *First told it was nerves. Was diagnosed by eye infirmary doctor. Was alone and no information given* ***(Multiple sclerosis)***

Huntington's disease diagnosis involved genetic testing and had unpleasant moments in the patients experience with the health services as illustrated below:

> *Was told the test was negative by the nurse and than told by the doctor that the test were positive. Patient was depressed when told of diagnosis. Patient's sister had committed suicide.*
>
> *"Was told about the gene and the doctor was good but the environment was not good to take it all in. Was just told the diagnosis and sent out"*

3.7.2. Hospital care

The cancer patients had more comments than the neurodegenerative disease patients about their hospital care. The feelings of the cancer patients about their hospital care were mixed. The cancer groups of patients especially those with lung and breast cancer had experienced treatment/care in two hospitals. Their main care was in hospital A and their radiotherapy was in hospital B. This group of patients were more than satisfied with services in hospital A (where they were treated as a "person") but were unhappy with their care in hospital B (where they felt that they were a "number" and not a "person"). The neurodegenerative patients had less to say about their hospital care. The multiple sclerosis group of patients were not satisfied with the explanations that they were given and were unhappy because they were refused treatment with the latest therapy (beta-interferon). The following are some examples from both cancer and neurodegenerative disease patients. There were four hospitals involved (A, B, C and D) and the following were the patients views about care in these hospitals. There were both positive and negative comments.

> *"Hospital A staff very good. Excellent care in Hospital A". **Lung cancer patient***
>
> *"No place for privacy in Hospital A. Problem is with the service and not the staff". In Hospital A had better care and better communication. **Lung cancer patient***
>
> *"No problem in Hospital A but problem in Hospital B". Has consultation before chemotherapy (in hospital A) but has no consultation before radiotherapy (in hospital B). **Lung cancer patient***
>
> *"just a number" in Hospital B. Problem with transport". **Lung cancer patient***

*"In Hospital B you are just a number, they talk over you and no cover put over you when you wait for treatment on a trolley, not treated as a person. In Hospital A you were a person". **Lung cancer patient***

Lack of communication in Hospital B and delay in radiotherapy. "No body listens".

*"Communication with doctors on Hospital B not good". **Lung cancer patient***

*Patient misdiagnosed for two and a half years. Long waiting time in follow up clinic due to shortage of doctors but Pain clinic doctors were good. **Lung cancer patient***

*"Very good care by Hospital A staff". "Treatment very good in Hospital A. First diagnosis good and quick in Hospital A but delay when had second lump". **Breast Ca***

*"Physio and speech therapist all work as a team in Hospital C". "No confidence in neurologist". **Multiple sclerosis***

*No communication from staff and no explanation given and patient was depressed and referred to psychiatrist. The professionals gave no help. Was told cannot have medication for multiple sclerosis by Hospital D **Multiple sclerosis***

*Doctor in Hospital C very good but not sure of procedures? **Huntington's disease***

3.7.3. Primary health care

Patients with a neurodegenerative disease had more comments about primary health care. On the contrary the cancer patients had less to say about their primary health care whereas the neurodegenerative patients, especially those suffering from multiple sclerosis, had many obstacles in accessing care from the primary health care services. Their main problem was the lack of information/care offered and they felt that this was due to lack of knowledge about multiple sclerosis by the GPs and district nurses. They received good care from the Multiple Sclerosis Therapy Centre in Glasgow. This is a voluntary organisation providing alternative therapy and counselling for multiple sclerosis patients. All the comments in the primary health care were about the GPs. The following are both positive and negative comments by the patients about their care.

*"No faith in GP". **Lung Ca:***

*"Good GP service". "GPs have no knowledge of benefits". **Breast Ca:***

"No problem with GP". No drugs but GP is good and learnt about Huntington's disease along with the patient. ***Huntington's disease:***

"Health care is very good". ***Huntington's disease:***

"No care, the primary health care leave it to the hospital and GP won't prescribe drugs due to cost". ***Multiple sclerosis:***

"GPs knowledge not good". Difficulties with care and access to treatment. ***Multiple sclerosis:***

patient had problems but had no understanding from health professionals. Always negative attitude from GPs. ***Multiple sclerosis:***

"Not much help from GP". ***Multiple sclerosis:***

Twelve years with GP and no diagnosis. Changed GP and was diagnosed within few months. Previous GP had no knowledge about multiple sclerosis. ***Multiple sclerosis:***

GPs knowledge about multiple sclerosis affects care of patients. Many patients contacted the Multiple Sclerosis Therapy Centre and felt better. ***Multiple sclerosis:***

3.7.4. Social services

Neurodegenerative condition patients had more comments than the cancer patients about social services. There were mixed comments about social services by the neurodegenerative condition patients but they were mostly negative. This was the only area of concern for the motor neurone disease patients and there were both positive and negative comments about the access to benefits and equipment. Only the colo-rectal patients from the cancer group had difficulties with the social services. For the colo-rectal patients this was their major concern and they were happy with the other areas of their care. The following are some comments from both cancer and neurodegenerative disease patients.

Problem is with the house. No help from social services. Physical aids to help the patient were difficult to get from social services. ***Colo-rectal Ca:***

"No carer service, am not claiming benefits and no help from them." ***Huntington's disease:***

"Good care and help with equipment" ***Huntington's disease***

Patient not happy with social services very slow to respond. Huntington's disease

"Received all necessary help for physical aids". Huntington's disease

"After council cuts lost the help of professional carer". Son received carer allowance after two years and a lot of struggle. Huntington's disease

Needs help and was told to see social services and received no help Huntington's disease

"Not sure about benefits". "Very interested in reading and knowing about illness". *Huntington's disease*

Problem finding out what is available mainly from social services. Once found out what is available than funding was a problem Huntington's disease

3.7.5. Information

Information: There was a general lack of information and this was highlighted by both groups of patients. The shortage of information affected their overall care and was found to be lacking as mentioned below. The following are some comments from both cancer and neurodegenerative disease patients.

No explanation was given about present symptoms Breast Ca

Not knowing about entitlements. Came to know about benefits after getting to know about it from a patient in the hospital. No information pack on what entitlement Breast Ca

Lack of knowledge about entitlement in social services Breast Ca

"No information from medical profession". Mostly self-thought about information on multiple sclerosis. Multiple sclerosis

"Accessing information is slow". *Self thought about multiple sclerosis. Multiple sclerosis*

"No information given". *Had to find out about multiple sclerosis by self as information poor regarding services and also follow-up. Multiple sclerosis*

Very good care by Hospital A staff Multiple sclerosis

4. Discussion

4.1. Introduction

The third and final part of this current PhD study was to assess and compare the needs of selected cancer and neurodegenerative disease patients requiring palliative care and also to ascertain their knowledge of the available palliative care services in the GGNHSB area. The first obstacle with the patients was similar to the problem encountered with service providers regarding the term "palliative care" or "hospice care". These were sensitive terms and equated as "terminal" by most patients especially those with non-cancer diseases. In order to overcome this from the initial stages with the patients included in this current study it was decided to use the term "chronic disease". All correspondence with patients stated that patients with various chronic diseases were being interviewed in order to bring together their views, which would be used to improve health services for chronic diseases in the GGNHSB area.

> *"In my experience, many non-cancer patients do not like the idea of associations with hospice and Macmillan / Marie Curie nurses as they very much associate this with cancer and dying". quote by a GP taken from the responses to the questionnaire survey of GPs and district nurses in part II of this current study*

4.2. Demographic data

The only significant differences between cancer and non-cancer patients was their age with the non-cancer patients being younger (0.004). There were significant differences for all patients between sex and ECOG (0.04), sex and carer (0.03) and age and carer (0.01).

4.2.1. Age

Addington-Hall and Karlsen (1999) conducted a secondary analysis of data in an UK population based retrospective survey of 2062 cancer and 1471 non-cancer deaths.[259] Their conclusion was that "age was not the crucial factor in determining how the palliative care needs of people who die from cancer differ from those of people who die from other causes". Their non-cancer sample consisted of circulatory system (69 percent), respiratory system (17 percent). Our sample of neurodegenerative disease and cancer patients found that the cancer patients were significantly (p= 0.004) older than the neurodegenerative disease patients were (see Table 38). For multiple sclerosis diseases our sample consisted of patients in their early 20's (see Figure 24). These younger neurodegenerative disease patients needing holistic palliative care are going to live longer then patient's with cancer (except for motor neurone disease patients where their 5-10 year survival rates are very low). The Scottish data from Ninewell Hospital in Dundee for motor neurone disease showed that 48 percent die within one year of diagnosis, 45 percent survive between one to five years and only seven percent survive over five years). Patients with circulatory and respiratory diseases are usually in the same age group (middle age or older) as those with cancer. Patients with neurodegenerative disease diseases (especially those with multiple sclerosis and Huntington's disease) are of a younger age group (from 20 years onwards) with physical disabilities that have an effect on their emotional, psychological and spiritual wellbeing for a longer period. Therefore age is a crucial factor in determining the palliative care needs of neurodegenerative disease patients compared with cancer patients. Hunter's study on community nursing providers perspective on palliative care services found that of the patients they cared for the youngest were those with multiple sclerosis (30% in 16-44 age group) and the oldest (75+ age group) were those with stroke, Parkinson's disease, ischaemic heart disease and cancer in that order. Those with motor neurone disease were between these two extremes.[140] These findings are similar to the GGNHSB patient sample.

4.2.2. Sex

The sample of patients with lung cancers had more males compared to females and for colorectal cancer there were similar numbers of males and females. This is consistent with the prevalence of these two diseases in the GGNHSB area (see Table 7 and 8). Hence a representative sample with regards to sex was obtained. There were more females in the sample of patients with multiple sclerosis, which is also consistent with the Scottish prevalence rates (see Table 10. There are no GGNHSB area rates available). Cheng (2001) found that in the USA, women with multiple sclerosis who had impaired mobility were a vulnerable population for receipt of preventive services (breast examinations, mammography and cervical smears).[260] This is an issue that needs to be looked at when planning services for female patients with multiple sclerosis.

4.2.3. Carer/ECOG

Another aspect of patients with neurodegenerative disease requiring palliative care being younger is its implication for carer availability for these patients. The main carer for both patients with cancer and neurodegenerative disease was their partner and the issue of respite and allowances were raised by both patients during the interviews (see figure 27). The neurodegenerative disease patients had increased physical disabilities compared to cancer patients and this was illustrated in their ECOG scores. This combined with the age of the patients with neurodegenerative disease poses problems for their long-term care.

4.3. NHP

Rothwell et al (1997) concluded from their study that patients with multiple sclerosis and possibly other chronic diseases are less concerned than their clinicians about physical disability.[102] The patients are concerned with other elements of their health status and quality of life and that clinicians should look at these patients in a holistic way. The current study showed that compared to patients with cancer, patients with neurodegenerative disease have statistically significant higher mean scores indicating greater problems with energy, pain, emotional reaction, social isolation and physical mobility components of the NHP. The current study did not assess physicians assessment of their patients physical disability.

Skilbeck et al's needs assessment looked at palliative care in COPD patients and it revealed a poor quality of life, relating to a higher degree of social isolation and emotional distress associated with low physical functioning, disability and physical symptoms.[110] In the current study patients with neurodegenerative disease diseases had statistically significant higher degree of social isolation, emotional distress and pain with low levels of energy and physical mobility, in comparison to patients with cancer diseases.

4.3.1. Multiple logistic regression

Pain (TP) and physical mobility (TPM) were the two main categories where differences were detected for cancer and non-cancer patients. It was mobility which demonstrated significant differences between cancer and non-cancer patients to two individual questions in NHP Part 1 after adjusting for all the covariants (see results section and Appendix 13a). It was also pain and mobility where the mean scores were significantly different for cancer and non-cancer patients (Figure 31). The differences in four pain question were all for non-cancer patients and three of these were for the covariant sex. ECOG was the other covariant responsible for differences in mobility and both cancer and non-cancer patients found it hard to dress themselves.

Initial cross-tabulation of all the demographic and NHP variables only revealed significant findings between Part 2 of NHP and type of condition (cancer and non-cancer) and ECOG. Logistic regression tests with Part 2 revealed significant differences between cancer and non-cancer patients for job, home life and interest and hobbies after adjusting for other variables and in all these instances the non-cancer patients scored higher than the cancer patients.

4.4. POS

In the mean scores calculated for the ten questions in POS, only in the questions relating to other symptoms, anxiety and family anxiety did the cancer patients score higher (higher is worse) than neurodegenerative disease patients. The two groups scored similarly on wasted time. For pain, availability of information, support, life worthwhile, self worth and personal affairs the neurodegenerative disease patients scored higher than the cancer patients as in the NHP results. Cross-tabulation findings showed differences in five out of the ten scores between cancer and non-cancer patients. ECOG had differences for wasted time and personal affairs. Depcat had differences for both cancer and non-cancer patients for self-worth, which had differences with age.

The correlation tests between NHP and POS showed significant relationships between similar categories of the responses from patients. The two main categories were pain and various aspects of emotion. This double testing of similar categories not only strengthens the responses from the patients and adds value to the patients' responses but also helps to validate the newer palliative care questionnaire (POS) with a tested, validated and proven generic outcome measure (NHP).

4.5. Patients' experiences

4.5.1. Non-cancer/neurodegenerative disease diseases

Addington-Hall et al (1998) looked at specialist palliative care needs in non-cancer diseases and concluded that clinicians and patient groups should work together with specialist palliative care services.[114] There is no mention of the community based primary care team who are usually the first to come in contact with these patients. If the primary healthcare team are not able to identify the palliative care needs of these patients it might be too late to help as permanent disabilities can develop especially in patients with neurodegenerative diseases. Carter et al (1998) found that the level of difficulty experienced by health professionals was similar for both multiple sclerosis and motor neurone disease.[104] These were resource issues, ability to remain positive in the face of progressive disability, interdisciplinary team problems and difficulties regarding patient care. The GPs and district nurses in GGNHSB area had less exposure and experience of problems relating to neurodegenerative disease diseases compared to cancer and were not able to offer as much support and palliative care. Kite et al (1999) looked at specialist palliative care and patients with a non-cancer diagnosis and concluded "defining management goals at the outset is particularly important".[120] The GPs and district nurses in GGNHSB area still found it difficult to accept that non-cancer diagnosis patients do require palliative care. Some GPs and district nurses felt that the burden on specialist care by cancer patients is not being met adequately and so they were reluctant to refer non-cancer patients to specialist palliative care team.

Ford (1995) in his article about informing patients that he/she has multiple sclerosis concluded that:

> *"It is difficult to tell a person that s/he has multiple sclerosis. The diagnosis is based on clinical findings and often cannot be made on first meeting. In many cases investigations do not help. When the diagnosis is made, the patient should be fully informed in the majority of cases. Guidelines have been developed for imparting the diagnosis. Early diagnosis will become increasingly important with the development of new treatment for multiple sclerosis".*[101]

This was in 1995 and nothing has changed. The multiple sclerosis patients in GGNHSB area had the longest interval from the onset of first symptom to the date of diagnosis and they received the least amount of information about their diagnosis. Some were told to go home and forget about their illness.

A search in the literature on studies relating to communication between health professionals and patients requiring palliative care mainly identified articles relating to cancer. There was one on multiple sclerosis[101] and most articles on non-cancer diseases were in the nursing or neurological journals. Both cancer and neurodegenerative disease patients in GGNHSB area had encountered distress when they were informed of the diagnosis. The multiple sclerosis patients were a younger patient group in the total patient sample and they were upset and angry at having an incurable illness and not being given any information or explanation. This was exacerbated by the delay in their diagnosis, sometimes by many years.

Krishnasamy et al's study (2001) found that the lung cancer patients were more comfortable talking to hospital doctors in the wards as compared to out-patient clinics. When talking to their GPs, the patients found that their home was more suitable than the GP clinics.[155]

4.5.2. Health care

This is the patient's experience with the care that is available. The cancer patients were receiving more care from the hospitals compared to home care or hospice services and their comments were more on their hospital. The neurodegenerative disease patients' comments were mixed and the multiple sclerosis patients experience the greatest number of difficulties and problems with hospital and primary care. The main problems for the multiple sclerosis patients were lack of information about all aspects of their illness and failure of the health care professionals to explain their illness. Access and aids from the social services was also sporadic. Cancer and non-cancer patients had difficulties especially for the neurodegenerative disease patients. However some of the motor neurone disease patients were satisfied with the care they received from social services.

The finding from Skilbeck et al was that current service provision for COPD focused on acute exacerbation's of these patients.[110] A similar situation in the current study was reported by the neurodegenerative disease patients in particular the multiple sclerosis patients, who experienced exacerbation and remission. There was little support during periods of remission. Skilbeck et al's recommendation was that there is a need to manage the health and social care interface more effectively, with a shift in emphasis from reactive ad hoc provision to a more proactive approach where the palliative care approach could be best suited to meet the needs identified.[110] Similar priorities for patients requiring palliative care would benefit all patients especially those with non-cancer diseases. There is a lack of co-ordination of health and social care services especially for the neurodegenerative disease patients in the current study. This might be overcome by having a designated key worker who could co-ordinate with all the service providers on behalf of the patient.

Changing long standing practice is going to need time and some amount of risk will have to be taken or else nothing will be achieved. This was well illustrated by a report titled "Changing practice: Overcoming resistance in a Specialist Community Palliative Care Team" by Hansford of what happened in St Christophers Home Care service in London.[261] The obstacles identified were the powerful myths about its good practice, views of the nursing staff were given greater priority and were protected when compared to the needs of patients and families[261]. This contradicts the palliative care ethos. The more senior the staff the more were the objections and proved the point that factual information was not sufficient to make a health professional change his or her mind as they felt threatened and disorientated by change.[261]

4.5.3. Voluntary service providers

At the end of the interview with each patient they were provided with a list of palliative care service providers in the GGNHSB area and were asked if they knew about these service, if they had used it or if they had no knowledge of the service. Only GGNHSB DNs were known to 2/3 of patients in all the six groups of patients (lung, breast and colo-rectal cancers, multiple sclerosis, motor neurone disease and Huntington's disease) and the social services were known by 2/3 to all of the patient groups except for the breast cancer group who were less aware of social services (see Table 46). It was surprising to find that voluntary sector service providers for cancer were not identified in the current study even by the cancer patients. A report by the Scottish Partnership Agency on "Palliative Cancer Care: The integration of Palliative Care with Cancer Services" found that in many case patients, their relatives and carers are unaware of the sources of support available to them.[8]

Social services was the one organisation who were found to be inadequate by the GPs, DNs and the patients. This was especially marked with the neurodegenerative disease patients. Hunter's study found that their community nurses had positive views of the various palliative care service providers but had negative views about the social work community care team.hunter[140] A recent study carried out by Krishnasamy (2001) after the completion of the current study, found that only one percent of the patients reported that the social services were helpful.[155]

4.6. Resources

In addition to lack of recognition of the need for palliative care for non-cancer patients resource both financial and human has been an obstacle for including non-cancer diseases under the palliative care category. Morch et al (1999) from Sweden reported on their "thirty years' experience with cancer and non-cancer patients in palliative home care". They provide palliative home care only if the patient desires and the medical staff agree that this kind of care was feasible.[262] They found that this improved the quality of life for the patient and for the society it offered a cost-effective care for the dying in the short term and reduced the need for hospital beds over the long term. One of the explanations that they provide for its success was that the Swedish health care system is particularly well resourced and there had been no particular shortage of financial or human resources.

Addington-Hall and McCarthy (1995) in their study on "Dying from cancer: results of a national population-based investigation" reported that adequate resources are required to meet the social and health care needs of cancer patients at home.[74] Wilson et al published (1995) their findings on "The need for inpatient palliative care facilities for non-cancer patients in the Thames Valley" that if the need is to be met, current facilities will be inadequate and additional beds and services will be required.[263] They found that for one year the non-cancer patients would need 66,000 bed-days compared to 40,000 bed-days for cancer patients in the same year.[263]

5. Conclusion

The objectives for the service users were accomplished and the following two null hypothesis were rejected as there were significant differences between the patients with cancer and non-cancer:

- There are no differences between the perceived health problems of patients with cancer (lung, breast and colo-rectal) and non-cancer diseases (neurodegenerative diseases - multiple sclerosis, motor neurone disease and Huntington's disease).
- There are no differences between the outcome of the care of patients with cancer (lung, breast and colo-rectal) and non-cancer diseases (neurodegenerative diseases - multiple sclerosis, motor neurone disease and Huntington's disease).

The last null hypothesis was that:

- The patients needing palliative care are aware of the palliative care services available in GGNHSB area.

This was not rejected, as there were palliative care services that were known and some that were unknown to the patients with cancer and neurodegenerative diseases.

Chapter 8

Conclusion and recommendations for the development of future palliative care services for cancer and non-cancer conditions

1. Introduction

The Scottish Executive's Palliative Care strategy and the NHS Greater Glasgow palliative care strategy are patient focused. This current study has identified the main issues, and has made recommendations that would assist GGNHSB in overcoming the obstacles which prevent them from achieving their palliative care strategy. A report based on this thesis will be presented to NHS Greater Glasgow Board to provide an evidence-based strategy for palliative care. This strategy will be for cancer patients and more importantly for non-cancer patients, who also require palliative care integrated into their framework of care.

The voluntary sector, public donations and fund raising programmes mainly fund the palliative care services for patients with cancer. There is a need for these to be widened to include patients with non-cancer who require palliative care services. Education of the public about the similarities in the needs of cancer and non-cancer disease patients and highlighting the present inequalities in the provision of palliative care services would help to increase the profile of the non-cancer diseases.

The review of the literature has highlighted the discrepancies in the provision of palliative care services for cancer and non-cancer patients. This study examined the palliative care service provision and found that the statutory and voluntary sectors were not able to include all patients with a diagnosis of non-cancer illnesses requiring palliative care. This is partly a resource issue and a lack of awareness of non-cancer patients needs. The finding from the questionnaire survey with the GPs and district nurses in the community highlighted the difficulties GPs and district nurses had in including non-cancer illnesses as requiring palliative care. They found providing palliative care for patients with a diagnosis of chronic, progressive and incurable diseases to be impossible due to their workload and the limited resources available to provide palliative care services. They identify priorities and made choices dependent upon the diagnosis and not on need. This strengthens the view that there is a lack of recognition of the palliative care needs of the patients with a diagnosis of non-cancer diseases. There is also an inability to accept that non-cancer patients have palliative care needs. This may be because of an incomplete understanding of what palliative care is and who should receive it. Palliative care originated for cancer patients ONLY from the beginning and palliative care for non-cancer patients has to be accepted and integrated into the present restricted world of palliative care.

The assessment of cancer and non-cancer patients' health status, their outcome of care and their palliative care needs in this study has shown that palliative care needs of the non-cancer patients were greater or at least equal to those of the cancer patients. Patients with non-cancer illness requiring palliative care, did not themselves realise that they were entitled to receive palliative care. This may be because of the association of palliative care with terminal care which makes this patient group feel that palliative care is only for the dying. This was the reason that the word palliative care was not included in any of the information sent to the patients involved in this study. Only the word chronic illness was used. The other two words used to define the requirement to receive palliative care are progressive and incurable. These two words were also excluded in all information given to the patients. Education and awareness raising campaigns, of the public and all service providers on the palliative care needs of non-cancer patients, would need to be integrated with implementation of palliative care services for non-cancer patients.

Through an evidence based public health approach this study has explored the above. The last figure (Figure 33) brings together the three aspects of this study and highlights the main issues that have emerged. This concluding chapter will discuss these issues and make recommendations from the findings. The main issues are: definition of palliative care, recognition and education, patient's choice, co-ordination and communication, palliative care services, resources for these services and future research. These main issues have been identified in all three areas of this current study and reinforce the validity of the issues raised by the voluntary and statutory sector, GPs and district nurses and cancer and non-cancer patients. This concluding chapter will analyse how these issues affect these three areas and how the issues can be managed.

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2. Discussion and recommendations

2.1. Definition

2.1.1. Main issues identified by current study

1. **No clear definition or understanding of the term palliative care by those providing and those using palliative care services (Involves part I, II and III of Figure 33).**

The crucial and most significant obstacle that I encountered during this current study was the definition of palliative care for all involved. Similar comments were made by Higginson that "*lack of clarity in definitions in palliative care leads to wide variations in practice*".[44] All the participants in the current study had difficulty in accepting the concept that WHO's definition of palliative care included non-cancer diseases which were given the same importance as cancer diseases. The service providers were trying hard to provide a palliative care service with limited human and financial resources. For them it was difficult to accept practically that they should become responsible for providing the same palliative care service for a group of patients who numbered more than the cancer patients[23] and would survive longer than cancer patients. Their acceptance would have been made easier if there were additional resources. GGNHSB in their document "*Palliative Care Services in Greater Glasgow - A Framework for the future*"[23] estimated the number of deaths per annum in their Health Board was 3,200 due to cancer and 6,300 due to potentially chronic, progressive and incurable non-cancer diseases.

The obstacle in the definition of palliative care was a problem not only for the mainly non-medical led voluntary sector service providers but it was also a dilemma for the GPs, district nurses and specialist palliative care service providers.

> *"Traditionally I have tended to think only patients with cancer qualify for hospice care/treatments". – quote by a GP taken from the responses to the questionnaire survey of GP's and district nurses in part II of this current study.*

> *District nursing team takes the lead in terminal/palliative care in my setting with close collaboration with the GPs. The Marie Curie sitting service requires to be extended to day sitters. The Marie Curie withdrew from two patients a few years ago because they were not terminal! Palliative / terminal care is one of the most satisfying areas of district nurse care and services should not become a separate service, it should be led by district nurses on nursing side" – quote by a DN taken from the responses to the questionnaire survey of GPs and district nurses in part II of this current study..*

Definitions should be clear, acceptable and practical and have to be agreed by all concerned. The definition of palliative care to which patients it applies cannot and should not be decided only by organisations (WHO), medical bodies (standing committees), or other service providers (voluntary and statutory). The patients and society as a whole must be involved. It is easy to come up with a definition without thinking through its implications and how it is going to be implemented. Expectations have been raised and now have to be fulfilled in order to provide just care for all concerned. Maybe for this sensitive and wide ranging issue of palliative care which has cost implications there should be wider consultation followed by a prolonged period of raising awareness and to make it explicit from the beginning about all the issues surrounding its implementation. This brings us to the next issue which is how this could be achieved.

