Guneri, Lara Margaret (2024) *Staff experiences of delivering end-of-life care in acute hospital settings: a qualitative framework study.* D Clin Psy thesis.

https://theses.gla.ac.uk/84478/

Staff Experiences of Delivering End-of-Life Care in Acute Hospital Settings: A Qualitative Framework Study

Lara Margaret Guneri

BSc (Hons) Psychology

MSc in Applied Psychology for Children and Young People

Submitted in partial fulfilment of the requirements for the degree of

Doctorate in Clinical Psychology

School of Health and Wellbeing

College of Medical, Veterinary and Life Sciences

University of Glasgow

April 2024

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Acknowledgements

First and foremost, I would like to extend a special thanks to all those who took part in the study. It was a privilege to hear you talk about your experiences of caring for people in the last stages of their life. The individuals you care for are lucky to have you on their side. Thank you for once again making me realise that it is the conversations that we shy away from the most that we need to have; and that we need to talk about death and dying.

Thank you to my academic supervisor, Professor Andrew Gumley, for all your support and guidance – your words of encouragement helped me push through the most difficult parts of the research process. Thank you to my field supervisor, Dr Clare McGowan, whose knowledge in the research area has been extremely valuable. I would also like to thank the Specialist Palliative Care Team at the Glasgow Royal Infirmary, and especially Dr Emma Dymond for welcoming me into their team and supporting the research. Thank you to Dr Naomi White for your contributions to the initial stages of the research.

To all my friends, thank you for providing an abundance of support. I am eternally grateful to my dad, Murat, and my sister, Ayda, for always being on my side and never getting bored of hearing the word *"tez."* Onur, thank you for being you and supporting me in being me; life is better with you. Rory, I kept wishing that I could hear your tiny footsteps outside my door while writing this thesis; I miss you every day.

I dedicate this thesis to my mum Feride. Thank you for showing me that life is worth living even when you know the end is near; thank you for taking the brave decision to talk about death and dying; thank you for teaching me the importance of truly listening; thank you for setting me up on this path that I am walking. You have made me the person I am today.

Chapter 1 Systematic Review

Psychological Interventions to Support Family Caregiver of Palliative Care Patients: A Systematic Review

Prepared in accordance with the author requirements for British Journal of Psychology

https://bpspsychub.onlinelibrary.wiley.com/hub/journal/20448295/homepage/forauthors.html

Abstract

Background Informal caregivers play a central role in providing care for palliative care patients. Caregivers experience high levels of burden, psychological distress and lower levels of quality of life. However, there is currently no guidance on what psychological therapies are available or most beneficial for caregivers of palliative care patients.

Aims The current systematic review aimed to explore the effectiveness of psychological interventions directed at caregivers of palliative care patients in improving mental health, quality of life and caregiver burden at end of treatment and at follow-up.

Design and Methods The following electronic databases were searched from their inception to October 2023: CENTRAL, EMBASE (OvidSP), PsychINFO (OvidSP), MEDLINE (OvidSP), and CINAHL. Trials assessing psychological interventions against active controls, treatment-as-usual, and waiting-list controls were included. Risk of bias was assessed using the Cochrane risk-of-bias assessment tool. Results were synthesized in a narrative review.

Results 13 randomized controlled trials comprising 1898 participants qualified for final inclusion in the systematic review. There was limited and conflicting evidence of effectiveness of psychological interventions directed at caregivers of palliative care patients due to heterogeneity in the types of interventions, how they were delivered and how they were evaluated. Methodological and design limitations of studies are discussed.

Conclusion Further research should aim to involve more diverse caregiver populations, standardise reporting of outcome measures, attrition and power calculations, and should advocate for stakeholder involvement in research design. Although no single psychological

intervention can be recommended over the other, on the basis of the literature presented, caregiver needs should be assessed alongside the patient in palliative care contexts.

Introduction

Palliative care is a broad term that refers to care provided at any point in the trajectory of a life-limiting illness that aims to improve the quality of life of patients and their families, and involves the holistic delivery of physical, psychosocial, and spiritual care (World Health Organization, 2020). Informal caregivers, such as family members, play a central role in providing care for the patient, particularly in advanced illness. Around 1 in 9 adults in the United Kingdom (Carers UK, 2021), and 1 in 5 adults in the United States are unpaid family caregivers (NAC & AARP, 2020) and the demand for family caregivers steadily increases as the number of people with chronic disease or terminal illness rises. The complexity of palliative care means that the emotional distress and burden that primary family caregivers suffer under can be particularly high. Caregiving tasks in the final phase of an illness may include symptom management, emotional and spiritual support, assistance with activities of daily living, decision-making, and coordinating and attending medical appointments (Candy et al., 2011). As a result, family caregivers confront enormous physical, emotional and financial challenges while providing and co-ordinating care for their dying family members.

Such challenges and stresses, often called caregiver burden, can affect aspects of caregivers' wellbeing. Perhaps unsurprisingly, studies conducted in various contexts and settings reveal that caregivers of palliative care patients show high levels of anxiety ranging from 32% to 50% (Perpina-Galvan et al., 2019; Götze et al., 2019) and depression ranging from 29% to 59% (Götze et al., 2014; Nipp et al., 2016). Due to the complexity of caring for terminally ill patients, caregivers often report low quality of life (QoL) compared the general population (Götze et al., 2014; Götze et al., 2016). Importantly, caregiver burden, which can be conceptualised as a multidimensional response to the set of physical, mental, and socioeconomic problems experienced by those caring for dying patients, has been shown to be an important predictor for anxiety and depression (Yu et al., 2021), and reduced quality of life (Song et al., 2011). Taken together, caregivers experience high levels of burden, psychological distress and lower levels of QoL, indicating that caregiver needs should also be at the forefront of holistic palliative care delivery.

Unmet caregiver needs have been consistently cited in literature (Alam, Zimmermann & Hannon, 2020; Wang et al., 2018). Accordingly, global guidelines highlight the importance of not only targeting palliative care to patients but also caregivers (World Health Organization, 2020). However, addressing caregiver needs may not be straightforward as their needs may be broad and may change during the illness and bereavement phase. It may also be that healthcare providers not always know how or when to provide support to caregivers and may feel that this is beyond their skills and resources. Therefore, it is crucial that the evidence for strategies and interventions to support caregivers of palliative care patients to be evaluated.

One of the earliest systematic reviews of interventions for family caregivers of cancer and palliative care patients was conducted by Harding and Higginson (2003) who identified 22 intervention studies published between 1966 and 2001. A range of intervention approaches such as home care, respite care, social network strategies, problem-solving and psychoeducation interventions were identified. However, they did not report on who delivered these interventions. Overall, they concluded that there was only a small body of evidence regarding the effectiveness of interventions as the bulk of the evidence came from studies that were graded as moderate to weak in terms of rigour. Furthermore, only five of the included studies were randomised controlled trials (RCTs), most did not report outcomes, had small sample sizes and used unvalidated measures which made it difficult to conclude on the effectiveness of the interventions.

Hudson et al. (2010) conducted a systematic review of psychosocial interventions for caregivers of palliative care patients published between 2000 and 2009. They identified 14 intervention studies that included psychoeducation, coping skills and symptom management training and sleep promotion, however did not report on who delivered these interventions. They concluded that the types of interventions and the rigour of study designs had slightly increased over the last decade, yet only three RCTs met the criteria for high quality evidence. Thus, they concluded that effective ways of providing psychosocial support for family caregivers was still in its infancy.