2.1.2. Recommendations:

I. **To promote a clear, simple and friendly definition of "palliative care" for health care workers and patients. A health and social strategy must be derived and the implications of implementing this strategy must be resourced. (Involves part I, II and III of Figure 33).**

2.2. Recognition and education:

2.2.1. Main issues identified by current study

2. **There is a lack of recognition of non-cancer diseases as having a requirement for palliative care. (Involves part I, II and III of Figure 33))**

3. **In the GGNHSB area education is lacking amongst health care workers, the patients and the public programmes to raise their awareness of the needs of non-cancer patients. (Involves part I, II and III of Figure 33)**

Until the early 1980s most hospices or palliative care services described their services as providing *terminal care.* In the UK since then such a phrase was felt to be a barrier to health professionals referring patients sufficiently early to benefit from care. Specialist in palliative care promoted the idea of *palliative care* from diagnosis in appropriate patients. Patients were discouraged by the phrase *terminal care.*[20] After the early 1980s the value of hospice-type care earlier in cancer care was being recognised and some services started to describe their services as *palliative care* rather than *terminal care.*[20] In the 1990s WHO included non-cancer patients with chronic, progressive and incurable illness to be recipients of palliative care.[1]

This current study found that this ethos had not filtered through to palliative care services and patients in the community and this was one of the obstacles in the recognition of non-cancer patients requiring palliative/terminal care. Patients and service providers still felt that palliative and terminal care were synonymous and so found it hard to understand how a patient with a illness that was not going to kill them in the near future could qualify for palliative/terminal care. This might be one of the reasons why specialist palliative care services are prepared to accept motor neurone disease patients (maximum 5 year prognosis) as those requiring palliative/terminal care more readily than multiple sclerosis or Huntington's disease patients (prognosis might be several decades for both these conditions).

In the current study all the service providers who participated were provided the new definition of palliative care from the WHO (first definition in 1990 and updated in 2002).[1] But whether these definitions were accepted by all the service providers involved in this current study or if all concerned were prepared to implement this was uncertain. This was because it was recommended that similar palliative care services should be developed for patients dying from diseases other than cancers[15]. In 2003, and nearly a decade after it was first recommended, there is still no concerted move to implement this basic total care that is the right of all patients whose disease is not responsive to curative treatment. The question is "*Who is responsible for implementing this? And how can this increased need be implemented without additional resources.*"

There have been a great number of articles in medical journals, and conferences and seminars highlighting the palliative care needs of patients with non-cancer diseases. There have been articles in the media but these have been sporadic and there is no continuous campaign to make a significant impact on the present status quo where the bulk of palliative care is for a patient with a diagnosis of cancer. One of the reasons for this has been that the various non-cancer diseases have been fighting their own corner and only providing evidence for individual diseases. For example, cardiac, respiratory, multiple sclerosis, motor neurone disease or HIV & AIDS all have their own support groups. When the word *"palliative care"* is used for cancer diseases people do not talk about individual cancers, they consider cancer as one entity. There are national charities such as the Marie Curie Cancer Care and Macmillan Cancer Relief for all types of cancers. But when the same word *(palliative care)* is used for non-cancer diseases there is a differentiation between the various body systems (CNS, Respiratory, Cardio-vascular system, or immune system – HIV & AIDS) and also differentiation within each body system (multiple sclerosis, Huntington's disease or motor neurone disease in CNS). This sub-division maybe diluting the impact of one collective voice and opinion.

A survey of the public in Scotland in 2003 found that only 19% had good knowledge of *palliative care*, 32% had no knowledge and 49% had some knowledge.[214] The survey also found that there was a negative response from a small percentage (3.7%) with regards to patients with HIV & AIDS right to receive palliative care.[214] There were 14% who were unsure whether those with chronic, progressive incurable lung and heart diseases merited access to palliative care services.

With the increasing prevalence of cancer in an ageing population, it is likely that many more will require the input of primary care services.[5] Palliative care is clearly an important and sensitive issue for patients with cancer and other progressive, incurable non-cancer diseases. Home support services and specialist palliative care facilities (hospices and hospital wards) are frequently required and a more co-ordinated approach is needed.[5] Recognition of symptoms and knowledge of how to treat them should be included in programmes of training of members of the Primary Health Care team.[149] In this current study respondents desired more education in palliative care.

Palliative care specialist should be involved in undergraduate and pre-registration training of all health care professionals and enhance the skills of the GPs and consultants in order to influence the palliative care of patients as a whole.[264] One of the barriers to specialist palliative care for all is that the specialist delivering specialist palliative care may have limited knowledge of the more up to date treatments of a variety of conditions.[265] This will involve developing and educating the palliative care specialists. There is also a need for continuous education at the general level of palliative care knowledge and a better level of training in the speciality for all doctors and nurses.[265] This increased general training and greater awareness of the benefits of specialist palliative care could lead to appropriate use of specialist teams for all patients requiring palliative care.

The Scottish Partnership Agency for Palliative and Cancer Care (SPA) is now called Scottish Partnership for Palliative Care. They have deliberately taken *cancer* out of their name at an AGM in 2002 to promote palliative care of non-cancer as well as cancer. This is a starting for the recognition of non-cancer patients' palliative care need and has to filter to the health professionals in the community. The following quote was made in relation to health care services:

> *"If you cannot provide a service for a medical condition then you do not look for the signs and symptoms of that medical condition because if you find the signs and symptoms you have to do something about it". quote by a GP taken from the responses to the questionnaire survey of GPs and district nurses in part II of this current study*

This is an ethical dilemma faced by many health care workers who are unable to provide palliative care on the basis of need to non-cancer patients.

2.2.2. Recommendations:

II. There is a need for recognition of non-cancer diseases as having a requirement for palliative care. This will have to be adequately resourced with staff and funds. (Involves part I, II and III of Figure 33)

III. There should be better co-ordination of education for all health care workers, the patients and the public in the GGNHSB area to raise awareness of the palliative care needs of non-cancer patients. (Involves part I, II and III of Figure 33)

2.3. Patient's choice:

2.3.1. Main issues identified by current study

4. **Patients did not have a choice of place of care. (Involves part II and III of Figure 33)**
5. **There is a lack of patients' involvement from the initial stages in care decisions with the healthcare professionals. (Involves part II and III of Figure 33)**
6. **The GPs and district nurses felt that there was a lack of choice of place of care and place of death for their patients. (Involves part II and III of Figure 33)**

This current study was community based assessing comparing the needs of patients. The NHS Quality Improvement Scotland's patient focus states that "*all services respond to patients' needs and preferences, and that patients are involved in decisions about their own care through effective two-way communication and information sharing*". These issues include: assessment; *patient involvement*; *patient information*; *patient/staff communication; patient feedback; access to services* and discharge arrangements.[21] Many of these issues (those in italics) have been validated by the results of this current study and have been highlighted as issues and are included in the studies recommendations.

A survey in 2003 of the public in Scotland found that[214]:

- 20% stated that they would like to be able to stay at home for as long as possible,
- nearly two thirds (65%) wanted information on palliative care to be generally available,
- most (85%) felt that hospice care was important and less than two thirds (63%) felt that hospitals should provide palliative care.

For patients with non-cancer diseases and the palliative care specialist the dilemma is *when does palliative care start?* The present agenda is one of clinician focus (the end of life) rather than patient focus (the need for symptom control and psychosocial support at any point of the illness trajectory).[264] This will disadvantage the patients with non-cancer diseases who require and need palliative care services early in their illness and raises the question "*why limit the focus to the end of life*?"[264]

For a patient the quality of life is determined by that person and so there will be individual variations. Tailoring treatment or care plans to the individual's own priorities makes sense.[266] Many times health will not be the number one priority or even in the top five. So it is always important and essential to involve the patient in any care plan that is being developed for that patient.[266] By combining patients' priorities with good basic care we could achieve the quality of life that the patients want, and be cost effective.

A patient's definition of palliative care is more than just nursing skills:

> *"It combines sharing, communication, and 'an interchange of love'. Care promises a steady and inexhaustible flow of support at every stage of living and dying. It understands the jangled interface between who the patient really is and the eroding impact of disease. You respect our will to fight on but gently shore us up and unobtrusively take over the burdens we let fall. The essence of care transcends systems and resides beyond them. The care we dream of is delivered with reassurance, born of experience, integrity and compassion. It encourages us to value each new day afresh, especially the day of death. It neither patronises nor cajoles but accepts the status quo with grace and creativity. It knows to maximise but never with pressure"*[266]

In the current study the views of the patients have been discussed in chapter seven and the issues highlighted by the non-cancer patients was one of lack of support from the community health care teams due to their lack of experience and knowledge of how to provide palliative care for them. As shown by this study this was despite the non-cancer patients having a greater need than cancer patients.

2.3.2. Recommendations:

IV. The GPs and district nurses felt that there was a need for choice of place of care and death for their patients. (Involves part II and III of Figure 33)) This will enable the patients (especially the non-cancer patients) to be involved with the healthcare professionals in care decisions from the initial stages (Involves part II and III of Figure 33)

V. There is a need to listen to and understand the needs of the patients (especially the non-cancer patients) and to promote patient centred planning for all future strategies in palliative care. (Involves part II and III of Figure 33) Patients' should be given the choice of place of care and of death. (Involves part II and III of Figure 33)

2.4. Co-ordination and communication:

2.4.1. Main issues identified by current study

7. **There is a lack of co-ordinated working between primary healthcare, social work community care and specialist palliative care teams to fulfil patients needs. (Involves part I, II and III of Figure 33)**
8. **There is a lack of communication of information between all those providing and receiving palliative care services especially for non-cancer diseases. (Involves part I, II and III of Figure 33)**

Lack of easily accessible information and lack of standardisation of data collected was one of the problems encountered by this current study. The three hospices in the GGNHSB area had individual software for recording activity data (one hospice was using HADS). This was identified during the course of this current study and GGNHSB with the help of

Information Services Department (ISD) in Edinburgh and the three hospices set up a working group to look into ways of integrating the data. After two years of work a six-month project was conducted and then nothing happened. Now the ISD is not providing support to the hospices that purchased the HADS software due to technical difficulties with upgrading HADS.

There has been a joint working partnership established between ISD and Scottish Partnership for Palliative Care (SPPC) to develop a minimum data set for specialist palliative care (in hospitals and hospices). They have linked up with the Clinical Standards Board Scotland to ensure that this minimum data set will cover all the data requirements of the Clinical Standards Board Scotland. The hospices using HADS are looking at purchasing new software to record their activity data and are working towards acquiring a data set that will be compatible with the minimum data set of ISD and SPA.[267] Hopefully this project, once completed, will help in the provision of an efficient and effective specialist palliative care service and also provide the necessary information and enable communication between the various palliative care service providers.

It was found that the various palliative care service providers in the UK worked in various ways (alone, with other organisations or as multidisciplinary teams), providing different levels and type of care (referred on discharge from hospital, direct referral from patient and families, health care, holistic care, education to health professionals or patients and families). They also had various funding sources which changed over time (NHS, Macmillan Cancer Relief, local hospice charities, voluntary organisations and individuals).[20]

The current study also found that there was no single assessment system for non-cancer patient's needs. The social services do their own assessment, the health teams do their own and if any voluntary organisation is involved than they do their own assessment. There seems to be no sharing of information between these service providers. There has to be an identified contact person, for each patient, who will co-ordinate the total care of that patient and their needs.

2.4.2. Recommendations:

VI. There is a need to improve/facilitate co-ordinated working between primary healthcare, social work community care and specialist palliative care teams by more joint working on palliative care projects. (Involves part I, II and III of Figure 33)

VII. There is a need to improve/increase palliative care services by communications in/between the three hospices, six hospitals, social services and the voluntary sector in the GGNHSB area. (Involves part I, II and III of Figure 33)

VIII. There is a need for information sharing between all those providing and receiving palliative care services, especially for patients with non-cancer diseases, to fulfil their needs. (Involves part I, II and III of Figure 33) A common electronic database for palliative care is required where all information and research can be easily accessed by all.

IX. There is a need for a named contact person who will co-ordinate the total holistic care from the various service providers for the patient (including the non-cancer patients) (Involves part I, II and III of Figure 33).

2.5. Service provision:

2.5.1. Main issues identified by current study

9. There are insufficient palliative care beds in hospices and care homes and no specialist palliative care beds in any hospital in the GGNHSB area for cancer patients. This is an even bigger problem for non-cancer patients. (Involves part II and III of Figure 33)
10. There is a lack of guidelines on when to refer cancer and non-cancer patients to specialist palliative care services. (Involves part II and III of Figure 33)
11. There is a lack of specialist palliative care services in the acute sector. (Involves part II and III of Figure 33)

The themes emerging from the quotes by GPs and district nurses in the current study were very similar qualitatively although different quantitatively. Resources either in the form of increased hospice beds, hospice at home service or a special palliative care ward in hospitals seem to be one of the ways whereby patients can receive palliative care in an appropriate environment if hospital admission is required.

The primary health care team and relatives will normally be involved when the patient with cancer is discharged from the secondary care setting for care at home and during the terminal stages. However they may need to refer to specialist palliative care staff or services for advice or support for the more complex cases. There is no mention of palliative care for non-cancer conditions in the guidelines.[6]

In 1997, it was found that 96-97% of specialist palliative care services were taken up by patients with cancer.[144] All inpatient discharges by speciality in Scotland for 2000/01 showed that there were 2268 all causes discharges for palliative medicine and of these, 2187 (96%) were for patients with cancer.[268] In 2003, it was found that in Scotland there were 4,809 outpatient appointments with a palliative medicine consultants and 90% of these were for patients with cancer.[268]

In the community the GP has long term responsibility for patients with non-cancer diseases and the GP should incorporate the palliative care approach from the time of initial investigation and diagnosis up to the more advanced stages, considering and addressing the psychosocial issues throughout.[264] There are concerns for the long term future of specialist palliative care if a major move is made to incorporate non-cancer diseases into palliative care services.[264] One of the suggested solutions is for the greater majority of the palliative care needs to remain the responsibility of GPs and the generalist hospital services, while specialist palliative care maintains a specialist advisory role for the majority of patients referred and provides long term continuity of care for only a small number of patients with the most complex needs.[264] This is an appropriate arrangement and consistent with the generalist-specialist interface on which the NHS was founded.[264] This is highlighted by the figure 4 (in chapter two - the literature review) which illustrates the present concept of generalist-specialist co-ordination for patients requiring palliative care. How much and how effective this model is must be evaluated.

Local health boards and the primary care trusts are responsible for assessing and meeting the health needs of the local population and this infrastructure should offer support and management strategies to allow palliative care services to develop.[269]

2.5.2. Recommendations:

X. Service remodelling and redesign is needed in both voluntary and statutory sectors to meet the needs of patients (especially the non-cancer patients). (Involves part I, II and III of Figure 33)

XI. Guidelines on when to refer the cancer and non-cancer patient to specialist palliative care services should be developed. (Involves part II and III of Figure 33)

XII. There is a need for specialist palliative care beds and services to be provided in the acute sector. (Involves part I, II and III of Figure 33)

XIII. Improved palliative care services are needed for cancer and non-cancer patients requiring palliative care (Involves part II and III of Figure 33):

- **by better utilisation of current services and increasing the number of hospice beds,**
- **by improving palliative care services in care homes,**
- **by creating designated palliative care beds in hospitals with the necessary qualified palliative care staff with sufficient funding.**

2.6. Resources:

2.6.1. Main issues identified by current study

12. **Lack of funding was an issue identified by all service providers. (Involves part I and II of Figure 33)**
13. **Despite the desire to help with non-cancer diseases, service providers in the voluntary and statutory sector, specialist palliative care teams and primary**

healthcare professionals have their finite resources for palliative care fully utilised with cancer patients at present. (Involves part I, II and III of Figure 33)

The current study found that given the finite resources, the statutory and voluntary sector and the primary care service providers find it difficult to accommodate non-cancer patients palliative care needs in the same way they do for cancer patients. All strategies for palliative care need to incorporate education, multi-professional palliative care and specialist services. There is need for palliative care to be extended to other services beyond cancer services. [270] This expansion would create a medical demand, which would require a doubling of the training places available and this expansion of specialist palliative care to include non-cancer diseases will have an effect on other specialists. The NHS Cancer Plan for England includes palliative care services and sets out future plans to increase investment in the NHS by 2004 to end inequalities in access to specialist palliative care. There are plans for increased integration between the charitable sector and the NHS and if they work to agreed national standards then the present NHS average funding of 39 percent would be increased to 50 percent for specialist palliative care units.[271]

There is also a view that care should be provided for non-cancer patients on the principles of the palliative care approach rather than arguing specifically that hospices and specialist palliative care services provide it.[20] The reason for this is that most of the hospices and specialist services lie outside the NHS and at best are partly funded by it and so do not have the authority to insist on this.[20] The clear message from the government[6;8;12;13] and the NHS[42;271] in the UK is that palliative care should not be restricted to terminally ill cancer patients yet studies show that almost all patients admitted to hospices and specialist palliative care services have cancer.[80;84;144]

A report from the workgroup on finance suggests that the NHS has good models of general health care for hard to reach groups, funded both by statutory and voluntary organisations. The weakness is that statutory healthcare finance in the UK, whilst stable at one level, is vulnerable to "flavours of the month" and long term central funding is very difficult to secure. Palliative care for cancer and non-cancer diseases do have multiple services and funding streams and communication difficulties are inevitable.[269] With regards to palliative care services, the issues are similar in England and Scotland even though the NHS health services are different. This is because the major part of funding for palliative care comes from the private sector and voluntary organisations which work similarly and have common goals across the borders. This only makes it more difficult for non-cancer diseases to be included.

Another argument put forward is that palliative care in general is not a high priority in the mainstream NHS purchaser's thinking and so palliative care for non-cancer diseases has an even greater problem in securing funding.[272] One of the reasons for this is the lack of evidence of how accessible services, especially residential and respite care, have become to non-cancer groups.[272] The Labour government has NHS as a priority and has recently made many structural changes to the NHS (for example single system, abolition of Trusts) and the risk of this is that palliative care services in general will be neglected in the immediate future in terms of both serious attention and review.[272] The lack of evidence and measurable improvements in palliative care for non-cancer diseases makes it difficult to justify in this culture of performance management and cost effectiveness.

In Scotland the research priorities from 1998 have been mental health, cardio-vascular diseases/stroke and cancer. In 2003 these three topics were still the research priorities with the addition of research on public health. The research topics in cancer are all concerning clinical trials and other areas related to cancer with no mention of palliative care, and when palliative care is not included as part of cancer research then there is less possibility of including non-cancer diseases in the research topics.

2.6.2. Recommendations:

XIV. There should be made available sufficient human and financial resources to provide palliative care services for both cancer and non-cancer diseases in the GGNHSB area. (Involves part I, II and III of Figure 33)

2.7. Research

2.7.1. Main issues identified by current study

14. There is a lack of evidence on the needs of non-cancer patients, on the best ways of meeting these needs and on the effectiveness and acceptability of available services

The underlying problem of need for palliative care services for non-cancer patients is the striking lack of scientific, empirical evidence on the needs of non-cancer patients, on the best ways of meeting these needs, and on the effectiveness and acceptability of services.[20] This current study has looked at and compared the needs of cancer and non-cancer patients. It has shown that the needs of the non-cancer patients were greater than those of the cancer patients and that service providers were unable to meet all the palliative care needs of non-cancer patients and also of some cancer patients. Further research is needed on the ways of best meeting these needs and on the effectiveness and acceptability of these services for non-cancer patients.

The following quote should encourage all palliative care researchers:

> *"I believe now is the time to grasp the nettle and try and work out what signs, symptoms and investigation results point towards the need for early palliation. We need hard facts so that we can actually know rather than just hope we are doing what is best for our patients. Without more research in this area we are in danger of failing to meet the palliative care needs of a large number of dying patients".*[273]

2.7.2. Recommendations:

XV. The identified research areas have to be encouraged to provide the evidence to justify the resources (human and financial) that need to be allocated to make palliative care services available to all on the basis of need rather than diagnosis.

3. Epilogue

The findings from the current study have shown that palliative care should be not just for patients with cancer but should be for all patients with a chronic, progressive and incurable disease. We also know that it should be available from the time of diagnosis. The current study has shown that patients with chronic, progressive and incurable diseases have as much right to and a greater need for palliative care as patients with cancer. What is required now is the recognition of this fact by all and the political will to make the necessary improvement in the palliative care services.

If palliative care, general and specialist, is not provided for patients with non-cancer diseases and is only available for patients with cancer then the following quote is most appropriate:

> *"How ironic that the justification for smoking and defaulting from breast or cervical screening would be the insurance that at least one's care and death would be well managed"*[265]

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Appendices

Table of Content

Appendix 1

Poster presentations I.

Palliative Care - A Community based health needs assessment in Greater Glasgow Health Board area.

Dr. Yoga Velupillai (Ph.D. Student). Prof. J. McEwen (Public Health), Prof. J. Welsh (Palliative Medicine) Dr. J. Womersley (GGNHSB). Funded by the GGNHSB. Started - June 97.

Background.

- Greater Glasgow Health Board has prepared a framework for future services in palliative care.
- An assessment of palliative care needs including those needs identified by patients & carers is needed to facilitate future strategy and development of palliative care.
- This is now being done in the Glasgow University Public Health & Palliative Medicine Departments and is being funded by the GGNHSB.

Aims & Objectives.

- To identify and document the various palliative care services available in Glasgow & to identify what they provide.
- To obtain from existing literature an epidemiological description of the likely needs.
- To identify the patients needs.
- To identify the carers needs
- To identify the palliative care priorities of the professionals providing the service.
- To recognise the effects of social deprivation on the QoL of patients and carers.

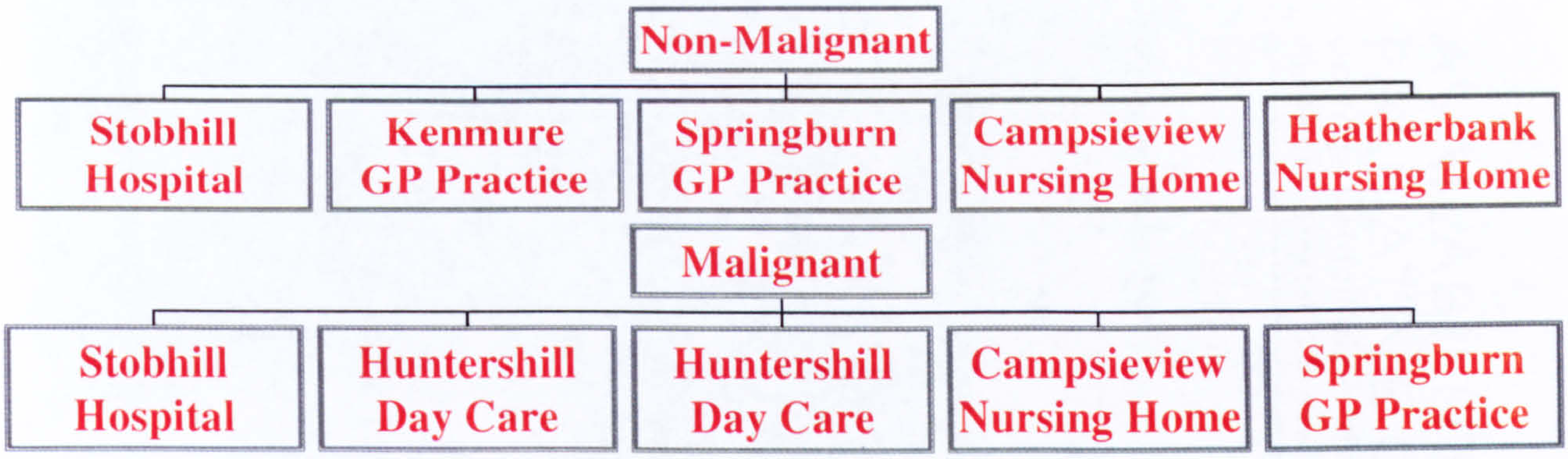
Methodology.

- Questionnaire for service providers.
- Questionnaire and focus group interviews for professionals working in the community.
- One to one interviews with patients and their carers (family & professionals) to identify their views and needs.
- Pilot study to test the questionnaires

Progress in the first six months.

- The various service providers in the GGNHSB area were identified and basic data about them and their activities were identified.
- Questionnaires were sent to the palliative care service providers in GGNHSB area
- A pilot study was carried out in the North-east sector with 10 patients and their carers.
- The activity data from the 3 hospices in the 3 sectors of GGNHSB were collected.
- Regular meetings with the supervisors and the GGNHSB were held to discuss progress.

Sample of patients and their carers for pilot study.



Service providers questionnaire.

❖ Initial number of providers identified	67	
❖ Final number of providers identified	59	(100%)
❖ Initial response without reminders	35	(59%)
❖ Number of reminders sent	24	(41%)
❖ Total response after reminder	52	(88%)

Plans for next six months.

- To analyse the pilot study and develop a method for the final survey.
- To identify the education & training facilities in palliative care available in the Scotland.
- To identify the flow of services & their usage - by the hospices and the various voluntary organisations in the GGNHSB area.
- To update and upgrade the data collected in the past six months.
- To prepare the final proposal for the Ph.D. and to apply for the ethical approvals for the study.

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Balornock Road, Glasgow G21 3UW
Telephone: 0141-201 3000
Fax No. 0141 201 3891

RESEARCH ETHICS COMMITTEE
Direct Line to secretary: 0141 201 3378
Please quote Stobhill Protocol No. On all future correspondence

GB/BG

10 September, 1997.

Dr. R. Milroy
Consultant Physician
Dept. of Respiratory Medicine
Stobhill NHS Trust.

Dear ~~Dr. Milroy~~ Robert,

PALLIATIVE CARE IN GREATER GLASGOW HEALTH BOARD AREA: A COMMUNITY BASED HEALTH NEEDS ASSESSMENT OF PATIENTS (WITH A CHRONIC PROGRESSIVE INCURABLE DISEASE) AND THEIR CARERS.

Stobhill Ref: 97/25

The above protocol was noted and approved at the meeting of the Research Ethics Committee on Monday 8 September, 1997.

The study may now proceed.

Yours sincerely,

GAVIN BOYD **BSC. (Hons) MD (Hons) FRCP (Edin.& Glas.)**
Chairman, Research Ethics Committee

APPENDIX 2a

Application for ethics approval –

13.05.98

To

Dr Charles Langan
Postgraduate Medicine
1 Horselethill Road
Glasgow G12 9LX

Dear Dr C Langan

Re: Ethical approval for a research entitled: "Palliative Care: A community based needs assessment in Greater Glasgow Health Board Area".

I am undertaking a PhD in the above-mentioned topic at the University of Glasgow. It is a joint research project between the Public Health and Palliative Medicine Departments in the Medical Faculty.

I had submitted a draft proposal for initial assessment as requested. I have now been informed by Professor McEwen to send a more detailed proposal, which I am enclosing. I would be most grateful if this proposal would be granted ethical approval at your earliest convenience.

Thanking you in anticipation.

Yours sincerely

Dr Yoganathan Velupillai
PhD Student
Public Health Department
2 Lilybank Garden
Glasgow University

Responsible investigators

Yoganathan Velupillai

Prof. James McEwen

Prof. John Welsh

Title of project

Palliative Care in Greater Glasgow Health Board Area: A community-based health needs assessment of patients (with a chronic progressive incurable disease) and their carers.

Summary of aim and background

The aim of this study is to undertake a comprehensive needs assessment in palliative care in the Greater Glasgow Health Board area and to compare these needs with the present available services.

Glasgow possess the largest number of areas in the UK recognised as being socially deprived. Inequalities relate to cancer and other non-cancer conditions in incidence and outcome of treatment. Palliative care is the active total care of patients whose disease is not responding to curative treatment. It includes symptom control, psychosocial and spiritual well being. The goal of palliative care is the achievement of the best QoL for patients and their families. The needs of the patient and their carers are of paramount importance in the planning of any palliative care service. This ethical committee submission relates to the qualitative needs assessment of patients and their carers in Glasgow.

Summary of methodology

The methods to be used are:

a. A questionnaire for the various service providers (NHS Hospitals, Hospices, Private Nursing homes, voluntary and public organisations) in the GGNHSB area.

b. A postal questionnaire for the professional carers (GP's and District Nurses) in the GGNHSB area.

c. The patients and their carers are to be assessed by one to one (semi-structured) interviews including QoL measures to assess views and needs. The interviews will be taped so as to help in the analysis. The patients and their carers will be identified by the GP Practice's, Hospice Director's, Hospital Consultant's and Nursing Home Director's.

Pilot studies will be undertaken to test the questionnaires and the qualitative one to one interviews with the patients and their carers to finalise the type of tool to be used to evaluate the patients and carers perceived needs.

Anticipated duration of project

Three years.

Drugs to be administered for experimental purposes None

Non-standard products to be administered for experimental purposes None

The use of radioactive materials None

Certificate of Indemnity Not required

Personal experience of principal researcher

Have a Masters degree in Public Health from Glasgow University. For the MPH project did a health needs assessment of refugees in Lebanon. The research which is now being undertaken is for a PhD in Public Health and Palliative Medicine at Glasgow University.

Patient Information Sheet

My name is Yoga and I have a Masters degree in Public Health from Glasgow University. I am attached to the Public Health and Palliative Medicine Departments at Glasgow University where I hope to obtain a PhD.

My research topic is "A Community based health needs assessment in Palliative Care for chronic diseases" in the Greater Glasgow Health Board Area. As part of this research I am interviewing patients like you and your carers so as to identify your needs. If you have no objections I would like to tape record this interview in order to help me analyse the results.

This research will look at your needs from your own point of view and I will then compare this with services currently available. This research will be essential in the future planning for better health services in Palliative Care for chronic diseases in the Greater Glasgow Health Board area.

This research will give you the opportunity to express your views on the type of care that you need. All information given in this interview will be treated with the strictest of confidence. Your identity will be protected at all times. If you do not want to be interviewed there is no problem and your care will not be affected in any way. All information obtained will be fully confidential and you will not be identified.

I have read the information sheet and had the opportunity to discuss this research with Yoga.

I agree to take part in this study YES/NO

Signed................................ Date................. Interviewee

Signed................................ Date................. Interviewer

If you have any questions or if you would like to contact me please do so at the following:

Yoga Velupillai Department of Public Health 2 Lilybank Gardens
University of Glasgow Glasgow G12 8RZ
Tel No: 0141 330 6434 (office hours) 0141 427 7545 (Home).

12. Financial implications

There are no financial implications involved in this research to any NHS Trust.

Declaration

I have read the declaration of Helsinki and intend in this research to comply with it in letter and spirit.

Name: Yoganathan Velupillai
Department: Department of Public Health University of Glasgow.
Signature: ....
Date: ....

Appendix 2b

Ethics Approval

Letter for ethics approval from Greater Glasgow Community/Primary Care Local Research Ethics Committee

GREATER GLASGOW COMMUNITY/PRIMARY CARE LOCAL RESEARCH ETHICS COMMITTEE

Chairman: Dr Mairi G B Scott
Deputy: Rev L Fisher
Administrative Secretary: Mrs E Dykes

ED/LC

18th June 1998

Dr Yoga
Department of Public Health
2 Lilybank Gardens
Glasgow
G12 8RZ

Dear Dr Yoga

Palliative Care: Community Based Health Needs Assessment GGHB Area

Thank you for attending the meeting on 11/06/98 to provide further information on your study.

The Committee had no objections to your study proceeding in this area with your participation.

Yours sincerely

M G B Scott
Chairperson

WEST OF SCOTLAND MEDICAL EDUCATION BOARD
1 Horselethill Road
Glasgow G12 9LX
Telephone: 0141-330 6955 *Fax:* 0141-330 4737

2 Lilybank Garden
Department of Public Health
Glasgow University
G12 8RZ

APPENDIX 2c

Informing changes to ethics committee

15th January 1999

Dr MGB Scott
Chairperson
Greater Glasgow Community/Primary Care
Local Research Ethics Committee

Your Ref.: ED/LC

Dear Dr Scott

Palliative Care: Community Based Health Needs Assessment GGNHSB Area.

Thank you for your letter dated 18 June 1998. I am writing to inform you that I would be changing the QoL tool to be used in this study. In my application I had said that I would be using the EORTC QLQ-C30 (Version 2.0) to assess the QoL of the patients.

I would now be using the following two tools:

1. Nottingham Health Profile.

2. Palliative Care Outcome Scale.

I have enclosed copies of both these tools for your approval. All other aspects of this study will be unchanged.

Thanking you in anticipation

Yours truly

Dr Yoganathan Velupillai

15th January 1999

Dr MGB Scott
Chairperson
Greater Glasgow Community/Primary Care
Local Research Ethics Committee

Your Ref.: ED/LC

Dear Dr Scott

Palliative Care: Community Based Health Needs Assessment GGNHSB Area.

With regards to the above mentioned study, I would like to inform that all patients will be informed of their right not to participate in this study. If they agree to participate in this study, they will have the right to refuse for the interviews to be taped.
The initial interviews will be to use the approved tools (Nottingham Health Profile and POS) for this study. These interviews will not be taped. Once suitable patients (12) have been identified than an in-depth interview will be conducted with their approval and these interviews will be taped with their consent.

Thanking you in anticipation

Yours truly

Dr Yoganathan Velupillai

Appendix 2d

Ethics Approval

Revised letter for ethics approval from Greater Glasgow Community/Primary Care Local Research Ethics Committee

GREATER GLASGOW COMMUNITY/PRIMARY CARE LOCAL RESEARCH ETHICS COMMITTEE

Chairman:	Dr Mairi G B Scott
Deputy:	Rev L Fisher
Administrative Secretary:	Mrs E Dykes

ED/LC

19th February 1999

Dr Y Velupillai
Department of Public Health
2 Lilybank Gardens
Glasgow
G12 8RZ

Dear Dr Velupillai

Palliative Care: Community Based Health Needs Assessment GGHB Area

Thank you for your letter of 15/01/99 in answer to the Committee's query. I am happy to give Chairman's approval for your study to proceed in this area.

Yours sincerely

M G B Scott
Chairperson

WEST OF SCOTLAND MEDICAL EDUCATION BOARD
1 Horselethill Road
Glasgow G12 9LX
Telephone: 0141-330 6955 *Fax:* 0141-330 4737

APPENDIX 3

Ten year data in GGNHSB by year of treatment by site and sex

GLASGOW FEMALES	YEAR TREATMENT BEGAN										
	87	**88**	**89**	**90**	**91**	**92**	**93**	**94**	**95**	**96**	**All**
LIP	3	3	1	6	6	4	9	4	2	3	41
TONGUE	7	3	6	7	8	8	8	6	5	13	71
SALIVARY GLAND	1	2	6	2	3	8	2	5	2	1	32
GUM	0	4	2	1	2	2	4	0	2	3	20
FLOOR MOUTH	1	7	5	6	4	6	4	9	6	2	50
OTHER MOUTH	8	8	3	5	7	4	5	10	15	7	72
OROPHARYNX	2	3	3	3	4	3	4	4	4	4	34
NASOPHARYNX	0	2	2	2	0	0	2	0	2	5	15
HYPOPHARYNX	3	5	4	3	3	1	1	6	8	4	38
UNSPECIF ORAL	2	0	3	2	4	2	5	0	1	2	21
OESOPHAGUS	63	67	68	76	42	53	73	69	59	48	618
STOMACH	99	98	98	97	89	88	91	80	88	82	910
DUODENUM ETC	6	3	6	3	8	3	5	6	3	5	48
COLON	**214**	**204**	**214**	**234**	**217**	**183**	**222**	**220**	**256**	**210**	**2174**
RECTUM	**94**	**82**	**86**	**87**	**91**	**67**	**60**	**87**	**71**	**89**	**814**
LIVER	10	16	21	11	26	19	18	12	12	18	163
GALL BLADDER	19	20	15	22	26	21	16	22	17	22	200
PANCREAS	50	50	60	57	49	51	62	67	56	58	560
PERITONEUM	4	3	2	3	2	3	2	1	3	2	25
UNSPECIF GUT	4	14	9	11	8	10	12	8	12	7	95
NOSE, EAR ETC	3	3	0	4	1	5	8	3	4	3	34
LARYNX	16	12	19	20	10	13	9	17	7	19	142
LUNG	**393**	**409**	**421**	**493**	**441**	**500**	**448**	**453**	**473**	**450**	**4481**
PLEURA	7	6	4	7	8	9	8	8	5	8	70
MEDIASTINUM	0	0	1	0	0	0	0	1	0	0	2
BONE	2	4	5	4	3	4	7	3	3	1	36
MUSCLE ETC	9	13	10	7	8	8	9	15	11	12	102
MELANOMA	46	50	42	56	43	66	58	58	59	47	525
OTHER SKIN	273	336	332	329	364	403	424	437	379	438	3715
FEMALE BREAST	**505**	**569**	**550**	**570**	**540**	**582**	**508**	**567**	**537**	**545**	**5473**
UTERUS	14	9	7	11	11	9	14	4	4	3	86
CERVIX	92	72	79	81	98	80	89	62	71	55	779
PLACENTA	0	0	0	0	1	0	0	0	0	0	1
ENDOMETRIUM	55	56	56	48	47	48	53	64	69	73	569
OVARY ETC	121	94	107	114	113	112	110	98	102	108	1079
VAGINA, VULVA	18	15	16	20	22	22	16	18	23	25	195
BLADDER	86	97	95	65	83	88	86	96	91	82	869
KIDNEY ETC	30	40	37	46	40	37	45	47	36	25	383
EYE	5	9	7	5	7	4	2	5	4	1	49
BRAIN	28	34	27	31	30	20	36	34	19	30	289
NERVOUS SYSTM	0	1	1	2	2	0	0	3	1	1	11
THYROID	15	16	6	8	11	14	8	17	17	15	127
OTH.ENDOCRINE	2	1	4	7	0	4	4	2	5	3	32
OTHER SITES	1	0	2	1	2	0	0	2	1	1	10
SEC.LYMPHNODE	11	11	8	7	7	5	5	4	6	5	69
SEC.RESP&DGST	51	59	56	46	54	59	40	66	44	91	566
SEC. OTHER	24	23	19	20	18	20	18	25	22	21	210
UNSPECIF SITE	44	59	62	66	56	59	50	60	57	46	559
LYMPHOSARCOMA	3	2	8	9	6	5	5	2	1	1	42
HODGKINS	8	8	14	7	12	11	9	18	7	12	106
LYMPHOMA	55	66	63	53	87	47	84	71	57	67	650
MULT MYELOMA	34	25	27	23	32	27	25	26	32	16	267
LYMP LEUKEMIA	19	15	14	17	20	19	22	23	22	16	187
MYEL LEUKEMIA	24	23	17	17	23	17	18	15	25	14	193
MONO LEUKEMIA	0	0	0	0	0	0	0	0	0	1	1
UNSPECIF LEUK	14	12	9	5	4	2	9	1	1	8	65

APPENDIX 3 Ten year data in GGNHSB by year of treatment by site and sex.

	GLASGOW MALES									
	87	88	89	90	91	92	93	94	95	96	All
LIP	11	9	5	9	10	11	3	8	4	5	75
TONGUE	8	9	15	18	16	15	13	13	8	23	138
SALIVARY GLND	5	5	4	1	6	2	0	1	3	5	32
GUM	0	2	4	1	0	0	1	5	4	2	19
FLOOR MOUTH	10	16	11	13	15	11	12	7	18	15	128
OTHER MOUTH	11	8	9	10	10	16	9	13	15	13	114
OROPHARYNX	5	5	14	12	12	5	16	10	7	7	93
NASOPHARYNX	3	4	3	2	3	3	2	3	0	4	27
HYPOPHARYNX	10	6	5	8	17	3	16	13	18	7	103
UNSPECIF ORAL	2	4	4	2	8	5	6	3	6	7	47
OESOPHAGUS	76	74	76	82	82	94	81	81	97	81	824
STOMACH	129	151	117	113	115	148	129	137	112	102	1253
DUODENUM ETC	6	7	4	8	4	2	6	3	7	4	51
COLON	**158**	**162**	**196**	**177**	**195**	**178**	**198**	**213**	**194**	**188**	**1859**
RECTUM	**97**	**88**	**81**	**117**	**125**	**115**	**107**	**92**	**99**	**117**	**1038**
LIVER	17	24	26	20	31	34	21	22	32	23	250
GALL BLADDER	17	12	10	11	15	12	9	12	15	12	125
PANCREAS	69	55	64	62	55	58	51	48	51	38	551
PERITONEUM	2	7	4	4	8	0	5	8	2	3	43
UNSPECIF GUT	6	8	7	10	8	7	10	15	12	3	86
NOSE, EAR ETC	3	4	5	4	5	4	2	7	4	8	46
LARYNX	48	46	51	48	53	59	59	58	39	55	516
LUNG	**814**	**725**	**755**	**698**	**763**	**727**	**713**	**708**	**653**	**594**	**7150**
PLEURA	35	39	52	44	40	41	38	35	35	43	402
MEDIASTINUM	1	1	0	0	0	1	0	0	1	4	8
UNSPECIF RESP	0	0	1	0	0	0	0	0	0	0	1
BONE	7	6	3	7	7	4	2	7	3	4	50
MUSCLE ETC	10	3	10	9	6	12	13	9	7	8	87
MELANOMA	23	27	35	39	28	36	34	33	36	37	328
OTHER SKIN	288	298	303	275	312	345	377	371	353	381	3303
MALE BREAST	1	3	2	7	4	1	1	1	4	0	24
PROSTATE	206	199	220	227	217	216	251	268	241	250	2295
TESTIS	29	24	36	29	38	21	31	33	24	22	287
PENIS,SCROTUM	11	11	7	6	13	7	1	14	6	15	91
BLADDER	183	180	155	173	156	175	166	178	152	143	1661
KIDNEY ETC	48	39	51	51	54	53	52	58	63	55	524
EYE	7	9	4	4	8	7	6	5	7	6	63
BRAIN	41	36	30	39	27	40	23	32	30	35	333
NERVOUS SYSTM	0	1	0	1	3	1	2	2	1	0	11
THYROID	4	5	2	4	8	2	4	6	4	4	43
OTH.ENDOCRINE	4	1	4	4	2	4	2	3	1	3	28
OTHER SITES	1	0	0	0	0	0	0	1	1	3	6
SEC.LYMPHNODE	7	2	3	7	7	6	4	8	8	9	61
SEC.RESP&DGST	31	40	39	46	46	52	53	40	49	57	453
SEC. OTHER	29	19	21	22	14	32	23	25	20	22	227
UNSPECIF SITE	46	58	65	41	37	51	39	55	40	36	468
LYMPHOSARCOMA	1	8	5	3	3	4	5	3	2	4	38
HODGKINS	15	12	8	6	10	20	15	8	19	14	127
LYMPHOMA	67	39	52	61	38	46	55	51	68	58	535
MULT MYELOMA	19	24	19	28	31	30	16	30	25	20	242
LYMP LEUKEMIA	31	33	21	21	21	23	23	33	22	20	248
MYEL LEUKEMIA	28	16	26	22	18	27	15	24	19	26	221
MONO LEUKEMIA	0	0	0	1	1	0	0	1	0	0	3
OTH. LEUKEMIA	0	1	0	0	0	0	1	0	0	0	2
UNSPECIF LEUK	4	6	6	2	6	1	4	4	3	2	38

APPENDIX 3 Ten year data in GGNHSB by year of treatment by site and sex.

	87	88	89	90	91	92	93	94	95	96	All
FEMALE BREAST	505	569	550	570	540	582	508	567	537	545	5473
PROSTATE	206	199	220	227	217	216	251	268	241	250	2295
LUNG Male	814	725	755	698	763	727	713	708	653	594	7150
LUNG Female	393	409	421	493	441	500	448	453	473	450	4481
COLON Male	158	162	196	177	195	178	198	213	194	188	1859
COLON -Female	214	204	214	234	217	183	222	220	256	210	2174
RECTUM Male	97	88	81	117	125	115	107	92	99	117	1038
RECTUM Female	94	82	86	87	91	67	60	87	71	89	814

APPENDIX 4

First letter to service providers in 1997

Dear

Re: Palliative Care: A community based needs assessment in Greater Glasgow Health Board Area.

I am undertaking a PhD in the above-mentioned topic at the University of Glasgow. It is a joint research project between the Public Health and Palliative Medicine Departments in the Medical Faculty.

As part of the research I am looking at the various services available in the Greater Glasgow Health Board area. From my initial search I have been able to identify the various services available and the personnel involved in the provision of such services.

I am herewith enclosing a questionnaire concerning palliative care services and personnel in the Greater Glasgow Health Board area. I would like to know the services and personnel available in your centre. I would be most grateful if you could kindly complete these and return them at your earliest convenience.

Your comments and update of any missing information will be appreciated and be of importance in compiling this invaluable data.

If you would like to contact me please phone during office hours. Tel No: 0141 330 6434.

Thanking you in anticipation.

Yours sincerely

Dr. Yoga Velupillai. (PhD Student.)

I hope the following will help in the completion of the questionnaire.

Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, control of other symptoms, the psychological, social and spiritual problems are paramount[2]. The goal of palliative care is the achievement of the best possible QoL for the patients and their families. Palliative care should not be associated exclusively with terminal care or with cancer care. Many patients need it early in the course of their disease, sometimes from the time of diagnosis.

At present, many patients do not receive palliative therapy for recurrent or advanced disease although this has been shown to be effective. In many cases patients and their relatives and carers are unaware of the sources of support available to them.

Conditions (diseases): requiring palliative care are Progressive incurable diseases.

All Cancer conditions.

Non-Cancer conditions:

Nervous System conditions: multiple sclerosis; motor neurone diseases; Dementia; Parkinsonism and Huntington's Chorea.

Immune System condition: AIDS and HIV.

Chronic progressive conditions: Lung, Cardiac, Renal and Liver conditions and Rheumatoid Arthritis.

Children: hereditary, congenital and metabolic disorders (e.g. muscular dystrophy, cardiac abnormalities) and cystic fibrosis.

APPENDIX 4a

First questionnaire to service providers in 1997

From:

PALLIATIVE CARE SERVICES AVAILABLE IN GGNHSB AREA		
	Yes/No	COMMENTS (including numbers)
Number of Beds		
In-Patient Care		
Radiotherapy		
Chemotherapy		
Symptom Control		
Rehabilitation		
Day Care		
Home Care Nursing		
Respite		
Hospice at Home		
Bereavement services		
Counselling for the bereaved		
Counselling for the patient		
Counselling for the parents		
Counselling for the carers		
Services for children & youth		
Pain Clinic		
Lymphoedema Clinic		
Breast Prosthesis Clinic		
Cancer Care		
MND Care		
HIV & AIDS Care		
Other Terminal Illness		
Terminal Care		
Palliative Care		
Physiotherapy		
Occupational Therapy		
Speech & Language Therapy		
Training in Palliative Care		
Training in Counselling		
Helpline		
Information (Leaflets/Video/Audio)		
Directory of Available Services		
Support Group		
Funding		
Use Volunteers		
Alternative Therapy		
Networking with other providers		
Chaplaincy Service		
Other Services		

PALLIATIVE CARE PERSONNEL AVAILABLE IN GGNHSB AREA		
	Yes/No	COMMENTS (including
Consultant in Palliative Medicine		
Associate/Registrars		
Matron/Deputy		
Sister		
Registered Nurse		
Enrolled Nurse		
Auxiliary Nurse		
Marie Curie Nurse		
Macmillan Home Care Nurse		
Breast Cancer Nurse Specialist		
Lymphoedema Nurse Specialist		
Clinical Oncology Nurse Specialist		
Cancer Genetic Nurse Specialist		
Clinical Nurse Specialist		
Clinical Paediatric Nurse Specialist		
Gynaec Oncology Nurse Specialist		
Clinical Trial Nurse Specialist		
Chemotherapy Nurse Specialist		
Radiotherapy Nurse Specialist		
Neuro Oncology Nurse Specialist		
Nursing Tutor		
Physiotherapist		
Occupational Therapist		
Chiropodist		
Speech Therapist		
Clinical Psychologist		
Oncology Dietician		
Radiographer		
Counsellors		
Social Worker		
Malcolm Sargent		
Volunteer Co-ordinator		
Volunteers		
Chaplain		
Alternative Medicine Therapist		
Administrators		
Pharmacist		
Marie Curie Home Care Sisters		
SHO		
Macmillan Lecturers in Palliative Med.		

Comments:

Appendix 5

List of service providers address

Centre Director
Hunters Hill Marie Curie Centre
Belmont Road, Springburn
Glasgow G21 3AY
Tel No: 0141 558 2555

Medical Director
St. Margaret's Hospice
East Barns St.
Clydebank G81 1EG
Tel No: 0141 952 1141

Director of Nursing & Quality
The Prince & Princess of Wales Hospice
71 Carlton Place Glasgow G5 9TD
Tel No: 0141 429 5599

Director of Nursing & Quality
Ground Floor Medical Block
Glasgow Royal Infirmary
84 Castle Street Glasgow G4 0SF
Tel No: 0141 211 4304

Nursing Adviser
Victoria Infirmary NHS Trust
Langside Rd. Glasgow G42 9TY
Tel No: 0141 201 5266

Macmillan Nurse
Stobhill Hospital
Baloroch Rd. Glasgow G21 3UW
Tel No: 0141 201 3669

Director of Nursing & Quality
(Gartnavel & Western Infirmary)
Administration Building
Western Infirmary Glasgow G11 6NT
Tel No: 0141 211 2499

Director of Nursing & Quality
Southern General Hospital
1345 Govan Rd. Glasgow G51 4TF
Tel No: 0141 201 1287

Macmillan Oncology Support Nurse
Beatson Oncology Unit
Western Infirmary Glasgow G11 6NT
Tel No: 0141 211 1865

Rachel House Childrens Hospice
The Avenue Kinross KY13 7EP
Tel No: 01577 865 777

POSY Yorkhill Childrens Hospital
Glasgow G3 8SJ
Tel No: 0141 631 3320

Sargent Cancer Care for Children
Royal Hospital for Sick Children
Schiehallion Unit Yorkhill
Glasgow G3 8SJ
Tel No: 0141 201 0000

Macmillan Paediatric Nurse
The Royal Hospital for Sick Children
Yorkhill Glasgow G3 8SJ
Tel No: 0141 201 9314

Addictions, Mental & Sexual Health Team
Greater Glasgow Health Board
Dalian House, P.O. Box 15327
Glasgow G3 8YZ
0141 201 4444

Principal Officer (Community Care Services)
House 2 Charing Cross Complex
20 India St. Glasgow G2 4PF
Tel No: 0141 287 8754

Senior Nurse (Projects)
GG Community & Mental Health Services
NHS Trust Gartnavel Royal Hospital
1055 Gt. Western Road
Glasgow G12 0XH
Tel No: 0141 211 3600

Heather Bank Nursing Home
Northgate Quadrant Glasgow G21 3RB
Tel No: 0141 558 3222

Campsie View Nursing Home
Canal Street Kirkintilloch
Glasgow G66 1QY
Tel No: 0141 777 8880

Macmillan Nurse Consultant
Top Flat Block 20 Western Court
100 University Place Glasgow G12 8SQ
Tel No: 0585 725 520

Regional Nurse Manager
21 Rutland Street Edinburgh EH1 2AH
Tel No: 0131 228 8766

Administrator
The Multiple Sclerosis Society in Scotland
2A North Charlotte Street
Edinburgh EH2 4HR
Tel No: 0131 225 3600

Multiple Sclerosis Therapy Centre
Unit 16 Chapel Street Industrial Estate
Maryhill Glasgow G20 9BD
Tel No: 0141 945 3344

Scotland Huntingdon's Association
Thistle House
61 Main Road
Elderlie PA5 9BA
Tel No: 01505 322245

Scotland Huntingdon's Association
Glasgow Advisory Service
Clarkston Clinic
56 Busby Road,
Clarkston G76 7AT.
Tel No: 0141 638 8246

Information Officer
Scottish Motor Neurone Disease Association
76 Firhill Road Glasgow G20 7BA
Tel No: 0141 945 1077

Scottish Motor Neurone Disease Association
Second Floor Langlands House
Southern General Hospital NHS Trust
1345 Govan Road Glasgow G51 4TF
Tel No: 0141 201 2456

Scotland Muscular Dystrophy Association
Yorkhill Hospital
Glasgow
Tel No: 0141

Project Co-ordinator
Alzheimer Scotland
Suite 269, Central Chambers
93 Hope Street Glasgow G2 6LD
Tel No: 0141 221 3845

BACUP Scotland
30 Bell St. Glasgow G1 1LG
Tel No: 0141 553 1553

CRUSE Scotland
Room 438/439 Baltic Chambers
50 Wellington St. Glasgow G2 6HJ
Tel No: 0141 248 2199

TAK TENT The Western Infirmary
Block C20 Western Court
100 University Place Glasgow G12 6SQ
Tel No: 0141 211 1932

PAIN Association Scotland
Cramond House
Cramond GLEBE Road
Edinburgh EH4 6NS
Tel No: 0131 312 7955

Breast Cancer Care
46 Gordon Street
Glasgow G1 3PU
Tel No: 0141 221 2233/44
Fax No: 0141 221 9499

Project Co-ordinator
Body Positive
3 Park Quadrant Glasgow G3 6BS
Tel No: 0141 332 5010
PHACE West
49 Bath Street Glasgow G2 2DL
Tel No: 0141 332 3838

ACET
PO Box 725 Glasgow G20 9PX
Tel No: 0141 945 5286

Glasgow HIV-AIDS Support Group
Suite 226 Baltic Chambers
50 Wellington Street Glasgow G2 6HJ
Tel No: 0141 211 8100

Information Officer
Strathclyde Carers Forum
11 Queens Crescent Glasgow G4 9AS
Tel No: 0141 353 2726

Crossroads (Scotland)
24 George Square Glasgow G2 1EG
Tel No: 0141 226 3793

Chief Executive
Friends for Life
Fifth Floor 52 St. Enoch Square
Glasgow G1 4DH
Tel No: 0141 204 2202

Salarc
2nd Floor 30 Bell Street
Glasgow G1 1LG
Tel No: 0141 552 3366

The Notre Dame Centre
1 Dundonald Road Glasgow G12 9LJ
Tel No: 0141 334 6131

Administrator
Look Good...Feel Better
Beatson Oncology Centre
Western Infirmary Glasgow G11 6NT
Tel No: 0141 211 1865

Jordanhill Counselling Unit
76 Southbrae Drive Glasgow G13 1PP
Tel No: 0141 950 3359
Tom Allan Centre
23 Elmbank Street Glasgow G2 4PB
Tel No: 0141 221 1535

The Carers Centre
10 Angus Street Springburn
Glasgow G21 1DN
Tel No: 0141 558 8001

The Princess Royal Trust
North & West Glasgow Carers Centre
1561 Great Western Rd.
Glasgow G13 1HN
Tel No: 0141 959 9871

The Princess Royal Trust
Glasgow East End Community Carers Centre
1061 - 1063 Tollcross Rd.
Glasgow G32 8UQ
Tel No: 0141 764 0550

GOLD Projects
1/3, 10 Petershill Court Glasgow G21 4PY
Tel No: 0141 558 1191
Administrator
The Princess Royal Trust
Glasgow South West The Dixon Community
656 Cathcart Road Glasgow G42 8AA
Tel No: 0141 423 6728

Possil Stress Centre
Ardoch House 25 Ardoch Street
Possilpark Glasgow G22 5QG
Tel No: 0141 347 1788

Information Officer ENABLE
6th Floor 7 Buchanan Street
Glasgow G1 3HL
Tel No: 0141 226 4541

Greater Glasgow Health Council
44 Florence Street Glasgow G5 0YZ
Tel No: 0141 429 7698

Hawthorn House Yorkhill NHS Trust
Yorkhill Glasgow G3 8SJ
Tel No: 0141 201 9257

Youth Counselling Services Agency
11 Forth Street
Pollokshields Glasgow G41 2SP

Health Action CSV
236 Clyde Street Glasgow G1 4JH
Tel No: 0141 204 1681

Information Officer
Womens Counselling & Resource Services
31 Stockwell Street, 2nd Floor
Glasgow G1 4RZ
Tel No: 0141 552 5483
Information Officer
Meridian
58 Fox Street Glasgow G1 4AU
Tel No: 0141 221 4443

MOSAIC Flat 1/R, Melville Street
Pollokshields Glasgow G41 2LN
Tel No: 0141 423 3690

San Jai Chinese Project
53 Rose Street Glasgow G3 6SF
Tel No: 0141 332 3978

GAMH Ethnic Minority Project
1st Floor Melrose House
15/23 Cadogen Street Glasgow G2 6QQ
Tel No: 0141 204 2770

Darnley Street Family Centre
175 Darnley Street
Pollokshields
Glasgow G41 2SY
Tel No: 0141 424 3920

APPENDIX 6

Second letter to service providers in 1999

16 June 1999

«Name» «Post» «Organisation»
«Address1» «Address2» «City» «Post_Code»

Dear «Name»

Re: Palliative Care - A community based needs assessment in Greater Glasgow Health Board Area.