The only meta-analysis was conducted by Candy et al. (2011) who synthesized 11 RCTs of interventions that supported caregivers of patients in the terminal phase of an illness that were published from 1872 to 2010. Only seven of the included interventions provided direct support to caregivers such as emotional support, skills training, and grief therapy and they were delivered by non-psychology health professionals. There was low quality evidence that interventions directly supporting the caregiver significantly reduced psychological distress and quality of life in the short term, yet none of the studies reported on caregiver burden. Thus, they concluded that although there was an increasing number of studies focused on caregiver interventions, the effectiveness of these interventions was still difficult to assess because of high attrition rates, short-term interventions or follow-up, selection bias, and small sample sizes.

Most recently, Chi et al. (2015) conducted a systematic review of behavioural and educational interventions that support family caregivers of end-of-life patients that were published between 2004 and 2014 and identified 14 studies. They highlighted that all interventions had developed treatment manuals which was an improvement compared to previous reviews. Most interventions were in the format of self-help interventions, and the rest were delivered by nurses or other non-psychology staff. Significant limitations such as high attrition rates, short-term interventions or follow-up, selection bias, and small sample sizes made it difficult to assess efficacy. They concluded that more rigorous RCTs were needed to replicate current effective interventions with larger samples.

Taken together, reviews to date have focused on broad-ranging caregiver interventions including; practical support, interventions that aim to increase coping skills such as providing problem solving, and interventions that aim to enhance wellbeing by providing counselling or relaxation. However, currently there is no systematic review that synthesizes evidence for psychological interventions that are based on a psychological model and delivered by professionals trained in psychology, for caregivers of palliative patients. This is perhaps unsurprising, as although central to its ethos, psychological support has often been identified as a weaker aspect of palliative care provision (Kozlov et al., 2017). Even when psychological interventions have been offered as part of palliative care its focus has mostly been on patients and not caregivers (Golijani-Moghaddam, 2014). Importantly, recent policy guidance in the UK emphasises the importance of improving psychological support in palliative care (NICE, 2019; Palliative Care Competence Framework Steering Group, 2014). However, there is currently no guidance on what psychological therapies are available or most beneficial for caregivers, therefore, a review of the effectiveness of interventions targeted at improving psychological outcomes of caregivers of palliative care patients is crucial.

Furthermore, because of limited amount of trial data, and the variability in the types of interventions and outcome measures, previous reviews have been limited in their capacity to answer important questions such as: which interventions provide greater potential benefit, how they are best delivered, and which caregivers might benefit most. Importantly, in recent years there have been improvements in the methodology of studies and more RCTs of caregiver interventions have been published and more studies have collected follow-up data, allowing the examination of long-term effects. Therefore, this systematic review sets out to evaluate the effectiveness of psychological interventions for caregivers of palliative care patients.

Research Question

In carers of palliative care patients, what is the evidence from RCTs that psychological interventions improve mental health, quality of life and caregiver burden at end of treatment and at follow-up, compared to any control?

Methods

A systematic review of RCTs was implemented using the PICO (Population, Intervention, Comparison, Outcomes) framework. The PRISMA statement (Page et al., 2021) and Cochrane Handbook for Systematic Reviews of Interventions Version 6.4 (Higgins et al.,

2023) were used as a guide for conducting and reporting this systematic review. Results were synthesised in a narrative review.

Study Identification and Search Strategy

The following electronic databases were searched from their inception to October 2023: CENTRAL, EMBASE (OvidSP), PsychINFO (OvidSP), MEDLINE (OvidSP), and CINAHL. Three categories of search terms were utilised in the search: (caregiver/carers/family/ spouse/partner/next of kin/significant other/informal caregivers/ relatives) AND (psychological intervention/treatment/therapy) AND (palliative care/end of life care/hospice care) (see Appendix 2 for search strategy). Search results were refined by relevant methodological filters used to identify RCTs by the Scottish Intercollegiate Guidelines Network (SIGN), as this enabled the retrieval of medical studies that most likely match SIGN's methodological criteria. Due to variance in reporting the nature of intervention in the titles and keywords, abstracts and full texts were hand searched to identify whether the intervention was psychological. Online trial registers were also searched to identify any relevant ongoing or recently completed trials. The reference lists of included studies, relevant systematic reviews and conference abstracts were also screened.