In Autumn 1997 I contacted you and followed up with a questionnaire about the services /personnel available in your work-place/organisation. Your response was very helpful in compiling a list of services/personnel available in the Greater Glasgow Health Board area. The GGNHSB are in the process of updating their framework for future service provision in palliative care and as a progression of this study I am repeating the questionnaire in-order to update the details.

I am herewith enclosing a questionnaire concerning palliative care services and personnel in the Greater Glasgow Health Board area. I would be most grateful if you could kindly complete these and return it, in the stamped addressed envelope supplied, at your earliest convenience. I am also enclosing a copy of the questionnaire you completed in 1997 for your reference.

Your comments and update of any missing information will be appreciated and be of importance in compiling this invaluable data.

If you would like to contact me please phone during office hours.

Tel No: 0141 330 6434.

Thanking you in anticipation.

Yours sincerely

Dr. Yoga Velupillai.

Researcher

APPENDIX 6a

Second questionnaire for service providers in 1999

Table for Services in Hospitals and Hospices.

From: ____

PALLIATIVE CARE SERVICES AVAILABLE IN GGNHSB AREA		
	Yes/No	COMMENTS (including numbers)
Number of Beds		
In-Patient Care		
Radiotherapy		
Chemotherapy		
Symptom Control		
Rehabilitation		
Day Care		
Home Care Nursing		
Respite		
Hospice at Home		
Bereavement services		
Counselling for the bereaved		
Counselling for the patient		
Counselling for the parents		
Counselling for the carers		
Services for children & youth		
Pain Clinic		
Lymphoedema Clinic		
Breast Prosthesis Clinic		
Cancer Care		
MND Care		
HIV & AIDS Care		
Other Terminal Illness		
Terminal Care		
Palliative Care		
Physiotherapy		
Occupational Therapy		
Speech & Language Therapy		
Training in Palliative Care		
Training in Counselling		
Helpline		
Information (Leaflets/Video/Audio)		
Directory of Available Services		
Support Group		
Funding		
Use Volunteers		
Alternative Therapy		
Networking with other providers		
Chaplaincy Service		
Other Services		

Table for Personnel in Hospitals and Hospices.

From: ____________________

PALLIATIVE CARE PERSONNEL AVAILABLE IN GGNHSB AREA		
	Yes/No	COMMENTS (including numbers)
Consultant in Palliative Medicine		
Associate/Registrars		
Matron/Deputy		
Sister		
Registered Nurse		
Enrolled Nurse		
Auxiliary Nurse		
Marie Curie Nurse		
Macmillan Home Care Nurse		
Breast Cancer Nurse Specialist		
Lymphoedema Nurse Specialist		
Clinical Oncology Nurse Specialist		
Cancer Genetic Nurse Specialist		
Clinical Nurse Specialist		
Clinical Paediatric Nurse Specialist		
Gynaec Oncology Nurse Specialist		
Clinical Trial Nurse Specialist		
Chemotherapy Nurse Specialist		
Radiotherapy Nurse Specialist		
Neuro Oncology Nurse Specialist		
Nursing Tutor		
Physiotherapist		
Occupational Therapist		
Chiropodist		
Speech Therapist		
Clinical Psychologist		
Oncology Dietician		
Radiographer		
Counsellors		
Social Worker		
Malcolm Sargent		
Volunteer Co-ordinator		
Volunteers		
Chaplain		
Alternative Medicine Therapist		
Administrators		

Comments:

____

Table for Services in Voluntary organisations

From: ____

PALLIATIVE CARE SERVICES AVAILABLE IN GGNHSB AREA		
	Yes/No	COMMENTS (including numbers)
Rehabilitation		
Day Care		
Home Care Nursing		
Respite		
Bereavement services		
Counselling for the bereaved		
Counselling for the patient		
Counselling for the parents		
Counselling for the carers		
Services for children & youth		
Pain Clinic		
Breast Prosthesis Clinic		
Cancer Care		
MND Care		
HIV & AIDS Care		
Other Terminal Illness		
Physiotherapy		
Occupational Therapy		
Speech & Language Therapy		
Training in Palliative Care		
Training in Counselling		
Helpline		
Information (Leaflets/Video/Audio)		
Directory of Available Services		
Support Group		
Use Volunteers		
Alternative Therapy		
Networking with other providers		
Chaplaincy Service		
Other Services		
Are you able to respond to the entire		
Will you be able to accept more requests?		

General comments: (also comment specifically on the last two questions)

____

Table for Personnel in Voluntary organisations

From: ______________________________

PALLIATIVE CARE PERSONNEL AVAILABLE IN GGNHSB AREA		
	Yes/No	COMMENTS (including numbers)
Registered Nurse		
Marie Curie Nurse		
Macmillan Home Care Nurse		
Breast Cancer Nurse Specialist		
Clinical Oncology Nurse Specialist		
Cancer Genetic Nurse Specialist		
Physiotherapist		
Occupational Therapist		
Chiropodist		
Speech Therapist		
Counsellors		
Social Worker		
Malcolm Sargent		
Volunteer Co-ordinator		
Volunteers		
Chaplain		
Alternative Medicine Therapist		
Administrators		
Do you have sufficient staff now?		
Would you like to have more staff?		

General comments: (also comment specifically on the last two questions)

____

PALLIATIVE CARE SERVICES in GREATER GLASGOW HEALTH BOARD AREA in 1997 (first column) and in 1999 (second column)

APPENDIX 7

	Hunter's Hill Marie Curie Hospice		St. Margaret's Hospice Clydebank		Prince & Princess of Wales Hospice		Marie Curie Nurse		Macmillan Nurse		Glasgow Royal Infirmary		Western Infirmary		Stobhill Hospital		Victoria Infirmary OPD		Southern General Hospital		Yorkhill Children's Hospital		Beatson in Western Infirmary		Rauchill Hospital For HIV & AIDS		Rachel House Kinross		Heatherbank Nursing Home		Campsieview Nursing Home	
Number of Beds	44	41	25	25	14	14	N	N	N	N	N	N	N		Y	Y	N			N	Y	Y	Y	N	2		8	8	70	70	Y	
In-Patient Care	Y	Y	Y	Y	Y	Y	N	N	N	N	N	Y	Y		Y	Y	N			Y	Y	Y	Y	Y	Y		Y	Y	Y	Y	Y	
Radiotherapy	N	N	N	N	N	N	N	N	N	N	N	N	Y		N	N	Y			Y	Y	Y	Y	Y	N		N	N	N	N	N	
Chemotherapy	N	N	N	N	N	N	N	N	N	N	Y	Y	Y		Y	Y	Y			Y	Y	Y	Y	Y	Y		N	N	N	N	N	
Symptom Control	Y	Y	Y	Y	Y	Y	N	N	N	N	Y	Y	Y		Y	Y	Y			Y	N	Y	Y	Y	Y		Y	Y	N	N	N	
Rehabilitation	Y	Y	Y	Y	Y	Y	N	N	N	N	N	Y	Y		Y	Y	N			Y	N	Y	Y	Y	Y		N	N	N	Y	N	
Day Care	15	Y	10	Y	Y	Y	N	N	N	N	N	N	Y	D	N	N	N	D	D	N	Y	Y	N	N	Y	D	Y	Y	N	N	N	D
Home Care Nursing	Y	Y	Y	Y	N	N	Y	Y	Y	Y	N	N	Y	I	Y	Y	N	I	I	N	N	Y	N	N	Y	I	N	N	N	N	N	I
Respite	Y	Y	Y	Y	Y	Y	N	N	N	N	N	N	Y	D	Y	Y	N	D	D	N	N	Y	N	N	Y	D	Y	Y	Y	Y	Y	D
Hospice at Home	N	Y	N	N	N	N	N	N	N	N	N	N	Y		N	Y	Y			N	N	N	N	N	N		N	N	N	N	N	
Bereavement services	Y	Y	Y	Y	Y	Y	N	N	N	N	Y	Y	Y	N	Y	Y	N	N	N	Y	N	Y	N	N	Y	N	Y	Y	N	N	N	N
Counselling for the bereaved	Y	Y	Y	Y	Y	Y	N	N	N	N	Y	Y	N	O	Y	Y	N	O	O	Y	Y	Y	N	N	Y	O	N	N	N	N	N	O
Counselling for the patient	Y	Y	Y	Y	Y	Y	N	N	N	N	Y	Y	Y	T	Y	Y	Y	T	T	Y	Y	Y	Y	Y	Y	T	N	N	N	N	N	T
Counselling for the parents	N	N	Y	Y	Y	N	N	N	N	N	Y	Y	N		Y	Y	N			Y	Y	Y	N	N	Y		N	N	N	N	N	
Counselling for the carers	Y	Y	Y	Y	Y	N	N	N	N	N	Y	Y	N	R	Y	Y	N	R	R	Y	Y	Y	Y	N	Y	R	N	N	N	N	N	R
Services for children & Youth	Y	Y	N	N	Y	N	N	N	N	N	N	N	Y	E	N	N	N	E	E	?	Y	Y	Y	Y	N	E	Y	Y	N	N	Y	E
Pain Clinic	N	N	N	N	Y	Y	N	N	N	N	N	Y	Y	S	Y	Y	Y	S	S	Y	N	Y	N	Y	N	S	N	N	N	N	N	S
Lymphoedema Clinic	Y	Y	N	N	N	N	N	N	N	N	N	N	Y	P	N	N	N	P	P	N	N	N	N	Y	N	P	N	N	N	N	N	P
Breast Prosthesis Clinic	N	N	N	N	N	N	N	N	N	N	Y	Y	Y	O	Y	Y	Y	O	O	N	N	N	Y	Y	N	O	N	N	N	N	N	O
Cancer Care	N	N	Y	Y	N	N	N	N	N	N	N	Y	Y	N	N	Y	Y	N	N	Y	N	N	Y	Y	N	N	Y	Y	N	N	Y	N
MND Care	Y	Y	Y	Y	Y	Y	N	N	N	N	N	Y	N	D	N		N	D	D	Y	N	N	N	N	N	D	N	N	N	N	Y	D
HIV & AIDS Care	N	N	Y	Y	Y	Y	N	N	N	N	Y	Y	Y		N	Y	N			Y	N	N	N	N	Y		Y	Y	N	N	Y	
Other Terminal Illness	Y	Y	Y	Y	Y	Y	N	N	N	N	N	Y	Y		Y	Y	N			Y	N	N	N	N	Y		Y	Y	N	N	Y	
Terminal Care	Y	Y	Y	Y	Y	Y	N	N	N	N	Y	Y	Y		Y	Y	N			Y	Y	Y	Y	Y	Y		Y	Y	Y	N	Y	
Palliative Care	Y	Y	Y	Y	Y	Y	N	N	N	N	Y	Y	Y		Y	Y	Y			Y	Y	Y	Y	Y	Y		Y	Y	N	N	Y	
Physiotherapy	Y	Y	Y	Y	Y	Y	N	N	N	N	Y	Y	Y		Y	Y	N			Y	Y	Y	Y	Y	Y		Y	Y	N	N	N	
Occupational Therapy	Y	Y	N	N	N	N	N	N	N	N	Y	Y	Y		Y	Y	N			Y	Y	Y	Y	Y	Y		N	N	N	N	Y	
Speech & Language Therapy	N	N	N	N	N	N	N	N	N	N	Y	Y	Y		Y	Y	N			Y	Y	Y	Y	Y	N		N	N	N	N	N	
Training in Palliative Care	Y	Y	Y	Y	Y	Y	N	Y	N	N	Y	Y	Y		Y	Y	Y			Y	N	N	N	Y	N		N	N	N	N	Y	
Training in Counselling	Y	Y	Y	Y	Y	N	N	N	N	N	Y	Y	Y		Y	Y	N			Y	N	N	N	N	N		N	N	N	N	Y	

PALLIATIVE CARE SERVICES in GREATER GLASGOW HEALTH BOARD AREA from 1997 to 1999

APPENDIX 7

	Hunter's Hill Marie Curie Hospice		St. Margaret's Hospice Clydebank		Prince & Princess of Wales Hospice		Marie Curie Nurse		Macmillan Nurse		Glasgow Royal Infirmary		Western Infirmary		Stobhill Hospital		Victoria Infirmary		Southern General Hospital		Yorkhill Children's Hospital		Beatson in Western Infirmary		Rauchill Hospital For HIV & AIDS		Rachel House Kinross		Heatherbank Nursing Home		Campsieview Nursing Home	
Help-line	N	Y	Y	Y	Y	Y	N	N	N	N	N	N	N		N	N	N			N	N	N	Y	N	Y		Y	Y	N	N	N	
Information Leaflet, Video, Audio	Y	Y	Y	Y	Y	Y	N	Y	N	N	Y	Y	Y		Y	Y	Y			Y	N	N	Y	Y	Y		Y	Y	N	N	Y	
Directory of Available Services	N	Y	Y	Y	N	Y	N	N	N	N	N	N	Y		Y	Y	N			N	N	Y	N	N	Y		N	N	N	N	N	
Support Group	Y	Y	Y	Y	N	Y	N	N	N	N	N	N	Y		Y	Y	N			Y	Y	N	Y	Y	N		N	N	N	N	N	
Funding	Y	Y	Y	Y	Y	Y	N	N	N	Y	N	N	Y		N	Y	N			N	Y	N	N	N	N		N	N	N	N	N	
Use Volunteers	Y	Y	Y	Y	Y	Y	N	N	N	N	N	Y	Y		Y	Y	Y			Y	N	N	Y	Y	N		Y	Y	N	N	Y	
Alternative Therapy	Y	Y	Y	Y	Y	Y	N	N	N	N	N	N	N		Y		N			Y	N	N	N	N	N		Y	Y	N	N	N	
Networking with other providers	Y	Y	Y	Y	Y	Y	N	Y	N	Y	Y	Y	Y		Y	Y	Y			Y	N	Y	N	Y	Y		Y	Y	N	Y	Y	
Chaplaincy Service	Y	Y	Y	Y	Y	Y	N	N	N	N	Y	Y	Y		Y	Y	Y			Y	Y	Y	Y	Y	Y		Y	Y	N	N	Y	
Other Services	Y	Y		Y				Y		Y					Y		Y				Y	N			Y		Y	Y	N	N		
PALLIATIVE CARE PERSONNEL in GREATER GLASGOW HEALTH BOARD AREA in 1997 (first column) and in 1999 (second column)																																
Consultant in Palliative Medicine	2	2	Y	2	3	2	N	N	N	N	Y	Y	Y		Y	Y	N			N	N	N	Y	Y	N		N	N	N	N	N	
Associate/Registrars	1	1	Y	Y	N	N	N	N	N	N	N	N	Y		N	N	N			N	N	N	Y	Y	N		N	N	N	N	N	
Matron/Deputy	1	2	Y	Y	1	1	N	N	N	N	N	N	Y	D	Y	Y	N	D	D	N	N	N	N	N	N	D	Y	Y	1	Y	Y	D
Sister	2	10	Y	Y	2	2	N	N	N	N	N	Y	Y	I	Y	Y	N	I	I	N	N	N	N	N	N	I	N	N	1	N	Y	I
Registered Nurse	27	34	Y	Y	12	11	N	N	N	N	N	N	Y	D	Y	Y	Y	D	D	N	N	N	N	N	N	D	Y	Y	6	Y	Y	D
Enrolled Nurse	6	4	Y	Y	5	3	N	N	N	N	N	N	Y		Y	Y	N			N	N	N	N	N	N		N	N	N	Y	Y	
Auxiliary Nurse	23	31	Y	Y	12	14	N	N	N	N	N	N	Y	N	Y	Y	Y	N	N	N	N	N	N	N	N	N	N	N	20	Y	Y	N
Marie Curie Nurse	N	N	N	N	N	N	Y	Y	N	N	N	N	N	O	N	N	N	O	O	N	N	N	N	N	N	O	N	N	N	N	N	O
Macmillan Home Care Nurse	N	N	Y	Y	Y	Y	N	N	2	2	N	N	N	T	N	N	Y	T	T	N	Y	Y	N	N	N	T	N	N	N	N	N	T
Breast Cancer Nurse Specialist	N	N	N	N	N	N	N	N	N	1	Y	Y	Y		Y	Y	Y			Y	N	N	Y	Y	N		N	N	N	N	N	
Lymphoedema Nurse Specialist	3	2	N	N	N	N	N	N	N	N	N	N	N	R	N	N	N	R	R	N	N	N	N	N	N	R	N	N	N	N	N	R
Oncology CNS	N	N	N	N	N	N	N	N	1	1	Y	Y	Y	E	N	N	N	E	E	N	Y	N	Y	Y	N	E	N	N	N	N	N	E
Cancer Genetic Nurse Specialist	N	N	N	N	N	N	N	N	1	1	Y	N	Y	S	N	N	N	S	S	N	Y	N	N	N	N	S	N	N	N	N	N	S
Palliative Care CNS	N	N	Y	Y	N	N	N	N	2	1	Y	Y	Y	P	6	Y	N	P	P	Y	Y	N	Y	N	N	P	N	N	N	N	N	P
Paediatric CNS	N	N	N	N	N	N	N	N	N	1	N	N	N	O	N	Y	N	O	O	Y	Y	Y	N	N	N	O	N	N	N	N	N	O
Paediatric Oncology CNS	N	N	N	N	N	N	N	N	1	N	N	N	N	N	N	N	N	N	N	N	Y	N	N	N	N	N	N	N	N	N	N	N
Colo-rectal Nurse Specialist	N	N	N	N	N	N	N	N	1	1	N	N	N	D	N	N	N	D	D	N	N	N	N	N	N	D	N	N	N	N	N	D
Neuro Oncology Nurse Specialist	N	N	N	N	N	N	N	N	1	1	N	N	Y		N	N	N			Y	N	N	Y	Y	N		N	N	N	N	N	

PALLIATIVE CARE PERSONNEL in GREATER GLASGOW HEALTH BOARD AREA in 1997 (first column) and in 1999 (second column)

APPENDIX 7	Hunter's Hill Marie Curie Hospice		St. Margaret's Hospice Clydebank		Prince & Princess of Wales Hospice		Marie Curie Nurse		Macmillan Nurse		Glasgow Royal Infirmary		Western Infirmary		Stobhill Hospital		Victoria Infirmary		Southern General Hospital		Yorkhill Children's Hospital		Beatson in Western Infirmary		Rauchill Hospital For HIV & AIDS		Rachel House Kinross		Heatherbank Nursing Home		Campsieview Nursing Home	
Nursing Tutor	2	2	2	Y	N	N	N	N	N	N	N	N	N		N	N	N			N	N	N	N	N	N	E	N	N	N	N	N	
Physiotherapist	1	1	Y	Y	Y	Y	N	N	1	1	Y	Y	Y		Y	Y	N			Y	N	N	Y	Y	1		Y	Y	N	N	N	
Occupational Therapist	2	2	N	Y	N	N	N	N	N	N	Y	Y	Y		Y	Y	N			Y	Y	N	Y	Y	1		N	N	N	N	N	
Chiropodist	Y	Y	Y	Y	N	Y	N	N	N	N	Y	Y	Y	D	Y	Y	N	D	D	Y	N	N	N	N	N	D	N	N	Y	N	N	D
Speech Therapist	N	N	N	N	N	N	N	N	1	N	Y	Y	Y	I	Y	Y	N	I	I	Y	Y	N	Y	N	N	I	N	N	N	N	N	I
Clinical psychologist	N	N	N	N	N	N	N	N	N	N	N	N	Y	D	Y	Y	N	D	D	Y	Y	Y	N	Y	N	D	Y	Y	N	N	N	D
Oncology Dietician	N	N	N	N	N	N	N	N	N	N	Y	Y	Y		N	N	N			N	Y	N	Y	Y	1		N	N	N	N	N	
Radiographer	N	N	N	N	N	N	N	N	1	1	N	Y	Y	N	N	N	N	N	N	Y	N	N	Y	N	N	N	N	N	N	N	N	N
Counsellors	Y	Y	Y	Y	Y	N	N	N	N	N	N	N	Y	O	N	N	N	O	O	N	N	N	Y	Y	2	O	Y	Y	N	N	N	O
Social Worker	2	2	N	N	Y	Y	N	N	N	N	Y	Y	Y	T	Y	Y	N	T	T	Y	Y	N	Y	N	3	T	N	N	N	N	N	T
Volunteer Co-ordinator	1	1	Y	Y	Y	Y	N	N	N	N	N	N	N		N	Y	N			N	N	N	N	N	N		Y	Y	N	N	N	
Volunteers	Y	Y	Y	Y	Y	Y	N	N	N	N	N	Y	Y	R	N	Y	N	R	R	Y	N	N	Y	N	N	R	Y	Y	N	N	Y	R
Chaplain	Y	1	Y	Y	Y	Y	N	N	N	N	Y	Y	Y	E	Y	Y	N	E	E	Y	Y	N	Y	N	1	E	Y	Y	N	N	Y	E
Alternative Medicine Therapist	Y	Y	Y	N	N	N	N	N	N	N	N	N	Y	S	N	N	N	S	S	N	N	N	Y	N	N	S	N	N	N	N	N	S
Administrators	Y	Y	Y	Y	Y	Y	N	N	N	N	N	N	N	P	N	N	N	P	P	Y	Y	N	Y	N	3	P	Y	Y	1	N	Y	P
Pharmacist	Y	Y					N	N	N	N	N		N	O	Y	Y	N	O	O		Y	N	N	N	N	O	N	N	N	N	N	O
Marie Curie Home Care Sisters	4	4	N		N	N	N	N	N	N	N		N	N	N		N	N	N		N	N	N	N	N	N	N	N	N	N	N	N
SHO	2	2				N	N	N	N	N	N		N	D	N		N	D	D		N	N	N	N	N	D	N	N	N	N	N	D
Macmillan Lecturers in Pall. Med.	Y		N		N	N	N	N	3	5	N		N		N		N				N	N	N		N		N	N	N	N	N	

*****All the tables in Appendix 7:** The first column for each service provider represents data collected from 1997 and the second column for each service provider represents data collected in 1999.*

PALLIATIVE CARE SERVICES in GREATER GLASGOW HEALTH BOARD AREA in 1997 (first column) and in 1999 (second column)

APPENDIX 7	BACUP		CRUSE		TAK TENT		PAIN Association Scotland		Breast Cancer Care		Malcolm Sargent (Sargent Cancer Care)		Body Positive		PHACE West		ACET	HIV & AIDS Carers		MND in Southern General Hospital		Multiple Sclerosis Association		Alzheimer's Scotland		Social Services		GGNHSB District Nurse		Gold Project	Possil Stress Centre	
Rehabilitation	N	N	N	N	N	N	N	N	Y	Y	N	N	N	N	N	N	N	N	N	Y	Y	N	N	N	N	N	N	Y	Y	N	N	N
Day Care	N	N	N	N	N	N	N	N	N	N	N	N	Y	Y	Y	N	Y	N	N	Y	Y	Y	Y	N	Y	N	N	Y	Y	Y	N	N
Home Care Nursing	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	Y	Y	Y	N	N	N	N	N	Y	Y	N	N	N
Respite	N	N	N	N	N	N	N	N	N	N	Y	Y	Y	N	N	N	Y	Y	Y	Y	Y	Y	N	Y	Y	N	N	Y	Y	Y	N	N
Bereavement services	Y	Y	Y	Y	N	N	N	N	N	N	N	Y	Y	Y	N	N	N	N	N	Y	N	N	N	N	N	N	N	Y	Y	N	N	N
Counselling for the bereaved	Y	Y	Y	Y	Y	Y	N	N	N	Y	Y	Y	Y	Y	N	N	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	N	Y	Y
Counselling for the patient	Y	Y	N	N	Y	Y	N	N	Y	Y	Y	Y	Y	Y	N	N	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	N	Y	Y
Counselling for the parents	Y	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	Y	Y	N	N	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	N	Y	Y
Counselling for the carers	Y	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	Y	Y	N	N	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Services for children & Youth	Y	Y	N	N	Y	Y	N	N	N	N	Y	Y	Y	Y	N	N	Y	Y	Y	Y	Y	N	N	Y	N	Y	Y	Y	Y	N	N	N
Pain Management Program	N	N	N	N	N	N	Y	N	N	N	N	N	N	N	N	N	N	N	N	Y	Y	N	N	N	N	N	N	N	N	N	N	N
Breast Prosthesis Clinic	N	N	N	N	N	N	N	N	Y	Y	N	N	N	N	N	N	N	N	N	N	Y	N	N	N	N	N	N	N	N	N	N	N
Cancer Care	Y	Y	N	N	N	N	N	N	N	Y	Y	Y	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	Y	Y	N	N	N
MND Care	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	Y	N	N	N	N	N	N	N	Y	Y	N	N	N
HIV & AIDS Care	N	N	N	N	N	N	N	N	N	N	N	N	Y	Y	Y	Y	Y	N	N	N	N	N	N	Y	Y	N	N	Y	Y	N	N	N
Other Terminal Illness	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	Y	N	N	Y	Y	N	N	Y	Y	N	N	N
Terminal Care	N	N	N	N	N	N	N	N	N	N	Y	N	N	N	N	N	Y	N	N	Y	N	Y	N	N	N	N	N	Y	Y	N	N	N
Palliative Care	N	N	N	N	N	N	N	N	N	N	Y	N	N	N	N	N	N	N	N	Y	N	Y	N	N	N	N	N	Y	Y	Y	Y	N
Physiotherapy	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	Y	Y	Y	Y	N	N	N	N	Y	Y	N	N	N
Occupational Therapy	N	N	N	N	N	N	N	N	N	N	N	N	Y	N	N	N	N	N	N	Y	Y	N	Y	N	N	N	N	Y	Y	N	N	N
Training in Palliative Care	N	N	N	N	N	N	N	N	N	Y	N	N	N	N	N	N	N	N	N	Y	Y	N	N	N	N	N	N	Y	Y	N	N	N
Training in Counselling	N	N	Y	Y	N	N	N	N	N	N	N	Y	N	N	N	N	N	Y	Y	Y	Y	Y	N	N	N	N	N	Y	Y	N	N	N
Help-line	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	N	N	N	Y	N	Y	N	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	N	N	N	N	N
Information Leaflet, Video, Audio	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	N	N	N	Y	N	N
Directory of Available Services	Y	Y	N	N	Y	N	N	N	Y	Y	N	N	N	N	N	Y	Y	Y	Y	N	N	Y	N	Y	N	Y	Y	N	N	Y	N	N
Support Group	N	N	Y	3	Y	Y	Y	Y	N	Y	N	Y	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y	Y	N	Y	Y	N	N	Y	N	N
Use Volunteers	Y	Y	Y	50	Y	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	Y	N	N	N	Y	Y	Y
Alternative Therapy	N	N	N	N	N	Y	Y	Y	N	N	N	N	Y	Y	N	N	N	Y	Y	Y	N	Y	Y	N	N	N	N	N	N	N	Y	Y
Networking with other providers	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
Chaplaincy Service	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	Y	N	N	N	N	N	N	N	Y	Y	N	N	N
Other Services	Y	Y	N	N	N	N	N	N	N	N	N	N	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	N	N	N	N	N	N	Y	N	N

PALLIATIVE CARE PERSONNEL in GREATER GLASGOW HEALTH BOARD AREA in 1997 (first column) and in 1999 (second column)

APPENDIX 7

	BACUP		CRUSE		TAK TENT		PAIN Association Scotland		Breast Cancer Care		Malcolm Sargent		Body Positive		PHACE West		ACET	HIV & AIDS Carers		MND in Southern General Hospital		Multiple Sclerosis		Alzheimer's		Social Services		GGNHSB District Nurse		Gold Project	Possil Stress Centre	
Registered Nurse	Y	2	N	N	N	N	N	N	Y	Y	N	N	N	N	N	N	N	N	N	Y	Y	Y	2	N	N	N	N	Y	Y	N	N	N
Enrolled Nurse	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	Y	N	N	N	N	N	N	Y	Y	N	N	N
Auxiliary Nurse	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	Y	N	N	N	N	N	N	Y	Y	N	N	N
Marie Curie Nurse	N	N	N	N	N	N	N	N	N	Y	N	N	N	N	N	N	N	N	N	Y	N	N	N	N	N	N	N	N	N	N	N	N
Breast Cancer Nurse Specialist	N	N	N	N	N	N	N	N	Y	Y	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N
Oncology CNS	Y	Y	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N
Cancer Genetic Nurse Specialist	N	N	N	N	N	N	N	N	Y	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N
Clinical Nurse Specialist	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	Y	N	N	N	N	N	N	N	Y	Y	N	N	N
Nursing Tutor	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	Y	Y	N	N	N
Physiotherapist	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	Y	Y	Y	Y	N	N	N	N	Y	Y	N	N	N
Occupational Therapist	N	N	N	N	N	N	N	N	N	N	N	N	Y	N	N	N	N	N	N	Y	Y	N	Y	N	N	N	N	Y	Y	N	N	N
Chiropodist	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	Y	Y	Y	Y	N	N	N	N	Y	Y	N	N	N
Speech Therapist	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	Y	Y	N	N	N	N	N	N	N	N	N	N	N
Counsellors	Y	5	Y	20	Y	Y	N	N	N	N	N	N	Y	Y	N	Y	N	Y	Y	N	N	Y	Y	Y	Y	Y	N	N	N	N	Y	Y
Social Worker	N	N	N	N	N	N	N	N	N	N	Y	Y	N	N	N	N	Y	N	N	Y	N	N	N	N	N	Y	Y	N	N	Y	N	N
Malcolm Sargent	N	N	N	N	N	N	N	N	N	N	Y	Y	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N
Volunteer Co-ordinator	N	Y	Y	N	N	1	Y	N	Y	Y	N	N	Y	N	Y	Y	Y	Y	Y	N	N	Y	N	Y	Y	Y	N	N	N	N	N	N
Volunteers	Y	3	Y	50	Y	10	15	25	Y	Y	N	N	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	N	N	Y	N	N	N	Y	Y	Y
Alternative Medicine Therapist	N	N	N	N	N	Y	N	N	N	N	N	N	Y	Y	N	N	N	N	N	Y		Y	Y	N	N	N	N	N	N	N	N	N
Administrators	N	Y	N	Y	Y	Y	Y	1	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	N		Y	Y	N	N	Y	N	Y	Y	N	Y	N

APPENDIX 7

PALLIATIVE CARE SERVICES in GREATER GLASGOW HEALTH BOARD AREA in 1997 (first column) and in 1999 (second column)

	CSV Health Action Project		Greater Glasgow Health Council		ENABLE		Crossroads		Friends for Life		SALARC		Notre Dame Centre		Meridian		Jordanhill Counselling Unit		Tom Allan Centre		Hawthorn House Yorkhill		Princess Royal Trust Eastend		Princess Royal Trust North & West		San Jai Chinese Project		G.A.M.H.	
Respite	N	D	N	N	N	N	Y	Y	Y		N		N	N	N	N	N	N	N	N	N	N	Y	Y	N	Y	N	N	N	D
Bereavement services	N	I	N	N	N	N	N	N	Y	C	N	C	N	N	N	N	Y	Y	Y	N	Y	Y	N	N	N	N	N	N	N	I
Counselling for the bereaved	N	D	N	N	Y	Y	N	N	Y	L	Y	L	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	N	N	Y	Y	Y	D
Counselling for the patient	N		N	N	N	N	N	N	Y	O	Y	O	Y	Y	Y	Y	Y	Y	Y	Y	N	N	N	N	N	N	Y	Y	Y	
Counselling for the parents	N	N	N	N	Y	Y	N	N	Y	S	Y	S	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	N	Y	Y	Y	Y	N
Counselling for the carers	N	O	N	N	N	N	N	N	Y	E	Y	E	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	O
Services for children & Youth	Y	T	N	N	N	N	N	N	Y	D	N	D	Y	Y	Y	Y	N	N	N	N	Y	N	N	Y	N	Y	Y	Y	Y	T
Training in Counselling	N		N	N	N	N	N	N	N		N		N	N	N	N	Y	Y	Y	Y	Y	N	N	N	N	N	N	N	N	
Help-line	N	R	N	N	Y	Y	N	N	Y	D	Y	D	N	Y	N	N	N	N	N	N	N	N	Y	N	Y	Y	N	N	Y	R
Information Leaflet, Video, Audio	Y	E	Y	Y	Y	Y	Y	N	N	O	Y	O	N	Y	Y	Y	N	Y	N	N	Y	Y	Y	Y	Y	Y	Y	N	Y	E
Directory of Available Services	N	S	Y	Y	Y	Y	N	N	Y	W	Y	W	N	N	N	Y	N	N	N	N	Y	Y	Y	Y	Y	Y	N	N	Y	S
Support Group	Y	P	N	N	Y	Y	N	N	N	N	Y	N	N	N	N	Y	N	N	Y	N	Y	Y	Y	Y	Y	Y	N	N	Y	P
Use Volunteers	Y	O	Y	N	Y	Y	N	N	Y		N		N	N	Y	Y	N	N	Y	Y	Y	N	Y	Y	Y	Y	Y	N	Y	O
Networking with other providers	Y	N	Y	N	Y	Y	N	N	Y		Y		Y	Y	N	N	N	N	N	N	Y	Y	Y	Y	Y	Y	Y	N	Y	N
Other Services	N	D	Y	N	Y	Y	N	N	N		Y		N	N	N	N	N	N	N	N	Y	Y	Y	Y	N	Y	Y	N	Y	D

PALLIATIVE CARE PERSONNEL in GREATER GLASGOW HEALTH BOARD AREA in 1997 (first column) and in 1999 (second column)

	CSV Health Action Project		Greater Glasgow Health Council		ENABLE		Crossroads		Friends for Life		SALARC		Notre Dame Centre		Meridian		Jordanhill Counselling Unit		Tom Allan Centre		Hawthorn House Yorkhill		Princess Royal Trust Eastend		Princess Royal Trust North & West		San Jai Chinese Project		G.A.M.H.	
Chiropodist	N		N	N	N	N	N	N	N		N		N	N	N	N	N	N	N	N	N	N	Y	N	Y	Y	N	N	N	
Counsellors	N		N	N	N	N	N	N	Y		N		N	Y	Y	Y	Y	Y	Y	Y	Y	2	Y	N	N	N	N	N	N	
Social Worker	N		N	N	N	N	N	N	Y		N		N	Y	N	N	N	N	N	N	N	N	N	N	Y	Y	Y	Y	N	
Volunteer Co-ordinator	N		N	N	N	N	N	N	Y		N		N	N	N	N	N	N	N	N	Y	N	N	N	N	N	N	N	Y	
Volunteers	N		N	N	Y	Y	N	N	Y		Y		N	N	Y	Y	N	N	Y	Y	Y	N	N	N	Y	Y	N	Y	Y	
Chaplain	N		N	N	N	N	N	N	N		N		N	N	N	N	N	N	N	Y	N	N	N	N	N	N	Y	Y	N	
Administrators	N		N	N	Y	Y	N	N	Y		Y		N	Y	Y	Y	N	N	N	N	Y	1	N	N	N	N	N	N	N	
Carers					Y	Y	Y	Y	Y																					

N = not providing; Y = providing; **N** or **Y** = shows change in practice over the two years;

APPENDIX 8

Activity data from the three hospices

Activity data from the three hospices for two years (1996 and 1997) were collected using the following format.

ACTIVITY DATA OF THE HOSPICES IN GGNHSB
Description
IN-PATIENTS
Total Number of days
Total bed days available
Total bed days occupied
Available beds
Patients admitted from home
Patients admitted from nursing/residential homes
Patients admitted from hospital
Patients admitted from other hospice
Total number of patients admitted
Number of new patients admitted
Number of repeat admissions
Patients discharged home
Patients discharged to nursing/residential home
Patient discharged to hospital
Deaths
Average occupied beds
Percentage bed occupancy
Turnover intervals
Average length of stay
DAY- CARE
Number of days open
New day care patients
Patients days available in the year
Days used by patients from home
Days used by centre in-patients
Number of patients offered a place
Number of places accepted by patients
Number of places declined by patients
Discharged from day care
Deaths

OUT-PATIENTS
New out-patients
OP attendance at specialist clinic at centre (med.)
OP attendance at specialist clinic at centre (non-med.)
New patients in pain clinic
Deaths
Number of consultations in pain clinic
HOME CARE
New home care patients
Re-admission to home care
Total number of visits
Home visits by doctors
Home visits by other staff
Hospital visits by doctors
Hospital visits by other staff
Case load per sister
Deaths of patients in home care

Comparison of the three Hospice activity were collected in selected events

Beds
Average Length of stay
In-Pt.
New Day-care Pt
Deaths
Pt. Days available
Places accepted
Pt. From West
Pt. From South
Pt From N.E
Others

Appendix 8 Table showing the activity data from the three hospices over a two year period

ACTIVITY DATA OF THE HOSPICES IN GGNHSB AREA						
	01/04/96 to 31/03/97	01/04/98 to 31/03/99	01/04/96 to 31/03/97	01/04/98 to 31/03/99	01/04/96 to 31/03/97	01/04/98 to 31/03/99
Description	**Huntershill**		**St. Margate's**		**Prince & Princess of Wales**	
IN-PATIENTS						
Total Number of days	365	365	365	365	365	365
Total bed days available	15,895	14,977	9125	9855		
Total bed days occupied	12,428	12,325	6193	6762		
Available beds	44	41	25	25	14	14
Patients admitted from home	395	411	193	171	183	225
Patients admitted from nursing/residential homes	1	5	3	6		
Patients admitted from hospital	152	137	97	114	45	52
Patients admitted from other hospice			2			
Total number of patients admitted	548	553	295	291	228	277
Number of new patients admitted	412	419	265	283	187	230
Number of repeat admissions	136	134	30	56	45	47
Patients discharged home	208	189	53	80	99	124
Patients discharged to nursing/residential home	1	11	1			
Patient discharged to hospital	14	11	6		5	6
Deaths	331	339	230	204	118	145
Average occupied beds	34	33.8	17			
Percentage bed occupancy	78.2	82.3	67.9		84	80
Turnover intervals	6.3	4.8	9.9	10.9		
Average length of stay	22.4	22.4	19.37	23	18.6	13.3

ACTIVITY DATA OF THE HOSPICES IN GGNHSB AREA

	01/04/96	01/04/98	01/04/96	01/04/98	01/04/96	01/04/98
	To 31/03/97	to 31/03/99	to 31/03/97	to 31/03/99	to 31/03/97	to 31/03/99
Description	**Huntershill**		**St. Margate's**		**Prince & Princess of Wales**	
DAY- CARE						
Number of days open	244	242	244	244	244	246
New day care patients	76	85	63	84	122	116
Patients days available in the year	3,472	3,048	2610	2610	3660	3,690
Days used by patients from home	1,798	1874				
Days used by centre in-patients	111	No record				
Number of patients offered a place					3306	3,511
Number of places accepted by patients	1909		1191	1021	2322	2,644
Number of places declined by patients					984	867
Discharged from day care			56	39	105	45
Deaths			17	51	24	70
OUT-PATIENTS						
New out-patients	213	250	Nil		Nil	
OP attendance at specialist clinic at centre (med.)	356	551	Nil		Nil	
OP attendance at specialist clinic at centre (non-med.)	1,358	1,645	Nil		Nil	
New patients in pain clinic	Nil		Nil		16	36
Deaths	Nil		Nil		16	33
Number of consultations in pain clinic	Nil		Nil		284	269
HOME CARE						
New home care patients	304	299	231	274	408 + 25	432 + 70
Re-admission to home care	138	79				
Total number of visits	3138	2,085	1427	1311		3,618
Home visits by doctors	240	159				
Home visits by other staff	2,898	1,926				349
Hospital visits by doctors	610	420				
Hospital visits by other staff	14	131				
Case load per sister	25-35	25			31	32
Deaths of patients in home care		153	81	128	327	389

Appendix 8 Table showing comparison of the activity of the three Hospices in selected events

	Huntershill-96	Huntershill-98	St Margaret's-96	St Margaret's-98	P&P of Wales-96	P&P of Wales-98
Beds	44	41	25	25	14	14
Av. Length of stay	22.4	22.4	19.4	23	18.6	13.3
In-Pt.	548	553	295	291	228	277
New Day-care Pt	76	85	63	84	122	116
Deaths	331	339	230	204	118	145
Pt. Days available	3472	3048	2610	2610	3660	3690
Places accepted	1909		1191	1021	2322	2644
	Huntershill		St Margaret's			
Pt. From West	15%		87%			
Pt. From South	15%		2.30%			
Pt From N.E	68%		1.50%			
Others	2%		9.20%			

APPENDIX 9

First pilot of GP's & DN's questionnaire

To

Dear «Title»«LastName»,

I am a PhD student in the Department of Public Health in Glasgow University. My PhD is on *"A community based needs assessment in Palliative Care in the Greater Glasgow Health Board (GGNHSB) area"*. My supervisors are Prof. J. McEwen (Public Health) and Prof. J. Welsh (Palliative Medicine).

As part of my study I am conducting a postal questionnaire survey of General Practitioners and District Nurses in the GGNHSB area. Before conducting the survey I would like to get some comments on my questionnaire. I would therefore be grateful if you could look at the enclosed questionnaire and covering letter and return it to me with your comments. The questionnaire should be a useful tool in obtaining information from palliative care service providers and should also be user friendly. All information provided will be treated confidentially. This study is also being undertaken as part of the GGNHSB's strategy for "Palliative Care in Greater Glasgow - A Framework for Services".

Please return in the enclosed replied paid envelope.

Thanking you in anticipation of your help.

Yours sincerely

Dr Yoga Velupillai

PhD Student, Department of Public Health

1. The length of this questionnaire is:

Too long ☐
Acceptable ☐
Too Short. ☐

2. The time taken to complete this questionnaire was ***10 / 15 / 20 / 25 / 30 / 35 / 40*** minutes.

Please add below any other comments you would like to make.

____

Thank you very much for your help.

General Practitioner and District Nurse Survey on Palliative Care Services

in the Greater Glasgow Health Board Area.

Age: ....

Sex: (M/F)

Primary qualification: ....

Specialist qualification: ....

Do you have qualification in Palliative Care: (Y/N) (MD/MSc/Diploma).

Have you attended course in Palliative Care: (Y/N) (1 Week/Few days/1 Day).

Have you attended conferences/seminars in Palliative Care: (Y/N).

Previous places of work: GP Practice (Y/N) Hospital (Y/N) Hospice (Y/N)

Present places of work: GP Practice (Y/N) Hospital (Y/N) Hospice (Y/N)

Number of years in present post: ....

Number of GP partners in the practice: 1 / 2 / 3 / 4 / 5 / 6 / 7

Hospices that you usually consult:-	Huntershill Marie Curie Centre:	(Y/N)
(regarding patients needing palliative care)	St. Margaret's Hospice Clydebank:	(Y/N)
	Prince & Princess Of Wales Hospice:	(Y/N)
Hospices that you usually refer:-	Huntershill Marie Curie Centre:	(Y/N)
(regarding patients needing palliative care)	St. Margaret's Hospice Clydebank:	(Y/N)
	Prince & Princess Of Wales Hospice:	(Y/N)

Hospitals that you usually consult (regarding patients needing palliative care): Glasgow Royal Infirmary (Y/N) Stobhill (Y/N) Western Infirmary (Y/N)

Gartnavel General (Y/N) Victoria Infirmary (Y/N) Southern General (Y/N)

Hospitals that you usually refer: (regarding patients needing palliative care) Glasgow Royal Infirmary (Y/N) Stobhill (Y/N) Western Infirmary (Y/N)

Gartnavel General (Y/N) Victoria Infirmary (Y/N) Southern General (Y/N)

Would you like to have	Information in Palliative Care:	(Y/N)
	Training in Palliative Care:	(Y/N)

I a. How adequately provided do you find the currently available Palliative Care Services for *patients with cancer?*

Please indicate how well you feel the needs of your *patients, with cancer*, are being met at present.

Please tick one box for each of the 17 items.

Urgent admission = within 24 hours of your request.

Services.	Very adequate	Fairly adequate	Fairly inadequate	Very inadequate	No experience
Cancer patients: urgent admission to hospice for symptom control.	☐	☐	☐	☐	☐
Cancer patient: urgent admission to hospice for terminal care	☐	☐	☐	☐	☐
Cancer patient: booked respite admission in hospice	☐	☐	☐	☐	☐
Cancer patient: urgent admission to hospital for symptom control	☐	☐	☐	☐	☐
Cancer patient: urgent admission to hospital for terminal care	☐	☐	☐	☐	☐
Palliative day-care for cancer patients	☐	☐	☐	☐	☐
Palliative home-care for cancer patients	☐	☐	☐	☐	☐
Palliative out-patient service for cancer patients	☐	☐	☐	☐	☐
Palliative Medicine Specialist for cancer patients	☐	☐	☐	☐	☐
Macmillan Nurses for cancer patients	☐	☐	☐	☐	☐
Marie Curie Nurses for cancer patients	☐	☐	☐	☐	☐
District Nurses for cancer patients	☐	☐	☐	☐	☐
Social Services for cancer patients	☐	☐	☐	☐	☐
Counselling services for cancer patients	☐	☐	☐	☐	☐
Care in the community for cancer patients	☐	☐	☐	☐	☐
Voluntary organisations for cancer patients	☐	☐	☐	☐	☐
Bereavement Services for relatives/carers of cancer patients	☐	☐	☐	☐	☐

I b. How adequately provided do you find the currently available Palliative Care Services for ***patients with non-cancer conditions needing palliative care?***

Please indicate how well you feel the needs of your ***patients, with non-cancer conditions needing palliative care***, are being met at present.

Please tick one box for each of the 17 items.

Urgent admission = within 24 hours of your request.

Non-cancer patients = non-cancer patients needing palliative care.

Services.	Very adequate	Fairly adequate	Fairly inadequate	Very inadequate	No experience
Non-Cancer patients: urgent admission to hospice for symptom control.					
Non-Cancer patient: urgent admission to hospice for terminal care					
Non-Cancer patient: booked respite admission in hospital					
Non-Cancer patient: urgent admission to hospital for symptom control					
Non-Cancer patient: urgent admission to hospital for terminal care					
Palliative day-care for non-cancer patients					
Palliative home-care for non-cancer patients					
Palliative out-patient service for non-cancer patients					
Palliative Medicine Specialist for non-cancer patients					
Macmillan Nurses for non-cancer patients					
Marie Curie Nurses for non-cancer patients					
District Nurses for non-cancer patients					
Social Services for non-cancer patients					
Counselling services for non-cancer patients					
Care in the community for non-cancer patients					
Voluntary organisations for non-cancer patients					
Bereavement Services for relatives/carers of non-cancer patients					

II a i. From your experience, has a bed been available when an admission to a ***Hospice*** has been requested for a ***patient with cancer?***

Services.	Always	Usually	Rarely	Never	No experience
Urgent admission (within 24 hours)					
Booked respite admission					

II a ii. From your experience, has a bed been available when an admission to a ***Hospice*** has been requested for a ***patient with non-cancer condition needing palliative care?***

Services.	Always	Usually	Rarely	Never	No experience
Urgent admission (within 24 hours)					
Booked respite admission					

Do you have any other comments on the availability to Hospices?

……

II b i. From your experience, has a bed been available for a ***patient with cancer*** when an admission to a ***Hospital*** has been requested?

Services.	Always	Usually	Rarely	Never	No experience
Urgent admission (within 24 hours)					
Booked respite admission					

II b. From your experience, has a bed been available for a ***patient with non-cancer condition (needing palliative care)*** when an admission to a ***Hospital*** has been requested?

Services.	Always	Usually	Rarely	Never	No experience
Urgent admission (within 24 hours)					
Booked respite admission					

Do you have any other comments on the availability to Hospitals?

……

II a:. Please indicate the ***priority and importance*** that you would like to see given to each of the following ***when planning future services for patients with cancer.***

Given finite resources, where would you put the emphasis?

Please tick one box for each of the 17 items.

Urgent admission = within 24 hours of your request

Services.	Very important High priority	Fairly important Moderate priority	Fairly unimportant Low priority	Very unimportant Very low priority	No experience
Cancer patients: urgent admission to hospice for symptom control.					
Cancer patient: urgent admission to hospice for terminal care					
Cancer patient: booked respite admission in hospice					
Cancer patient: urgent admission to hospital for symptom control					
Cancer patient: urgent admission to hospital for terminal care					
Palliative day-care for cancer patients					
Palliative home-care for cancer patients					
Palliative out-patient service for cancer patients					
Palliative Medicine Specialist for cancer patients					
Macmillan Nurses for cancer patients					
Marie Curie Nurses for cancer patients					
District Nurses for cancer patients					
Social Services for cancer patients					
Counselling services for cancer patients					
Care in the community for cancer patients					
Voluntary organisations for cancer patients					
Bereavement Services for relatives/carers of cancer patients					

III b:. Please indicate the ***priority and importance*** that you would like to see given to each of the following ***when planning future services for patients with non-cancer conditions needing palliative care.*** Given finite resources, where would you put the emphasis?

Please tick one box for each of the 17 items.

Urgent admission = within 24 hours of your request

Non-cancer patients = non-cancer patients needing palliative care.

Services.	Very important High priority	Fairly important Moderate priority	Fairly unimportant Low priority	Very unimportant Very low priority	No experience
Non-Cancer patients: urgent admission to hospice for symptom control.					
Non-Cancer patient: urgent admission to hospice for terminal care					
Non-Cancer patient: booked respite admission in hospital					
Non-Cancer patient: urgent admission to hospital for symptom control					
Non-Cancer patient: urgent admission to hospital for terminal care					
Palliative day-care for non-cancer patients					
Palliative home-care for non-cancer patients					
Palliative out-patient service for non-cancer patients					
Palliative Medicine Specialist for non-cancer patients					
Macmillan Nurses for non-cancer patients					
Marie Curie Nurses for non-cancer patients					
District Nurses for non-cancer patients					
Social Services for non-cancer patients					
Counselling services for non-cancer patients					
Care in the community for non-cancer patients					
Voluntary organisations for non-cancer patients					
Bereavement Services for relatives/carers of non-cancer patients					

IVa: From your experience, could you please ***Rank*** how important each of the following palliative care service is, in your caring ***for your patients with cancer at home.***

Please tick one box for each of the 17 items.
The ranking order is : 1 = ***Very important and*** 5 = ***Least important***

Services.	**1**	**2**	**3**	**4**	**5**
Cancer patients: urgent admission to hospice for symptom control.					
Cancer patient: urgent admission to hospice for terminal care					
Cancer patient: booked respite admission in hospice					
Cancer patient: urgent admission to hospital for symptom control					
Cancer patient: urgent admission to hospital for terminal care					
Palliative day-care for cancer patients					
Palliative home-care for cancer patients					
Palliative out-patient service in Hospice for cancer patients					
Palliative out-patient service in Hospital for cancer patients					
Palliative Medicine Specialist in Hospice for cancer patients					
Palliative Medicine Specialist in Hospital for cancer patients					
Macmillan Nurses for cancer patients					
Marie Curie Nurses for cancer patients					
District Nurses for cancer patients					
Social Services for cancer patients					
Counselling services for cancer patients					
Care in the community for cancer patients					
Voluntary organisations for cancer patients					
Bereavement Services for relatives/carers of cancer patients					

IVb: From your experience, could you please *Rank* how important each of the following palliative care service is, in your caring for your patients ***for patients with non-cancer conditions needing palliative care at home.***

Please tick one box for each of the 17 items.