Eligibility Criteria

Studies were included if they were: (a) an RCT reported in full; (b) aimed at family caregivers of palliative care patients; (c) had psychological intervention as an active treatment; (d) had a no-treatment or active control condition; (e) reported psychological distress, caregiver burden, or QoL outcomes.

I. Types of Studies

Only RCTs published in full in peer reviewed journals were included in this review. RCTs are considered the ‘gold standard’ when evaluating the effectiveness of psychological interventions, and the use of RCTs in systematic reviews is strongly recommended by the Cochrane Handbook (Higgins et al., 2023). Uncontrolled trials, case studies, observational studies, and qualitative studies were not included in this review. Studies were not excluded based on publication date as per the Cochrane guidance.

II. Types of Participants

In order for studies to be included, participants included adult family carers (e.g., spouses, parents, adult children) of palliative care patients. The lack of consensus concerning the use of “palliative” and the diversity of palliative care patients has been highlighted in literature. Therefore, for the purposes of this review palliative care patients were defined as patients with a progressive, life-threatening disease with no possibility of obtaining remission or stabilisation and are receiving an interdisciplinary care approach that focuses on the quality at the end of life (van Mechelen et al., 2013).

III. Types of Interventions and Comparisons

Studies that included at least one trial arm that consisted of a psychological intervention, with at least one comparator arm (treatment as usual, waiting list control, active control) were included in the review. Psychological interventions were classed as any intervention that is designed based on a psychological model, theory or framework and is delivered by a health care professional trained in psychology, or by another health care professional (e.g.

social workers or nurses) with relevant training in the therapeutic modality or supervised by a health care professional qualified in psychology. Interventions were excluded if they were (a) patient focused; (b) designed to support carers during bereavement; (c) involving carers of patients with non-life-threatening illnesses.

IV. Outcomes

Changes in scores in caregiver QoL, psychological distress (i.e. anxiety or depressive symptoms), and caregiver burden before and after the psychological intervention were of importance for this review. If included studies conducted follow-up data collection, data from all time-points were extracted. When multiple measures were used to assess the same outcome domain, the more frequently used measure within the field was selected to improve comparability across trials. Qualitative outcome measures were excluded.

Screening

Following the initial search duplicates were removed. The titles and abstracts were then reviewed to identify any studies that clearly did not meet the inclusion criteria. An initial scope of the literature has revealed heterogeneity among the use of “palliative care.” Therefore, abstracts were hand searched to identify whether the intervention involves caregivers of palliative care patients as defined in the inclusion criteria. Finally, full texts were examined for compliance with the eligibility criteria. The screening process and any exclusions were reported on a PRISMA flow diagram including reasons for exclusion.

Data Extraction

Data from each included study was extracted independently by the main reviewer. A data extraction form was be developed using the Cochrane template. Caregiver demographics, nature of illness, intervention characteristics (e.g., modality, length, delivery format) and treatment outcomes (post-treatment and follow-up) were extracted. The accuracy of the extracted data was verified by a second reviewer for 20% of the studies.