The ranking order is : 1 = *Very important and* 5 = *Least important*

Services.	1	2	3	4	5
Non-Cancer patients: urgent admission to hospice for symptom control.					
Non-Cancer patient: urgent admission to hospice for terminal care					
Non-Cancer patient: booked respite admission in hospital					
Non-Cancer patient: urgent admission to hospital for symptom control					
Non-Cancer patient: urgent admission to hospital for terminal care					
Palliative day-care for non-cancer patients					
Palliative home-care for non-cancer patients					
Palliative out-patient service in Hospice for non-cancer patients					
Palliative out-patient service in Hospital for non-cancer patients					
Palliative Medicine Specialist in Hospice for non-cancer patients					
Palliative Medicine Specialist in Hospital for non-cancer patients					
Macmillan Nurses for non-cancer patients					
Marie Curie Nurses for non-cancer patients					
District Nurses for non-cancer patients					
Social Services for non-cancer patients					
Counselling services for non-cancer patients					
Care in the community for non-cancer patients					
Voluntary organisations for non-cancer patients					
Bereavement Services for relatives/carers of non-cancer patients					

V: Please add below any other comments you would like to make.

....

..... *Thank you very much for your help.*

Please return in the enclosed SAE to: Dr Yoga Velupillai, 2 Lilybank Gardens,
Department of Public Health, Glasgow University, G12 8RZ. Tel No: 0141 330 6434.

Responses from pilot study for a questionnaire on: "General Practitioner and District Nurse Survey on Palliative Care Services in the GGNHSB Area".

Total number of questionnaires sent out for the pilot study were : 36

Response received from : 24

Comments	**No**
1. The length of this questionnaire is: Too long	3
2. Acceptable	21
3. Too short	0
4. Time taken to complete this questionnaire: 10 min	8
5. 15 min	11
6. 20 min	4
7. 25 min	0
8. 30 min (this person said "acceptable")	1
9. Change (Y / N) to (YES / NO)	2
10.Put question mark where necessary	2
11.The word "adequate" does it have degrees of adequacy?	4
12.Number the items in the tables	1
13.Some corrections in the wording and phrasing in the format	6
14.There were misunderstanding in question III which has been corrected	2
15.Number the questions on page 1 of the questionnaire	2
16.Place Age & Sex comments on top together	3
17.Not to have too many font sizes	1
18.Give option of "Other" when asking about the place of work?	1
19.Page 2&3 to combine [1&2; 4&5]; [6&7; 8&9] (ref. to letter from Dr S McKay)	1
20.Include question on appropriate time of referral? (ref. Letter from Dr S Mckay)	1
21.Question 13 on page 2&3 of questionnaire to read "Palliative nursing care in the	2
22.Question 14 on page 2&3 of questionnaire to read "Palliative Care Sister input	2
23.The lay out of the matrix in question II-IV were too much	3
24. Give a closing date for replies to questionnaire	2
25. Give a choice about receiving summary	1
26. Free draw unprofessional/distasteful	4
27.Have a GGNHSB employee to be a co-signatory in the covering letter	1
28.Print double sided to decrease the number of pages	3
29.User friendly questionnaire	1
30.Clear and quick to do	4
31.Looks OK	3
32.Looks good	5
33.Found question V very general and so could not answer	1
34.Asking GP's & DN's if they worked at present in a Hospital or Hospice seems a strange question?	1
35.There was a point about the district nurse only working in GP practice	1
36. Explain in more detail the importance of the study and its results	1
37. Explain the importance of asking for age	1
38.Would like to know the number of patients treated (Palliative) by the GP/DN	1
39.To include Lymphoedema as one of the Chronic conditions	1
40.Not clear about the word "Psychological support"	4
41.Question 17 & 18 on page 2 & 3 of questionnaire - not clear about "Care in the Community" & "Voluntary organisations" very general	2

NB: The responses typed in bold have been taken into account and the necessary changes have been made in the amended questionnaire in Appendix 5.

APPENDIX 9a

Second pilot of GP's & DN's questionnaire

General Practitioner and District Nurse Survey on Palliative Care Services in the Greater Glasgow Health Board Area.

Replies from GP's (in Bold type)
3 returned the completed questionnaire and with comments,
2 returned uncompleted questionnaire but with comments,
2 returned only comments without the questionnaire.

Replies from Nurse's (not in Bold type)
6 returned the completed questionnaire and with comments
1 returned uncompleted questionnaire but with comments,
1 returned only comments without the questionnaire.
(answers were related to their work!)
Please circle the appropriate answers where applicable.

Age group: 20-24 (1) **/ 25-29** (2) **/ 35-39 (1)** (1) **/ 40-44 (1)** (2) **/ 45-49 (1).**

Sex:. M (6) / F (1) (8)

Current Post: GP (7) DN (5) Macmillan nurse (2) Locality manager (1)

1. Do you have a qualification in Palliative Care?: (Yes (0) /No (3)) (Yes (1) / No (4))

1a. The qualification that I have is: MSc (0) / Diploma (0) / Other: _______

MSc (0) / Diploma (0) / Other: ENB 931 (1); Care of the terminally ill.

2. Have you ever attended a course in Palliative Care?: (Yes 2)/No (1)) (Yes(4)/No(2))

2a. The course was for: 1 (1) / 2 / 3 / 4 (1) **/ 5** (1) **Day / 1 / 2 / 3 / 4 Week /**

Other: Other:(1) 6 weeks (1)

3. Have you attended conferences / seminars in Palliative Care in the last year?:

(Yes (1) / No (1)) (Yes (1) / No (6))

4. Do you at present work in a: Hospital? (Yes (0)/No (3))Hospice? (Yes (1) / No (2)).

Hospital? (Yes (0) / No (6)) Hospice? (Yes (2) / No (4)).

5. Have you in the past worked in a: Hospital? (Yes(3)/No(0)) Hospice?(Yes(1)/No (2))

Hospital? (Yes (5) / No (1)) Hospice? (Yes (1) / No (5)).

6. *Hospices* to which you usually refer your patients needing palliative care are:

St Margaret's (2) Huntershill (1) St Margaret's (5)

7. *Hospitals* to which you usually refer your patients needing palliative care are:

Western Infirmary (2) Stobhill (1) Western and Gartnavel (4)

8. Would you find it useful to have more information on Palliative Care?:

(Yes (1) / No (2)) (Yes (6) / No (0))

9. Would you find it useful to have more training in Palliative Care?:

(Yes (3) / No (0)) (Yes (6) / No (0))

If yes, what form would you like this to take?:

Seminar (1) / Tutorials (1) / Hospice attachment (2) / Written information / Others: Practical - syringe drivers etc.

Seminar (4) / Tutorials (5) / Hospice attachment / Written information (2) / Others: (2) Trust training sessions.

Your views on current services.

I : In the table below, please indicate *your views from your experience* on the currently available Palliative Care Services.

If you *have used* the service listed in the left column, then *circle the Y* in the *first column in that section,* and then continue to tick *one box* in the other two columns in that section.

If you *have not used* the service listed in the left column, then *circle the N* in the *first column in that section,* and then proceed to *the next section/row.* Please repeat this for all the 19 rows.

SERVICES	For cancer patients					For non-Ca patients				
*Urgent admission = within 24 hours of your request.	**Have Used**	**Adequate**	**Adequate**	**Inadequate**	**Inadequate**	**Have Used**	**Adequate**	**Adequate**	**Inadequate**	**Inadequate**
1. Urgent admission* to ***hospice*** for symptom control.	*Y*	2	4	1		*Y*	1			
2. Booked respite admission in ***hospice.***	*Y*	3	4			*Y*	3	1		
3. Urgent admission* to ***hospital*** for symptom control.	*Y*	2		1	1	*Y*	1		1	1
4. Palliative Outpatient service in ***hospital.***	*Y*	1	3	1		*Y*	1		1	
5. Palliative Outpatient service in ***hospice.***	*Y*	3	2			*Y*	2			
6. Palliative Medicine specialist in ***hospice.***	*Y*	3	3			*Y*	1			
7. Palliative Medicine specialist in ***hospital.***	*Y*	1	3			*N*				
8. Palliative Medicine specialist for ***home visits.***	*Y*	2	1			*Y*	2	1		
9. Palliative Day-care in the ***hospice.***	*Y*	3	4			*Y*	1			
10. Palliative Home-care by ***district nurse.***	*Y*	3	5			*Y*	2	3		
11. Palliative Home care by ***Marie Curie Community nursing service.***	*Y*	2	2			*Y*	2	1		
12. Palliative Home-care by ***Marie Curie Home care Sisters.***	*Y*	2	2			*Y*	1	1		
13. Palliative Home-care by ***Macmillan community nurse.***	*Y*	3	2		1	*Y*	1	1		
14. Home help by the Social services.	*Y*	1	1	1	3	*Y*	1	1	1	2
15. Social workers from the Social services department.	*Y*		2	1	1	*Y*		1	1	2
16. Occupational therapist from the Social services department.	*Y*		2	1	2	*Y*	1		1	3
17. Access to equipment from the Social services.	*Y*		1	2	1	*Y*		1	2	2
18. Access to equipment from the health board.	*Y*		1	1	3	*Y*		1	1	1
19. Telephone advice (24 hours) for palliative care issues.	*Y*	1		1		*Y*	1		1	

Your views on future services

II:. We are attempting to prioritise the services mentioned in this table. Please indicate the ***importance*** that you would like to see given to each of the following ***when planning future services.*** If you were given ***finite resources***, where would you put the ***emphasis?***

Please tick ***one box*** for ***cancer patients*** and ***one box*** for ***non-cancer patients*** on each of the 19 lines.

Replies from GP's

SERVICES	For cancer patients					For non-cancer patients				
*Urgent admission = within 24 hours of your request.	**Very important/ High priority**	**Fairly important/ Moderate priority**	**Fairly unimportant/ Low priority**	**Unimportant/ Very low priority**	**No experience**	**Very important/ High priority**	**Fairly important/ Moderate priority**	**Fairly unimportant/ Low priority**	**Unimportant/ Very low priority**	**No experience**
1. Urgent admission* to ***hospice*** for symptom control.	2	1				3				
2. Booked respite admission in ***hospice.***	2	1				2		1		
3. Urgent admission* to ***hospital*** for symptom control.	2		1			2	1			
4. Palliative Outpatient service in ***hospital.***	1		1	1			2		1	
5. Palliative Outpatient service in ***hospice.***	1	2				1		1	1	
6. Palliative Medicine specialist in the ***hospice.***	2	1				1		1	1	
7. Palliative Medicine specialist in ***hospital.***	1		1		1			2		1
8. Palliative Medicine specialist for ***home visit.***	1	1		1		1	1		1	
9. Palliative Day-care in the ***hospice.***	2	1				1		1		
10.Palliative Home-care by ***district nurse.***	2	1				2	1			
11.Palliative Home care by ***Marie Curie Community nursing service.***	1	1			1	1	1			1
12.Palliative Home-care by ***Marie Curie Home care Sisters.***	1	1			1	1		1		1
13.Palliative Home-care by ***Macmillan community nurse.***	1	2				1	1	1		
14.Home help by the Social services.	1	2				2	1			
15.Social workers from the Social services department.			1	1	1		1		1	1
16.Occupational therapist from the Social services department.	1	1	1			1	1	1		
17.Access to equipment from the Social services.	2			1		2			1	
18.Access to equipment from the health board.	1		2			1	1	1		
19.Telephone advice (24 hours) for palliative care issues.	1		2			1		2		

Replies from Nurses.

SERVICES	For cancer patients					For non-Ca patients				
*Urgent admission = within 24 hours of your request.	Very important/ High priority	Fairly important/ Moderate priority	Fairly unimportant/ Low priority	Unimportant/ Very low priority	No experience	Very important/ High priority	Fairly important/ Moderate priority	Fairly unimportant/ Low priority	Unimportant/ Very low priority	No experience
1. Urgent admission* to ***hospice*** for symptom control.	5		1			3				
2. Booked respite admission in ***hospice.***	1	4		1		1	2			
3. Urgent admission* to ***hospital*** for symptom control.	2	2		1		2	1			
4. Palliative Outpatient service in ***hospital.***		4		1			3			
5. Palliative Outpatient service in ***hospice.***	3	2	1			1	2			
6. Palliative Medicine specialist in the ***hospice.***	4	1	1			2	1			
7. Palliative Medicine specialist in ***hospital.***	2	3		1		1	2			
8. Palliative Medicine specialist for ***home visit.***	3	1	1			1	1	1		
9. Palliative Day-care in the ***hospice.***	6					3				
10.Palliative Home-care by ***district nurse.***	5	1				3				
11.Palliative Home care by ***Marie Curie Community nursing service.***	5	1				2	1			
12.Palliative Home-care by ***Marie Curie Home care Sisters.***	5		1			2		1		
13.Palliative Home-care by ***Macmillan community nurse.***	5					3				
14.Home help by the Social services.	4	2				2	1			
15.Social workers from the Social services department.	2	3	1			1	2			
16.Occupational therapist from the Social services department.	5	1				3				
17.Access to equipment from the Social services.	4	1	1			2		1		
18.Access to equipment from the health board.	6					3				
19.Telephone advice (24 hours) for palliative care issues.	6					3				

III: Please read the following statements and then circle the most appropriate answer in your opinion.

The codes are: 1 = Very Important / High Priority.

2 = Fairly Important / Moderate Priority. 3 = Fairly Unimportant / Low Priority.

4 = Unimportant / Very Low Priority.

a). All doctors should be capable of providing good general palliative care.

1 (3) 2 (0) 3 (0) 4 (0)

1 (4) 2 (2) 3 (0) 4 (0)

b). A good standard of palliative care should be a core service provided by all hospital specialist. **1 (2)**

2 (1) 3 (0) 4 (0)

1 (3) 2 (2) 3 (1) 4 (0)

c). Hospital consultants who wish to refer patients to a hospice service should consult the GP first. **1 (1)**

2 (0) 3 (2) 4 (0)

1 (2) 2 (1) 3 (3) 4 (0)

d). The general practitioner should co-ordinate the provision of palliative care, with others being brought in to supplement the primary care team in providing additional support, advice, guidance and care where appropriate.

1 (2) 2 (1) 3 (0) 4 (0)

1 (1) 2 (4) 3 (1) 4 (0)

e). The general practitioners should provide assessment, symptom control, and be involved in promoting psychosocial well being.

1 (2) 2 (1) 3 (0) 4 (0)

1 (2) 2 (3) 3 (0) 4 (0)

f). General practitioners ideally need protected time to deal competently and sensitively with this patient group and their families.

1 (1) 2 (1) 3 (1) 4 (0)

1 (4) 2 (2) 3 (0) 4 (0)

g). All nurses should be capable of providing good general palliative care.

1 (3) 2 (0) 3 (0) 4 (0)

1 (4) 2 (2) 3 (0) 4 (0)

h). Community and practice nursing staff require further training in palliative care.

1 (0) 2 (2) 3 (1) 4 (0)

1 (6) 2 (0) 3 (0) 4 (0)

i). In health centres and/or localities one or more nurses trained in palliative care should be encouraged to develop this as a special interest.

1 (0) 2 (0) 3 (1) 4 (2)

1 (5) 2 (1) 3 (0) 4 (0)

j). The nurse above (i) trained in palliative care should provide assessment, advice about symptom control, and be involved in promoting psychosocial well being.

1 (0) 2 (1) 3 (0) 4 (2)

1 (4) 2 (2) 3 (0) 4 (0)

k). Patients need to have their symptoms stabilised before they leave hospital.

1 (1) 2 (2) 3 (0) 4 (0)

1 (4) 2 (1) 3 (1) 4 (0)

l). Leaflets describing palliative care services available should be in the relevant languages.

1 (1) 2 (2) 3 (0) 4 (0)

1 (4) 2 (2) 3 (0) 4 (0)

m). Access to hospice and specialist palliative care services by members of ethnic minority communities, requires to be improved.

1 (0) 2 (1) 3 (2) 4 (0)

1 (2) 2 (4) 3 (0) 4 (0)

n). Access to hospice and specialist palliative care services by young adults (particularly those in the 16-24 year age group) requires to be improved.

1 (1) 2 (0) 3 (2) 4 (0)

1 (3) 2 (3) 3 (0) 4 (0)

o). Access to hospice and specialist palliative care services of people with learning difficulties requires to be improved.

1 (0) 2 (1) 3 (2) 4 (0)

1 (0) 2 (5) 3 (0) 4 (0)

p). Services for patients suffering from protracted neurological disorders such as motor neurone disease, multiple sclerosis and Huntingdon's chorea, should be reassessed.

1 (1) 2 (2) 3 (0) 4 (0)

1 (3) 2 (2) 3 (0) 4 (0)

q). Respite and support for family carers is required during periods of intense physical and psychological distress.

1 (2) 2 (1) 3 (0) 4 (0)

1 (5) 2 (1) 3 (0) 4 (0)

r). There should be routine formal assessment of bereaved carers to identify those at high risk. **1 (0)**

2 (0) 3 (3) 4 (0)

1 (3) 2 (2) 3 (1) 4 (0)

s). After formal assessment bereaved carers should have access to information on the full range of bereavement services available.

1 (0) 2 (2) 3 (1) 4 (0)

1 (5) 2 (1) 3 (0) 4 (0)

t). Pharmacists should be encouraged to work closely with patients and their families where drug regimens may be causing confusion.

1 (1) 2 (0) 3 (1) 4 (1)

1 (4) 2 (0) 3 (2) 4 (0)

u). There should be greater liaison with pharmacists and general practitioners where drug regimens may be causing confusion for the patients and their relatives.

1 (1) 2 (0) 3 (1) 4 (1)

1 (4) 2 (0) 3 (2) 4 (0)

IV a: From your experience, has a bed been available when an admission to a ***Hospice*** has been requested for Palliative Care?

Always (0)	**Usually (2)**	**Rarely (1)**	**Never (0)**	**No experience (0)**
Always (1)	Usually (4)	Rarely (0)	Never (0)	No experience (1)

IV b: From your experience, has a bed been available when an admission to a ***Hospital*** has been requested for Palliative Care?

Always (0)	**Usually (2)**	**Rarely (1)**	**Never (0)**	**No experience (0)**
Always (0)	Usually (1)	Rarely (3)	Never (0)	No experience (1)

V: Please rank [1 (very important) to 5 (unimportant)] according to importance (in your view) the ***best place***, for most of your patients receiving ***terminal palliative care***, to ***die?:***

GP's Home .1; 1;
Hospital .4; 4;
Hospice .2; 1
Nursing home .3; 1

Nurse's Home. 1; 1; 1; 1; 1.
Hospital .3; 3; 3; 3. 4.
Hospice .1; 1; 2; 2; 2; 1.
Nursing home .3; 4; 4; 4; 4.

VI: Mention three main obstacles, which prevent your patients dying in the setting of their choice.

GP's
1. Families ability to cope (2).
2. Family and patients often change their mind (1).
3. Availability of nurse 24 hrs. / weekend (1).
4. Support for carers e.g. night sisters (1).
5. Availability of equipment at home (1).
6. Lack of immediately available hospice bed (1).

Nurses
1. Symptoms not under control (3).
2. GP's unsure of symptom control (1).
3. The need for more support (2).
4. Too late referral to appropriate support service (1).
5. Complexity of the care needing to be provided (1).
6. Family not coping (3).
7. On call GP's not knowing the patients family (1).
8. Availability of beds (2).
9. Unsuitable to travel / too ill.

VII: At what stage do you think patients with incurable disease should be referred to the Specialist Palliative Care Team for appropriate support?

i) At diagnosis?..(Yes (1) / No (2)) (Yes (6) / No (0))
ii) When symptom control is difficult?........(Yes (2) / No (0)) (Yes (1) / No (0))
iii) When the family can no longer cope?....(Yes (1) / No (1)) (Yes (1) / No (0))
iv) When death is imminent?........................(Yes (1) / No (1)) (Yes (0) / No (1))
v) When future problems are anticipated?.(Yes (2) / No (0)) (Yes (1) / No (0))

Summary of responses to second pilot of questionnaire

Total number of questionnaires sent out to GP's for the pilot study were : 10
Response received from GP's: 7

Comments		Number
1. The length of this questionnaire is:	Too long	5
2.	Acceptable	
3.	Too short	
4. Time taken to complete this questionnaire:	10 min	
5.	15 min	3
6.	20 min	
7.	25 min	
8.	30 min	

Comments by GP's
1. Looks much worse than it is. Might be better to slim down additional "non-question material". Do prize draws get people out of bed? Keep focus on questions 1 and 2 . It is a serious topic worthy of consideration.
2. This is an excellent questionnaire. It is long but I hope GP's will respond as it will make a difference to the service providers. Your covering letter makes this clear. I have just submitted an application for money to set up a formal GP education programme in palliative care for South Glasgow (in conjunction with Dr Sheila McGettrick at the hospice). Your results will be very informative when it comes to decide priority areas of education. I am on the GGNHSB palliative care forum run by Dr Womersley so I am sure it would be OK to send me a copy of your results/replies when you have them - if it is OK with you of course. In the questionnaire to give the option to "circle" more than one if desired on page 1.
3. Too long by mile (time taken 15-20 min)?
4. I think this questionnaire is good as far as it goes. It will take more than 10 min to complete. This took me about 20 min. I would be surprised, though, if there was a large return from GP's.
5. Many of the categories are confusingly similar. What do you mean by a palliative care specialist, is this a doctor, a nurse or could it be either. There doesn't seem to be any system for replacing staff who are sick/maternity leave and patients suddenly lose their services. I have not placed a very high value on telephone advice, but in retrospect this might be helpful - and the district nursing team should be able to access this advice as well. To have a specialist DN in palliative care "as well as" a Macmillan nurse seems awfully complex and hierarchical.
6. I didn't wish to complete the questionnaire. It is too long. Asks too many possible alternatives. Is not appealing to the eye. Would be better set out with more space than questions.
7. Too long. (but sent back a fully completed questionnaire).
8.

Total number of questionnaires sent out to Nurse's for this pilot study were : 10
Response received from Nurses: 8

Results.		Number
1. The length of this questionnaire is:	Too long	
2.	Acceptable	7
3.	Too short	
4. Time taken to complete this questionnaire:	10 min	
5.	15 min	3
6.	20 min	1
7.	25 min	1
8.	30 min	1
9.	40 min	1

Comments by DN's
1. Macmillan nurse and only visit cancer patients.
2. I am not a district nurse. I am a Macmillan nurse so I felt some of it was not relevant to myself. It may be worth checking who you are sending your questionnaires to. I do not see any other patients than Cancer patients. Good luck with your study.
3. I think the questions are suitable and relevant. I think it may be helpful to add another choice to Q's 4 & 5 including Community.
4. Completed the full questionnaire but did not give any comments.
5. Questionnaire a valuable tool, and I believe if nurses have the time to read, understand and fill it in, the information would be most valuable to structure care for these most vulnerable patients.
6. a) If confidential - why ask for the name? b) Why is age and sex asked for? Is it appropriate? c) Who is the Palliative Medicine Specialist - is it the consultant? d) Question II - is the no experience section required? You don't have to have experience of something to determine its importance (? Knowledge of this should be sufficient to determine importance). You might not have come across some of the listed problems. However you may still feel that these are highly important. I feel that all these will be put down as important or very important. Surely resources will not allow all these services to be improved. Therefore would it be useful to have a section numbering these in order of priority from 1-19. e) Question III m - are services different for ethnic minorities? Question III n - I don't think access is a problem for young adults. The problem is that hospices are usually full of older people. Therefore younger patients are reluctant to go. The problem is service provision and perhaps the only answer is building a hospice for young adults or a section within a hospice for young adults or improve support at home. (so it is Service Provision that needs to be improved not Access) perhaps this question should be re-worded like Question "p" (this would seem more appropriate). f) Overall this appears to be a good questionnaire and covering letter. I hope these comments are useful.
7. More training is required for community staff. There is a long waiting list for beds in the hospice.
8. I think it is important to give patients a contact name and number even if they do not require nursing care at present.

APPENDIX 10.

Main study questionnaire for GPs and district nurses

CONFIDENTIAL

PALLIATIVE CARE SERVICES
in
GREATER GLASGOW HEALTH BOARD.

GENERAL PRACTITIONERS' and DISTRICT NURSES'

views and perceptions

on PRESENT and FUTURE services.

«Title» «Initial» «Surname»
«Address1»
«Address2» «Address3»
«Post_Code»

Dear «Title» «Surname»

General Practitioner and District Nurse Survey on Palliative Care Services (part of a Palliative Care needs assessment) in the Greater Glasgow Health Board Area.

Greater Glasgow Health Board is in the process of planning and implementing a Palliative Care Service. As part of this we are looking at the views of General Practitioners and District Nurses. We would therefore be most grateful if you could kindly complete the enclosed questionnaire and return it at your earliest convenience in the S.A.E. provided.

By completing this questionnaire, spending *15-20 minutes* of your time *Now*, You will:

1. **Influence the form of Palliative Care Service development in GGNHSB.**
2. **Benefit *your patients* in the *Future.***
3. **Ensure that you receive a summary of the survey findings.**

The serial numbers written on the bottom left hand corner of the S.A.E. are to help me with the analysis of the data and also to enable me to send the study findings to those who have requested them. The confidentiality of all respondents will be maintained at all times. No names or identifiable characteristics of the respondents will be mentioned in any report or published papers from this survey. The S.A.E. will be shredded on receipt.

Thank you.

Yours sincerely

Dr. Yoga Velupillai
Researcher
Public Health Dept.
Glasgow University

Professor Jim McEwen
Henry Mechan Chair of Public Health
and Head of Department
Glasgow University

Professor John Welsh
Head of Department
Palliative Medicine
Glasgow University

The definitions of Palliative Care for this survey.

Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Paramount is the control of pain and the control of other symptoms including psychological, social and spiritual problems. The goal of palliative care is the achievement of the best possible QoL for the patients and their families. Palliative care is not associated exclusively with terminal care or with cancer care. Many patients need it early in the course of their disease, sometimes from the time of diagnosis.

At present, many patients do not receive palliative care for recurrent or advanced disease although this has been shown to be effective. In many cases patients, their relatives and carers are unaware of the sources of support available to them.

Conditions requiring *palliative care* are *chronic, progressive* and *incurable* diseases. They consist of the following two groups:

a) Cancer conditions.

b) non-cancer conditions:

i) Conditions of the immune system:	AIDS and HIV.
ii) Conditions of the nervous system:	multiple sclerosis; motor neurone diseases; Dementia; Parkinsonism & Huntington's disease.
iii) Advanced chronic progressive conditions:	Respiratory, Cardiac, Renal and Liver conditions and Rheumatoid Arthritis.
iv).Conditions of Childhood:	Cystic fibrosis and hereditary, congenital & metabolic disorders (e.g. muscular dystrophy, cardiac abnormalities).

Palliative Medicine Specialist **is a Medical Doctor trained in Palliative Medicine and eligible for the Specialist register.**

Palliative Care Specialist **is usually a Registered Nurse trained in Palliative Care or a specially trained Professional Allied to Medicine (PAM).**

Specialist Palliative Care Team is a multidisciplinary team comprising health care professionals trained in palliative care. The team may be based in a hospice or acute hospital trust.

General Practitioner and District Nurse Survey on Palliative Care Services in the Greater Glasgow Health Board Area.

Please circle the appropriate answers where applicable.

Age group: 20-29 / 30-39 / 40-49 / 50-59 / 60-69.
Sex: M / F

Current Post: ______________________________

1. Have you ever attended a course in Palliative Care? .... (Yes / No).
1a. Have you attended conferences / seminars in Palliative Care in the last year? (Yes/No).
2. Would you find it useful to have more information on Palliative Care? .(Yes / No).

3. Would you find it useful to have more training in Palliative Care? .. (Yes / No).

If yes, what form would you like this to take? Seminar .... (Yes / No).
Tutorials .... (Yes / No).
Hospice attachment. (Yes / No).
Written information. (Yes / No).

Others...........

Your views on current services.

I : In the table below, please indicate ***your views from your experience*** on the currently available Palliative Care Services.
If you ***have used*** the service listed in the left column, then ***circle the Y*** in the ***first column in that section,*** and then continue to tick ***one box*** in the other two columns in that section.
If you ***have not used*** the service listed in the left column, then ***circle the N*** in the ***first column in that section,*** and then proceed to ***the next section/row.***
Please repeat this for all the 16 rows.

SERVICES	For cancer patients			For non-cancer patients		
	Have Used	**Adequate**	**Inadequate**	**Have Used**	**Adequate**	**Inadequate**
1. Palliative Outpatient service in ***hospital.***	*Y/N*			*Y/N*		
2. Palliative Outpatient service in ***hospice.***	*Y/N*			*Y/N*		
3. Palliative Medicine specialist in ***hospice.***	*Y/N*			*Y/N*		
4. Palliative Medicine specialist in ***hospital.***	*Y/N*			*Y/N*		
5. Palliative Medicine specialist for ***home visits.***	*Y/N*			*Y/N*		
6. Palliative Day-care in the ***hospice.***	*Y/N*			*Y/N*		
7. Palliative Home-care by ***district nurses.***	*Y/N*			*Y/N*		
8. Palliative Home care by ***Marie Curie Community nursing service.***	*Y/N*			*Y/N*		
9. Palliative Home-care by ***Marie Curie Home care Sisters.***	*Y/N*			*Y/N*		
10.Palliative Home-care by ***Macmillan community nurses.***	*Y/N*			*Y/N*		
11.Home help by the Social services.	*Y/N*			*Y/N*		
12.Social workers from the Social services department.	*Y/N*			*Y/N*		
13.Occupational therapist from the Social services department.	*Y/N*			*Y/N*		
14.Access to equipment from the Social services.	*Y/N*			*Y/N*		
15.Access to equipment from the health board.	*Y/N*			*Y/N*		
16.Telephone advice (24 hours) for palliative care issues.	*Y/N*			*Y/N*		

Your views on future services

II:. We are attempting to prioritise the services mentioned in this table. Please indicate the ***importance*** that you would like to see given to each of the following ***when planning future services.*** If you were given ***finite resources***, where would you put the ***emphasis?***

Please tick ***one box*** for ***cancer patients*** and ***one box*** for ***non-cancer patients*** on each of the 16 rows.

1* = Very important / High priority. **3* = Fairly unimportant / Low priority.**
2* = Fairly important / Moderate priority. **4* = Unimportant / Very low priority.**

SERVICES	For cancer patients				For non-cancer patients			
	1	2	3	4	1	2	3	4*
1. Palliative Outpatient service in *hospital.*								
2. Palliative Outpatient service in ***hospice.***								
3. Palliative Medicine specialist in the ***hospice.***								
4. Palliative Medicine specialist in *hospital.*								
5. Palliative Medicine specialist for ***home visit.***								
6. Palliative Day-care in the ***hospice.***								
7. Palliative Home-care by ***district nurses.***								
8. Palliative Home care by ***Marie Curie Community nursing service.***								
9. Palliative Home-care by ***Marie Curie Home care Sisters.***								
10.Palliative Home-care by ***Macmillan community nurses.***								
11.Home help by the Social services.								
12.Social workers from the Social services department.								
13.Occupational therapist from the Social services department.								
14.Access to equipment from the Social services.								
15.Access to equipment from the health board.								
16.Telephone advice (24 hours) for palliative care issues.								

III: Please read the following statements and then *circle* the most appropriate answer in your opinion.

The codes are **1 = Very Important / High Priority.**
2 = Fairly Important / Moderate Priority.
3 = Fairly Unimportant / Low Priority.
4 = Unimportant / Very Low Priority.

a). Hospital consultants who wish to refer patients to a hospice service should consult the GP first.

1 2 3 4

b). The general practitioner should co-ordinate the provision of palliative care, with others being brought in to supplement the primary care team in providing additional support, advice, guidance and care where appropriate.

1 2 3 4

c). General practitioners ideally need protected time to deal competently and sensitively with this patient group and their families.

1 2 3 4

d). Community and practice nursing staff require further training in palliative care.

1 2 3 4

e). In health centres and/or localities one or more nurses trained in palliative care should be encouraged to develop this as a special interest.

1 2 3 4

f). The nurse above (e) trained in palliative care should provide assessment, advice about symptom control, and be involved in promoting psychosocial well being.

1 2 3 4

g). Access to hospice and specialist palliative care services by members of ethnic minority communities, requires to be improved.

1 2 3 4

h). Access to hospice and specialist palliative care services by young adults (particularly those in the 16-24 year age group) requires to be improved.

1 2 3 4

i). Access to hospice and specialist palliative care services of people with learning difficulties requires to be improved.

1 2 3 4

j). There should be routine formal assessment of bereaved carers to identify those at high risk.

1 2 3 4

k). After formal assessment bereaved carers should have access to information on the full range of bereavement services available.

1 2 3 4

l). Pharmacists should be encouraged to work closely with patients and their families to advice on drug regimens.

1 2 3 4

m). There should be greater liaison with pharmacists and general practitioners where drug regimens may be causing confusion for the patients and their relatives.

1 2 3 4

IV a. From your experience, has a ***bed been available*** when an ***admission*** to a ***Hospice*** has been requested for ***Palliative Care***?

Always Usually Rarely Never No experience

Do you have any other comments on the ***availability of beds in Hospices***?

____

IV b: From your experience, has a ***bed been available*** when an ***admission*** to a ***Hospital*** has been requested for ***Palliative Care***?

Always Usually Rarely Never No experience

Do you have any other comments on the ***availability of Hospital beds***?

____

V: ***In your opinion*** where would ***your terminally ill patients*** prefer to die? Please ***rank*** the following in order of importance ***[1 = most important and 4 = least important]:***

Home ....(________)
Hospital ....(________)
Hospice ....(________)
Nursing home ....(________)

VI: Mention ***three main obstacles***, which prevent ***your patients dying*** in the ***setting*** of ***their choice***.

1. ______________________________________
2. ______________________________________
3. ______________________________________

VII: When do you think ***patients*** with ***incurable disease*** should be ***referred*** for the ***FIRST time*** to the *Specialist Palliative Care Team?*

(Please complete all the options).

i) At diagnosis?..(Yes / No)
ii) When symptom control is difficult?..................(Yes / No)
iii) When future problems are anticipated?.............(Yes / No)
iv) When the family can no longer cope?.............(Yes / No)
v) When death is imminent?................................(Yes / No)

VIII: From memory how many ***patients*** with ***Palliative Care needs*** have you ***cared for*** in the ***last one year***?

Cancer cases:	**0**	**1 - 5**	**6 - 10**	**11 - 15**	**16 - 20**	**> 20.**
Non-cancer cases:	**0**	**1 - 5**	**6 - 10**	**11 - 15**	**16 - 20**	**> 20.**

IX: Please add below any other comments you would like to make.

Please send me a copy of the results of this questionnaire ***Yes / No.***

Thank you.

Thank you very much for your help.

Please return in the enclosed SAE

For any inquiry please contact:

Dr Yoga Velupillai,
2 Lilybank Gardens,
Department of Public Health,
Glasgow University, G12 8RZ.
Tel. No: 0141 330 6501.

APPENDIX 11

Views of GP's and DN's on current services for cancer patients in the GGNHSB area.

CURRENT SERVICES (responses of GP's in BOLD and DN's not in bold)	Have used (Y = Yes / N = No, 9 = non-respondents)	Y = Adequate / N = Inadequate/ 8 = not applicable / 9 = non-respondents.
1. Palliative Outpatient service in *hospital.*	**Y 142 [56%]/N 114 [44%] 9 (16).** Y 139 [50%]/N 138 [50%] 9 (31). P = .222	**Y 98 [73%]/N 36 [27%] 8 (114) 9 (24).** Y 91 [73%]/N 34 [27%] 8 (138) 9 (45).. p = .952
2. Palliative Outpatient service in *hospice.*	**Y 246 [93%]/N 18 [7%] 9 (8).** Y 197 [69%]/N 87 [31%] 9 (24). P = .000	**Y 214 [93%]/N 16 [7%] 8 (18) 9 (24).** Y 167 [93%]/N 13 [7%] 8 (87) 9 (41). P = .917
3. Palliative Medicine specialist in *hospice.*	**Y 255 [96%]/N 10 [4%] 9 (7).** Y 185 [66%]/N 97 [34%] 9 (26). P= .000	**Y 231 [97%]/N 8 [3%] 8 (10) 9 (23).** Y 161 [96%]/N 7 [4%] 8 (97) 9 (43). P = .666
4. Palliative Medicine specialist in *hospital.*	**Y 119 [46%]/N 140 [54%] 9 (13).** Y 108 [40%]/N 164 [60%] 9 (36). P = .146	**Y 94 [87%]/N 14 [13%] 8 (140) 9 (24).** Y 73 [71%]/N 30 [29%] 8 (164) 9 (41). P = .004
5. Palliative Medicine specialist for *home visits.*	**Y 210 [81%]/N 50 [19%] 9 (12).** Y 171 [61%]/N 111 [39%] 9 (26). P = .000	**Y 181 [92%]/N 16 [8%] 8 (50) 9 (25).** Y 129 [85%]/N 23 [15%] 8 (111) 9 (45). P = .039
6. Palliative Day-care in the *hospice.*	**Y 231 [88%]/N 32 [12%] 9 (9).** Y 218 [78%]/N 63 [22%] 9 (27). P = .002	**Y 208 [96%]/N 8 [4%] 8 (32) 9 (24).** Y 179 [91%]/N 18 [9%] 8 (63) 9 (48). P = .023
7. Palliative Home-care by *district nurses.*	**Y 254 [97%]/N 9 [3%] 9 (9).** Y 246 [87%]/N 36 [13%] 9 (26). P = .000	**Y 225 [96%]/N 10 [4%] 8 (9) 9 (28).** Y 185 [85%]/N 33 [15%] 8 (36) 9 (54). P = .000
8. Palliative Home care by *Marie Curie Community nursing service.*	**Y 230 [88%]/N 32 [12%] 9 (10).** Y 254 [88%]/N 34 [12%] 9 (20). P = .883	**Y 195 [91%]/N 19 [9%] 8 (32) 9 (26).** Y 198 [87%]/N 30 [13%] 8 (34) 9 (46). P = .152
9. Palliative Home-care by *Marie Curie Home care Sisters.*	**Y 216 [85%]/N 38 [15%] 9 (18).** Y 229 [80%]/N 57 [29%] 9 (22). P = .130	**Y 181 [92%]/N 15 [8%] 8 (38) 9 (38).** Y 177 [87%]/N 27 [13%] 8 (57) 9 (47). P = .069
10. Palliative Home-care by *Macmillan community nurses.*	**Y 237 [91%]/N 24 [9%] 9 (11).** Y 183 [65%]/N 97 [35%] 9 (28). P = .000	**Y 189 [88%]/N 26 [12%] 8 (24) 9 (33).** Y 132 [82%]/N 29 [18%] 8 (97) 9 (50). P = .108
11. Home help by the Social services.	**Y 246 [94%]/N 17 [6%] 9 (9).** Y 252 [88%]/N 36 [12%] 9 (20). P = .016	**Y 124 [56%]/N 99 [44%] 8 (17) 9 (32).** Y 96 [43%]/N 126 [57%] 8 (36) 9 (50). P = .009
12. Social workers from the Social services department.	**Y 190 [73%]/N 72 [27%] 9 (10).** Y 210 [75%]/N 72 [25%] 9 (26). P = .607	**Y 77 [44%]/N 100 [56%] 8 (72) 9 (23).** Y 79 [41%]/N 112 [59%] 8 (72) 9 (45). P = .678
13. Occupational therapist from the Social services department.	**Y 159 [62%]/N 99 [38%] 9 (14).** Y 220 [79%]/N 60 [21%] 9 (28). P = .000	**Y 52 [36%]/N 92 [64%] 8 (99) 9 (29).** Y 115 [58%]/N 85 [42%] 8 (60) 9 (48). P = .000
14. Access to equipment from the Social services.	**Y 200 [76%]/N 62 [24%] 9 (10).** Y 222 [79%]/N 58 [21%] 9 (28). P = .408	**Y 51 [28%]/N 129 [72%] 8 (62) 9 (30).** Y 66 [33%]/N 132 [67%] 8 (58) 9 (52). P = .294
15. Access to equipment from the health board.	**Y 153 [59%]/N 105 [41%] 9 (14).** Y 261 [91%]/N 25 [9%] 9 (22). P = .000	**Y 66 [48%]/N 73 [52%] 8 (105) 9 (28).** Y 118 [51%]/N 114 [49%] 8 (25) 9 (51). P = .529
16. Telephone advice (24 hours) for palliative care issues.	**Y 65 [25%]/N 196 [75%] 9 (11).** Y 66 [24%]/N 212 [76%] 9 (30). P = .753	**Y 52 [90%]/N 6 [10%] 8 (196) 9 (18).** Y 45 [79%]/N 12 [21%] 8 (212) 9 (39). P = .114

Views of GP's and DN's on current services for non-cancer patients in the GGNHSB area.

CURRENT SERVICES (responses of GP's in BOLD and DN's not in bold)	Have used (Y = Yes / N = No, 9 = non-respondents)	Y = Adequate / N = Inadequate/ 8 = not applicable / 9 = non-respondents.
1. Palliative Outpatient service in *hospital.*	**Y 53 [23%]/N 181 [77%] 9 (38).** Y 75 [30%]/N 173 [70%] 9 (60). P = .059	**Y 26 [53%]/N 23 [47%] 8 (181) 9 (42).** Y 48 [69%]/N 22 [31%] 8 (173) 9 (65). P = .086
2. Palliative Outpatient service in *hospice.*	**Y 58 [25%]/N 179 [75%] 9 (35).** Y 73 [29%]/N 175 [71%] 9 (60). P = .219	**Y 48 [89%]/N 6 [11%] 8 (179) 9 (39).** Y 44 [69%]/N 20 [31%] 8 (175) 9 (69). P = .009
3. Palliative Medicine specialist in *hospice.*	**Y 62 [26%]/N 175 [74%] 9 (35).** Y 61 [25%]/N 182 [75%] 9 (65). P = .791	**Y 54 [95%]/N 3 [5%] 8 (175) 9 (40).** Y 44 [82%]/N 10 [18%] 8 (182) 9 (72). P = .030
4. Palliative Medicine specialist in *hospital.*	**Y 28 [12%]/N 204 [88] 9 (40).** Y 56 [23%]/N 183 [77%] 9 (69). P = .001	**Y 13 [54%]/N 11 [46%] 8 (204) 9 (44).** Y 29 [58%]/N 21 [42%] 8 (183) 9 (75). P = .755
5. Palliative Medicine specialist for *home visits.*	**Y 18 [8%])N 212 [92%] 9 (42).** Y 59 [24%]/N 185 [76%] 9 (64). P = .000	**Y 12 [75%]/N 4 [25%] 8 (212) 9 (44).** Y 29 [59%]/N 20 [41%] 8 (185) 9 (74). p = .255
6. Palliative Day-care in the *hospice.*	**Y 38 [17%]/N 190 [83%] 9 (44).** Y 77 [32%]/N 166 [68%] 9 (65). P = .000	**Y 29 [81%]/N 7 [19%] 8 (190) 9 (46).** Y 48 [69%]/N 22 [31%] 8 (166) 9 (72). P = .190
7. Palliative Home-care by *district nurses.*	**Y 127 [54%]/N 107 [46%] 9 (38).** Y 185 [73%]/N 70 [27%] 9 (53). P = .000	**Y 113 [95%]/N 6 [5%] 8 (107) 9 (46).** Y 145 [89%]/N 18 [11%] 8 (70) 9 (75). P = .074
8. Palliative Home care by *Marie Curie Community nursing service.*	**Y 32 [14%]/N 199 [86%] 9 (41).** Y 72 [29%]/N 176 [71%] 9 (60). P = .000	**Y 24 [86%]/N 4 [14%] 8 (199) 9 (45).** Y 41 [64%]/N 23 [36%] 8 (176) 9 (68). P = .036
9. Palliative Home-care by *Marie Curie Home care Sisters.*	**Y 28 [13%]/N 196 [87%] 9 (48).** Y 51 [21%]/N 196 [79%] 9 (61). P = .018	**Y 20 [87%]/N 3 [13%] 8 (196) 9 (53).** Y 31 [66%]/N 16 [34%] 8 (196) 9 (65). P = .064
10. Palliative Home-care by *Macmillan community nurses.*	**Y 35 [15%]/N 192 [85%] 9 (45).** Y 36 [15%]/N 200 [85%] 9 (72). P = .961	**Y 25 [83%]/N 5 [17%] 8 (192) 9 (50).** Y 22 [71%]/N 9 [29%] 8 (200) 9 (77). P = .251
11. Home help by the Social services.	**Y 190 [79%]/N 50 [21%] 9 (32).** Y 234 [89%]/N 28 [11%] 9 (46). P = .002	**Y 83 [48%]/N 91 [52%] 8 (50) 9 (48).** Y 97 [46%]/N 113 [54%] 8 (28) 9 (70). P = .768
12. Social workers from the Social services department.	**Y 166 [69%]/N 76 [31%] 9 (30).** Y 213 [82%]/N 46 [18%] 9 (49). P = .000	**Y 59 [39%]/N 93 [61%] 8 (76) 9 (44).** Y 84 [44%]/N 109 [56%] 8 (46) 9 (69). P = .378
13. Occupational therapist from the Social services department.	**Y 156 [66%]/N 79 [34%] 9 (37).** Y 212 [83%]/N 45 [17%] 9 (51). P = .000	**Y 52 [37%]/N 90 [63%] 8 (79) 9 (51).** Y 83 [44%]/N 108 [56%] 8 (45) 9 (72). P = .209
14. Access to equipment from the Social services.	**Y 166 [70%]/N 73 [30%] 9 (33).** Y 209 [81%]/N 50 [19%] 9 (49). P = .004	**Y 39 [26%]/N 111 [74%] 8 (73) 9 (49).** Y 54 [29%]/N 133 [71%] 8 (50) 9 (71). P = .557
15. Access to equipment from the health board.	**Y 109 [46%]/N 128 [54%] 9 (35).** Y 233 [90%]/N 27 [10%] 9 (48). P = .000	**Y 41 [42%]/N 57 [58%] 8 (128) 9 (46).** Y 100 [48%]/N 109 [52%] 8 (27) 9 (72). P = .325
16. Telephone advice (24 hours) for palliative care issues.	**Y 22 [9%]/N 212 [91%] 9 (38).** Y 35 [14%]/N 211 [86%] 9 (62). P = .102	**Y 14 [82%]/N 3 [18%] 8 (212) 9 (43).** Y 20 [67%]/N 10 [33%] 8 (211) 9 (67). P = .248

APPENDIX 12

Views of GP's and DN's on future services in palliative care in the GGNHSB area for cancer patients

FUTURE SERVICES	For cancer patients.					
(responses of GP's in BOLD and DN's not in bold)	p =	1*	2*	3*	4*	9
1. Palliative Outpatient service in *hospital.*	.000	**82 (32%)** 165 (57%).	**108 (42%)** 100 (35%).	**44 (17%)** 18 (6%).	**21 (8%)** 5 (2%).	**17** 20
2. Palliative Outpatient service in ***hospice.***	.039	**186 (72%)** 240 (82%).	**59 (23%)** 46 (16%).	**9 (4%)** 4 (1%).	**3 (1%)** 2 (1%).	**15** 16
3. Palliative Medicine specialist in the ***hospice.***	.235	**210 (82%)** 255 (87%).	**38 (15%)** 32 (11%).	**7 (3%)** 3 (1%).	**2 (1%)** 2 (1%).	**15** 16
4. Palliative Medicine specialist in ***hospital.***	.000	**106 (41%)** 189 (65%).	**95 (37%)** 84 (29%).	**40 (16%)** 12 (4%).	**15 (6%)** 4 (1%).	**16** 19
5. Palliative Medicine specialist for ***home visit.***	.000	**146 (57%)** 226 (77%).	**81 (31%)** 58 (20%).	**29 (11%)** 7 (2%).	**2 (1%)** 2 (1%).	**14** 15
6. Palliative Day-care in the ***hospice.***	.266	**172 (67%)** 211 (73%).	**71 (28%)** 67 (23%).	**9 (4%)** 10 (4%).	**4 (2%)** 1 (0%).	**16** 19
7. Palliative Home-care by ***district nurses.***	.020	**208 (80%)** 256 (87%).	**39 (15%)** 31 (11%).	**10 (4%)** 2 (1%).	**2 (1%)** 4 (1%).	**13** 15
8. Palliative Home care by ***Marie Curie Community nursing service.***	.002	**156 (62%)** 217 (75%).	**68 (27%)** 61 (21%).	**26 (10%)** 11 (4%).	**3 (1%)** 1 (0%).	**19** 18
9. Palliative Home-care by ***Marie Curie Home care Sisters.***	.424	**159 (64%)** 201 (69%).	**66 (27%)** 73 (25%).	**22 (9%)** 16 (6%).	**2 (1%)** 2 (1%).	**23** 16
10. Palliative Home-care by ***Macmillan community nurses.***	.475	**163 (64%)** 183 (63%).	**62 (25%)** 81 (28%).	**26 (10%)** 21 (7%).	**2 (1%)** 4 (1%).	**19** 19
11. Home help by the Social services.	.104	**142 (55%)** 183 (63%).	**101 (39%)** 91 (31%).	**13 (5%)** 13 (5%).	**1 (0%)** 5 (2%).	**15** 16
12. Social workers from the Social services department.	.000	**61 (25%)** 113 (39%).	**98 (39%)** 127 (44%).	**71 (29%)** 38 (13%).	**19 (8%)** 12 (4%).	**23** 18
13. Occupational therapist from the Social services department.	.000	**79 (31%)** 147 (50%).	**111 (44%)** 112 (38%).	**56 (22%)** 25 (9%).	**7 (3%)** 8 (3%).	**19** 16.
14. Access to equipment from the Social services.	.000	**117 (47%)** 229 (78%).	**90 (36%)** 46 (16%).	**40 (16%)** 16 (6%).	**4 (2%)** 2 (1%).	**21** 15
15. Access to equipment from the health board.	.000	**96 (39%)** 261 (89%).	**100 (41%)** 27 (9%).	**40 (16%)** 4 (1%).	**8 (3%)** 3 (1%).	**28** 13
16. Telephone advice (24 hours) for palliative care issues.	.000	**86 (34%)** 201 (68%).	**94 (37%)** 62 (21%).	**56 (22%)** 28 (10%).	**18 (7%)** 2 (1%).	**18** 15

(1* = Very important/High priority. 2* = Fairly important/Moderate priority. 3* = Fairly unimportant/Low priority 4* = Unimportant/Very low priority. 9 = Non-Respondents)

Views of GP's and DN's on future services in palliative care in the GGNHSB area for non-cancer patients.

FUTURE SERVICES (responses of GP's in BOLD and DN's not in bold)	For non-cancer patients.					
	P =	1*	2*	3*	4*	9
1. Palliative Outpatient service in *hospital.*	.000	**70 (30%)** 135 (49%).	**104 (45%)** 108 (39%).	**45 (19%)** 21 (8%).	**14 (6%)** 12 (3%).	**39** 32
2. Palliative Outpatient service in *hospice.*	.035	**76 (33%)** 122 (44%).	**104 (44%)** 109 (40%).	**37 (16%)** 31 (11%).	**17 (7%)** 13 (5%).	**38** 33
3. Palliative Medicine specialist in the *hospice.*	.001	**91 (39%)** 154 (56%).	**86 (37%)** 82 (30%).	**41 (18%)** 27 (10%).	**16 (7%)** 12 (4%).	**38** 33
4. Palliative Medicine specialist in *hospital.*	.000	**72 (31%)** 162 (58%).	**99 (42%)** 81 (29%).	**46 (20%)** 27 (10%).	**17 (7%)** 8 (3%).	**38** 30
5. Palliative Medicine specialist for *home visit.*	.000	**72 (31%)** 154 (56%).	**103 (44%)** 88 (32%).	**46 (20%)** 24 (9%).	**12 (5%)** 8 (3%).	**39** 34
6. Palliative Day-care in the *hospice.*	.002	**85 (37%)** 134 (50%).	**98 (42%)** 105 (39%).	**36 (16%)** 18 (7%).	**12 (5%)** 12 (5%).	**41** 39
7. Palliative Home-care by *district nurses.*	.012	**159 (68%)** 222 (80%).	**53 (23%)** 42 (15%).	**15 (6%)** 7 (3%).	**7 (3%)** 7 (3%).	**38** 30
8. Palliative Home care by *Marie Curie Community nursing service.*	.000	**75 (33%)** 141 (52%).	**88 (39%)** 91 (34%).	**53 (23%)** 22 (8%).	**11 (5%)** 18 (7%).	**45** 36
9. Palliative Home-care by *Marie Curie Home care Sisters.*	.001	**71 (32%)** 121 (45%).	**85 (38%)** 96 (35%).	**56 (25%)** 34 (13%).	**13 (6%)** 20 (7%).	**47** 37
10. Palliative Home-care by *Macmillan community nurses.*	.001	**71 (31%)** 113 (42%).	**79 (35%)** 99 (37%).	**66 (29%)** 39 (14%).	**11 (5%)** 20 (7%).	**45** 37
11. Home help by the Social services.	.015	**135 (57%)** 197 (70%).	**84 (35%)** 70 (25%).	**15 (6%)** 10 (4%).	**3 (1%)** 5 (2%).	**35** 26
12. Social workers from the Social services department.	.000	**67 (29%)** 127 (45%).	**89 (39%)** 117 (42).	**56 (24%)** 28 (10%).	**19 (8%)** 9 (3%).	**41** 27
13. Occupational therapist from the Social services department.	.000	**83 (35%)** 154 (54%).	**100 (43%)** 107 (38%).	**44 (19%)** 17 (6%).	**8 (3%)** 6 (2%).	**37** 24
14. Access to equipment from the Social services.	.000	**107 (46%)** 213 (75%).	**92 (40%)** 58 (21%).	**27 (12%)** 9 (3%).	**6 (3%)** 3 (1%).	**40** 25
15. Access to equipment from the health board.	.000	**85 (37%)** 236 (83%).	**93 (41%)** 41 (14%).	**40 (18%)** 3 (1%).	**9 (4%)** 4 (1%).	**45** 24
16. Telephone advice (24 hours) for palliative care issues.	.000	**60 (26%)** 158 (56%).	**88 (38%)** 86 (31%).	**57 (25%)** 29 (10%).	**28 (12%)** 7 (3%).	**39** 28

(1* = Very important/High priority. 2* = Fairly important/Moderate priority. 3* = Fairly unimportant/Low priority 4* = Unimportant/Very low priority. 9 = Non-Respondents)

Appendix 13

Multiple logistic regression of GPs & district nurses results

Dependent Variable (GP/DN Future services)	Covariates	p value
1Future Cancer Services	GROUP(1)	<0.001
1Future Non-cancer Services	GROUP(1)	<0.001
2Future cancer services	Q2INFO(1)	0.011
2Future non-cancer services	GROUP(1)	0.040
	Q1ACONF(1)	0.036
3Future non-cancer services	GROUP(1)	0.004
	Q1ACONF(1)	0.003
4Future cancer services	GROUP(1)	<0.001
4Future non-cancer services	GROUP(1)	<0.001
	Q1ACONF(1)	0.027
5Future cancer Services	GROUP(1)	0.001
	Q2INFO(1)	0.014
5Future Non-cancer Services	GROUP(1)	<0.001
	Q1ACONF(1)	0.007
6Future non-cancer services	GROUP(1)	0.003
7Future non-cancer services	GROUP(1)	0.040
	Q1ACONF(1)	0.013
8Future non-cancer services	GROUP(1)	<0.001
9Future cancer services	AGE	0.024
	AGE (1)	0.012
9Future non-cancer services	GROUP(1)	0.004
10Future non-cancer services	GROUP(1)	0.001
12Future cancer services	GROUP(1)	<0.001
12Future non-cancer services	GROUP(1)	<0.001
	Q2INFO(1)	0.008
13Future Cancer Services	GROUP(1)	<0.001
	Q1ACONF(1)	0.034

Dependent Variable (GP/DN Future services)	Covariates	p value
13Future Non-cancer Services	GROUP(1)	<0.001
14Future cancer services	GROUP(1)	<0.001
14Future non-cancer services	GROUP(1)	<0.001
15Future cancer services	GROUP(1)	<0.001
15Future non-cancer services	GROUP(1)	<0.001
16Future cancer services	GROUP(1)	<0.001
	Q2INFO(1)	0.035
16Future non-cancer services	GROUP(1)	<0.001
	Q2INFO(1)	0.043

Dependent Variable (GP/DN Statements)	Covariates	p value
Statement-a	GROUP(1)	<0.001
	AGE	0.024
	AGE (1)	0.053
	AGE (2)	0.012
Statement-c	Q2INFO(1)	0.003
Statement-d	GROUP(1)	0.030
	Q2INFO(1)	0.009
Statement-e	GROUP(1)	<0.001
	AGE	0.055
	AGE (1)	0.017
	Q2INFO(1)	0.017
Statement-f	GROUP(1)	0.013
	Q2INFO(1)	0.010
Statement-g	GROUP(1)	<0.001
	Q2INFO(1)	0.033
Statement-h	GROUP(1)	<0.001
	AGE	0.037
	Q2INFO(1)	0.013
Statement-I	GROUP(1)	<0.001
	AGE	0.050
	Q2INFO(1)	0.055
Statement-j	GROUP(1)	<0.001
	AGE	0.006

Dependent Variable (GP/DN Statements)	Covariates	p value
	AGE (1)	0.016
Statement-k	GROUP(1)	<0.001
	AGE	0.008
	AGE (1)	0.004
Statement-l	GROUP(1)	<0.001
	AGE	0.026
	AGE (1)	0.014
Statement-m	GROUP(1)	<0.001
	Q2INFO(1)	0.010

Dependent Variable (GP/DN Responses on)	Covariates	p value
Hospice beds	GROUP(1)	0.008
	Q1ACONF(1)	0.011
Die in hospital	GROUP(1)	<0.001
	Q1COURSE(1)	0.024
Die in Nursing home	GROUP(1)	<0.001
	Q1COURSE(1)	0.017
Refer to specialist palliative care team - at diagnosis	GROUP(1)	<0.001
	Q1ACONF(1)	0.007
Refer to specialist palliative care team - Symptom Control difficult	GROUP(1)	0.011
	AGE	0.051
	AGE (1)	0.016
Refer to specialist palliative care team - Problem anticipated	GROUP(1)	<0.001
Refer to specialist palliative care team - death imminent	GROUP(1)	<0.001
	Q1COURSE(1)	0.041
Number of Cancer Pt. seen in last year	GROUP(1)	<0.001
	Q1ACONF(1)	0.005
Number of non-cancer Pt seen in last year	GROUP(1)	<0.001

Appendix 13a

Multiple logistic regression of patients results

Dependent Variable NHP	Covariates	p value
TIRED ALL THE TIME	ECOG	0.021
PAIN AT NIGHT	SEX(1)	0.021
	ECOG	0.024
UNBEARABLE PAIN	CARER	0.047
PAINFUL TO CHANGE POSITION	ECOG	0.020
HARD TO BEND	TYPE(1)	0.004
	ECOG	0.011
EVERYTHING IS AN EFFORT	HS	0.037
WAKES UP EARLY	HS	0.054
FINDS IT HARD TO CONTACT PEOPLE	TYPE(1)	0.004
	SEX(1)	0.053
	CARER	0.016
THE DAYS DRAG	ECOG	0.023
FINDS STAIRS OR STEPS DIFFICULT	TYPE(1)	0.020
	ECOG	0.047
FINDS IT HARD TO REACH FOR THINGS	SEX(1)	0.004
	ECOG	0.011
HAS PAIN WHEN WALKS	SEX(1)	0.047
	ECOG	0.035

Dependent Variable NHP	Covariates	p value
LOSES TEMPER EASILY	AGE	0.049
HAS PAIN WHEN STANDING	ECOG	0.043
FINDS IT HARD TO DRESS	ECOG	0.003

Dependent Variable NHP Part II	Covariates	p value
FEELS THAT LIFE IS NOT WORTH LIVING	ECOG	0.019
NEEDS HELP TO WALK OUTSIDE	TYPE(1)	0.003
HAS PAIN WHEN USING STAIRS OR STEPS	SEX(1)	0.012
WAKES UP DEPRESSED	SEX(1)	0.049
HAS PAIN WHEN SITTING	CARER	0.062
	ECOG	0.056
JOB OF WORK	TYPE(1)	0.000
LOOKING AFTER THE HOME	SEX(1)	0.009
	DEPCAT	0.060
	ECOG	0.010
HOME LIFE	TYPE(1)	0.040
INTEREST & HOBBIES	TYPE(1)	0.044

Dependent Variable POS	Covariates	p value
PAIN	SEX(1)	0.033
OTHER SYMPTOMS	TYPE(1)	0.034
SUPPORT	TYPE(1)	0.012
	HS	0.045
LIFE WORTHWHILE	TYPE(1)	0.041
	CARER	0.097
PERSONAL AFFAIRS	AGE	0.039
	ECOG	0.002

APPENDIX 16

General Practitioners Information Sheet.

Dear Dr.

My name is Yoga and I have a Masters degree in Public Health from

Glasgow University. I am attached to the Public Health and Palliative

Medicine Departments at Glasgow University where I am working towards a PhD.

My research topic is "A Community based health needs assessment in Palliative Care for chronic diseases" in Greater Glasgow Health Board Area. As part of this research **I am interviewing patients, with chronic, progressive and incurable diseases who may require palliative care, so as to identify their needs and to assess the care they are receiving.**

I have obtained ethical approval from the Greater Glasgow Community/Primary Care Local Research Ethics Committee (copy attached). The tools (which are both widely used and validated instruments) that I will be using for my interview are:

The Nottingham Health profile.

The Palliative Care Outcome Scale

The patients' identity will be protected at all times. If they do not want to be interviewed, this will of course be respected and their care will not be affected in any way. All information obtained will be fully **confidential and they will not be identified.**

This assessment will look at their **needs and the care that they are receiving from their own point of view** and I will then compare this with services currently available. This research will be essential in the **future planning** for better health services in **Palliative Care for chronic diseases** in the Greater Glasgow Health Board area.

If you have any questions or if you would like to contact me please do so at the following:

Yoga Velupillai Department of Public Health 1 Lilybank Gardens

University of Glasgow, Glasgow G12 8RZ

Tel No: 0141 330 6501 (office hours) 01236 826 427 (Home).

"A community based health needs assessment in palliative care for chronic diseases".

Your patient named ______________________________ has been identified as a potential candidate for this study. If you have no objection to me contacting them, could you please return the completed consent form in the stamped addressed envelope supplied.

Thanking you in anticipation

Yours faithfully

Yoga

Consent from General Practitioners for contacting their patient.

I have no objection to Yoga Velupillai, (PhD Student) from the Department of Public Health in Glasgow University, contacting my patient ____________________________

to request if they would be willing to be take part in the above-mentioned study.

The patients address is: ....

....

....

....

Signature ________________________________ Date ____________

Name: ________________________________

Clinic: ________________________________

____

____

APPENDIX 17

Patient information letter

Date
ADDRESS
Dear

My name is Yoga Velupillai and I have a Masters degree in Public Health from Glasgow University. I am attached to the Public Health and Palliative Medicine Departments at Glasgow University where I am working towards a PhD.

My research is on health problems and need for services for patients with various chronic diseases in the Greater Glasgow Health Board Area. As part of this research **I am interviewing a number of people to identify their needs and to assess the care they are receiving or feel that would be of benefit to them. I have spoken to your GP and have obtained permission to contact you to ask if you would agree to be involved in the study. Your involvement would be an interview, which would take place in your home at a time convenient to you.**

All information given in this interview will be treated with the **strictest of confidence.** Your identity will be protected at all times. If you do not want to be interviewed there is no problem. Should you wish to withdraw at any time, you can without having to give a reason for doing so. Your wishes will of course be respected and there will be no further contact with you. Your care will not be affected in any way. All information obtained will be fully **confidential and you will not be identified.**

This assessment will look at **your needs and the care that you are receiving from your own point of view** and I will then compare this with services currently available. This research will be essential in the **future planning** for better health services **for chronic diseases** in the Greater Glasgow Health Board area.

If you are willing to take part in this study I would be most grateful if you could sign the enclosed consent letter and return it to me in the stamped addressed envelope supplied. I will then contact you to make the necessary arrangements.

If you have any questions or if you would like to contact me please do so at the following:

Yoga Velupillai; Department of Public Health 1 Lilybank Gardens; University of Glasgow; Glasgow G12 8RZ; Tel No: 0141 330 6501 (office hours) 01236 826 427 (Home).

Thanking you in anticipation.; Yours faithfully,

Patient Consent letter.

My name is Yoga and I have a Masters degree in Public Health from Glasgow University. I am attached to the Public Health and Palliative Medicine Departments at Glasgow University where I am working towards a PhD.

My research is on health problems and need for services for patients with various chronic diseases in the Greater Glasgow Health Board Area. As part of this research **I am interviewing a number of people to identify their needs and to assess the care they are receiving or feel that would be of benefit to them. Your interview will be in your home at your convenience.**

All information given in this interview will be treated with the **strictest of confidence.** Your identity will be protected at all times. If you do not want to be interviewed there is no problem. Should you wish to withdraw at any time, you can without having to give a reason for doing so. Your wishes will of course be respected and there will be no further contact with you. Your care will not be affected in any way. All information obtained will be fully **confidential and you will not be identified.**

This assessment will look at **your needs and the care that you are receiving from your own point of view** and I will then compare this with services currently available. This research will be essential in the **future planning** for better health services **for chronic diseases** in the Greater Glasgow Health Board area.

I have read the information form. I agree to take part in this study **YES/NO**

Signed: .... Date ....

Please print your name: ....
Contact Telephone number: ....

Thank you.

APPENDIX 18

List of service providers used to determine patient's awareness

Organisation	Know about it.		Have used it		No knowledge	
Huntershill Marie Curie Centre						
St. Margaret's Hospice						
The Prince & Princess of Wales Hospice						
Macmillan Nurse						
Marie Curie Nurse						
Greater Glasgow Health Board District Nurse						
Social services – Community Care Services						
BACUP Scotland						
CRUSE Bereavement Care						
TAK TENT						
Pain Association Scotland						
Breast Cancer Care						
Sargent Cancer Care for Children						
Body Positive						
PHASE West						
Positive Steps Partnership						
Glasgow HIV-AIDS Support Group						
Multiple Sclerosis Therapy Centre						
Strathclyde Carers Forum						
Crossroads (Scotland)						
Friends for Life						
The Notre Dame Centre						
Jordanhill Counselling Unit						
Tom Allan Centre						
Hawthorn House						
The Springburn Carers Centre						
Look Good..Feel Better						
Rachel House Children's Hospice						
ENABLE						
Greater Glasgow Health Council						
The Princess Royal Trust Glasgow South West						
The Princess Royal Trust Eastend						
The Princess Royal Trust Southside						
Possil Stress Centre						
Scotland Huntington's Association						
Scotland Muscular Dystrophy Association						
Scottish Motor Neurone Disease Association						
Alzheimer Scotland						

APPENDIX 19

Codes used in SPSS for NHP & POS

Diagnosis

1 = MND; 2 = HD; 3 = MS;

4 = Lung Cancer; 5 = Breast Cancer; 6 = Colo-rectal Cancer

Type

1 = Non-cancer; 2 = Cancer

Age

1 = 20-39 years; 2 = 40-59 years; 3 = 60+ years

Sex

0 = Males; 1 = Females

Depcat

1 = Carstairs 1 & 2; 2 = Carstairs 3-5; 3 = Carstairs 6 & 7

Health Sector

1 = North-East; 2 = West; 3 = South

Carer

0 = Self;

1 = Partner;

Others were (2 = Children; 3 = Friends; 4 = Services; 5 = Others; 6 = Parent)

ECOG

0 = Normal; 1 = Light work;

2 = Self-care, no work, up >50%

3 = Limited self-care & bed or Chair >50%; 4 = Completely disabled

NHP questionnaire

- TEN (NHP) = ENERGY
  - EN1 = Tired all the time
  - EN2 = Everything is an effort
  - EN3 = Soon loses energy
- TP (NHP) = PAIN
  - P1 = Pain at night
  - P2 = Unbearable pain
  - P3 = Painful to change position
  - P4 = Has pain when walks
  - P5 = Has pain when standing
  - P6 = Is in constant pain
  - P7 = Has pain when using stairs or steps
  - P8 = Has pain when sitting
- TEM (NHP) = Emotional reaction
  - EM1 = Things are getting him down
  - EM2 = Has forgotten how to enjoy himself
  - EM3 = Feeling on edge
  - EM4 = The days drag
  - EM5 = Loses temper easily
  - EM6 = Thinks he is losing control
  - EM7 = Worry keeps him awake
  - EM8 = Feels that life is not worth living
  - EM9 = Wakes up depressed

- TSL (NHP) = Sleep
    - SL1 = Needs tablets to sleep
    - SL2 = Wakes up early
    - SL3 = Lies awake for most of the night
    - SL4 = Takes a long time to get to sleep
    - SL5 = Sleeps badly at night
- TSO (NHP) = Social isolation
    - SO1 = Feels lonely
    - SO2 = Finds it hard to contact people
    - SO3 = Cannot get close to anyone
    - SO4 = Feels he is a burden to others
    - SO5 = Finds it hard to get on with others
- TPM = Physical mobility
    - PM1 = Can walk only indoors
    - PM2 = Hard to bend
    - PM3 = Is unable to walk at all
    - PM4 = Finds stairs or steps difficult
    - PM5 = Finds it hard to reach for things
    - PM6 = Finds it hard to dress
    - PM7 = Finds it hard to stand for long
    - PM8 = Needs help to walk outside

POS questionnaires

- POS 1 = (Pain) Over the past three days, have you been affected by pain.
- POS 2 = (Other symptoms) Over the past three days, have other symptoms e.g. nausea, cough or constipation been affecting how you feel
- POS 3 = (Anxiety) Over the past three days, have you been feeling anxious or worried about your illness or treatment.
- POS 4 = (Family anxiety) Over the past three days, have any of your family or friends been anxious or worried about you.
- POS 5 = (Information) Over the past three days, how much information have you been given.
- POS 6 = (Support) Over the past three days, have you been able to share how you are feeling with your family or friends.
- POS 7 = (Life worthwhile) Over the past three days, have you felt that life was worthwhile.
- POS 8 = (Self-worth) Over the past three days, have you felt good about yourself as a person.
- POS 9 = (Wasted time) Over the past three days, how much time do you feel has been wasted on appointments relating to your healthcare, e.g. waiting around for transport or repeating tests.
- POS 10 = (Personal affairs) Over the past three days, have any practical matters resulting from your illness, either financial or personal, been addressed.

APPENDIX 20

Breakdown of the patient sampling process

	Pt. Identified	GP's						
Diagnosis		Letter sent	Replied Yes	Replied No	No Response	Pt. Died	Total reply	
MS	70	70	49	1	20		50	
MND	26	26	16	2	6	2	20	
HD	15	15	13	0	2		13	
CNS	111	111	78	3	28	2	83	
	Pt. Identified	GP's	Patients					
		Replied Yes	Letter sent	Replied No	No Response	Pt. Died	Replied Yes	Interviewed
MS	70	49	49	1	18		30	30
MND	26	16	16	1	6		9	9
HD	15	13	13	0	4		9	9
CNS	111	78	78	2	28		48	48
	Pt. Identified	GP's						
Diagnosis	Identified	Letter sent	Replied Yes	Replied No	No Response	Pt. Died	Total reply	
Lung	51	51	42	5		4	47	
Breast	29	29	26	3			29	
Colo-rectal	18	18	9	1	5	3	10	
CANCER	98	98	77	9	5	7	86	
	Pt. Identified	GP's	Patients					
		GP's said Yes	Letter sent	Replied No	No Response	Pt. Died	Replied Yes	Interviewed
Lung	51	42	41	10	16	2	14	14
Breast	29	26	26	3	8	3	12	12
Colo-rectal	18	9	9			1	8	8
CANCER	98	77	76	13	24	6	34	34

Summary of breakdown of the patient sampling process

	Pt. Identified	GP Contacted	GP said Yes	GP said No	Pt. Died	No Response	Pt. Contacted	Pt. Said Yes	Pt. said No	Pt. Died	No Response
MS	70	70	49	1		20	49	30	1		18
MND	26	26	16	2	2	6	16	9	1		6
HD	15	15	13	0		2	13	9			4
LUNG	51	51	42	5	4		41	14	10	2	16
BREAST	29	29	26	3			26	12	3	3	8
COLO-REC	18	18	9	1	3	5	9	8		1	
TOTAL	**209**	**209**	**155**	**12**	**9**	**33**	**154**	**82**	**15**	**6**	**52**

	Pt. Identified	GP Contacted	GP said Yes	GP said No	Pt. Died	No Response	Pt. Contacted	Pt. Said Yes	Pt. said No	Pt. Died	No Response
CNS	111	111	78	3	2	28	78	48	2		28
CANCER	98	98	77	9	7	5	76	34	13	6	24
TOTAL	209	209	155	12	9	33	154	82	15	6	52

APPENDIX 21

Number of CNS patients' who know of the available palliative care services

Organisation	Know about it.			Have used it			No knowledge		
	MND	HD	MS	MND	HD	MS	MND	HD	MS
Huntershill Marie Curie Centre	4	5	25	0	0	0	5	4	5
St. Margaret's Hospice	2	1	13	0	0	0	7	8	17
The Prince & Princess of Wales Hospice	4	5	21	1	0	0	4	4	9
Macmillan Nurse	3	5	22	0	0	0	6	4	8
Marie Curie Nurse	2	5	19	0	0	0	7	4	11
Greater Glasgow Health Board District Nurse	7	8	13	6	1	9	2	0	8
Social services - Community Care Services	8	6	14	5	1	7	1	2	9
BACUP Scotland	1	2	3	0	0	0	8	7	27
CRUSE Bereavement Care	1	4	9	0	0	0	8	5	21
TAK TENT	0	3	8	0	0	0	9	6	22
Pain Association Scotland	1	2	6	0	0	0	8	7	24
Breast Cancer Care	4	4	14	0	0	0	5	5	16
Sargent Cancer Care for Children	1	2	6	0	0	0	8	7	24
Body Positive	0	1	2	0	0	0	9	8	28
PHASE West	1	1	1	0	0	0	8	8	29
Positive Steps Partnership	0	1	1	0	0	0	9	8	29
Glasgow HIV-AIDS Support Group	1	2	10	0	0	0	8	7	20
Multiple Sclerosis Therapy Centre	2	3	30	0	0	0	7	6	0

Organisation	Know about it.			Have used it			No knowledge		
	MND	HD	MS	MND	HD	MS	MND	HD	MS
Strathclyde Carers Forum	2	2	5	0	0	0	7	7	25
Crossroads (Scotland)	1	4	10	1	0	2	8	5	18
Friends for Life	1	1	0	0	0	1	8	8	29
The Notre Dame Centre	1	2	4	0	0	0	8	7	26
Jordanhill Counselling Unit	1	1	2	0	0	0	8	8	28
Tom Allan Centre	1	3	7	0	0	0	8	6	23
Hawthorn House	0	1	1	0	0	0	9	8	29
The Springburn Carers Centre	0	1	3	0	0	0	9	8	27
Look Good..Feel Better	0	2	2	0	0	0	9	7	28
Rachel House Children's Hospice	2	3	7	0	0	0	7	6	23
ENABLE	0	2	6	0	0	0	9	7	24
Greater Glasgow Health Council	2	4	8	1	0	1	6	5	21
The Princess Royal Trust Glasgow South West	1	2	10	0	0	0	8	7	20
The Princess Royal Trust Eastend	1	2	2	0	0	0	8	7	28
The Princess Royal Trust Southside	2	2	2	1	0	0	7	7	28
Possil Stress Centre	0	1	2	0	0	0	9	8	28
Scotland Huntington's Association	2	9	4	0	5	0	7	0	26
Scotland Muscular Dystrophy Association	2	5	6	0	0	0	7	4	24
Scottish Motor Neurone Disease Association	9	6	7	7	0	0	0	3	23
Alzheimer Scotland	2	6	7	0	0	0	7	3	23

Number of Cancer patients' who know of the available palliative care services

Organisation	Know about it.			Have used it			No knowledge		
	Lung	Breast	Colo-rectal	Lung	Breast	Colo-rectal	Lung	Breast	Colo-rectal
Huntershill Marie Curie Centre	13	9	5	1	2	0	0	1	3
St. Margaret's Hospice	0	6	4	0	2	2	14	6	4
The Prince & Princess of Wales Hospice	5	5	4	0	1	1	9	6	3
Macmillan Nurse	5	9	6	2	3	4	7	0	2
Marie Curie Nurse	9	8	2	1	1	0	4	3	6
Greater Glasgow Health Board District Nurse	10	10	6	5	7	3	4	2	2
Social services – Community Care Services	10	10	5	6	5	1	4	2	3
BACUP Scotland	4	5	1	1	3	0	10	7	7
CRUSE Bereavement Care	0	4	2	0	1	0	14	7	6
TAK TENT	3	4	1	0	0	0	11	8	7
Pain Association Scotland	0	0	1	0	0	0	14	12	7
Breast Cancer Care	5	10	3	0	3	0	9	2	5
Sargent Cancer Care for Children	0	2	1	0	0	0	14	10	7
Body Positive	0	0	0	0	0	0	14	12	8
PHASE West	0	0	0	0	0	0	14	12	8
Positive Steps Partnership	0	1	0	0	0	0	14	11	8
Glasgow HIV-AIDS Support Group	3	4	2	0	0	0	11	8	6
Multiple Sclerosis Therapy Centre	2	2	2	0	0	0	12	10	6

Organisation	Know about it.			Have used it			No knowledge		
	Lung	Breast	Colo-rectal	Lung	Breast	Colo-rectal	Lung	Breast	Colo-rectal
Strathclyde Carers Forum	2	1	1	0	0	0	12	11	7
Crossroads (Scotland)	1	3	2	0	0	0	13	9	6
Friends for Life	1	0	0	0	0	0	13	12	8
The Notre Dame Centre	0	2	0	0	0	0	14	10	8
Jordanhill Counselling Unit	1	1	0	0	0	0	13	11	8
Tom Allan Centre	2	3	2	0	0	0	12	9	6
Hawthorn House	1	0	0	0	0	0	13	12	8
The Springburn Carers Centre	3	2	0	0	0	0	11	10	8
Look Good..Feel Better	0	1	1	0	1	0	14	10	7
Rachel House Children's Hospice	1	3	1	0	0	0	13	9	7
ENABLE	1	1	0	0	0	0	13	11	8
Greater Glasgow Health Council	3	3	2	1	1	0	11	8	6
The Princess Royal Trust Glasgow South West	2	1	2	0	0	0	12	11	6
The Princess Royal Trust Eastend	2	1	0	0	0	0	12	11	8
The Princess Royal Trust Southside	2	1	0	0	0	0	12	11	8
Possil Stress Centre	1	1	0	0	0	0	13	11	8
Scotland Huntington's Association	1	1	1	0	0	0	13	11	7
Scotland Muscular Dystrophy Association	3	1	3	0	0	0	11	11	5
Scottish Motor Neurone Disease Association	2	2	3	0	0	0	12	10	5
Alzheimer Scotland	2	2	3	0	0	0	12	10	5