Assessment of Risk of Bias

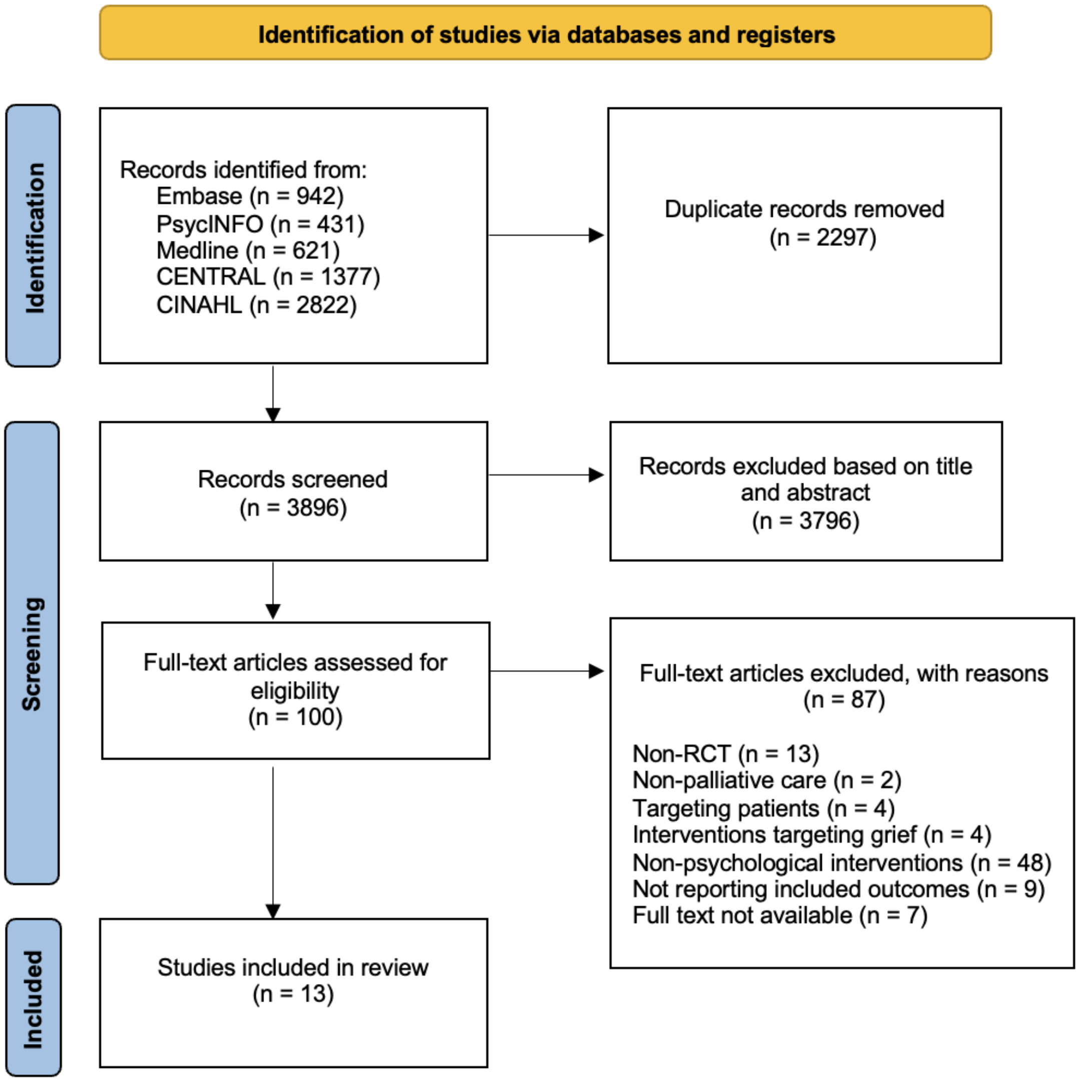
Assessment of risk of bias of included studies was assessed using The Cochrane Collaboration Risk of Bias tool (Higgins et al., 2016). The tool assesses the following elements: selection bias (randomisation process), performance bias (deviations from the intended interventions), attrition bias (missing outcome data), detection bias (measurement of the outcome) and reporting bias (selection of reported results). The results of were presented through standard tables and narrative description about each of the elements.

Results

Study Selection

Figure 1 illustrates the process by which articles were screened for inclusion using the PRISMA flow diagram (Page et al., 2021). CENTRAL, EMBASE (OvidSP), PsychINFO (OvidSP), MEDLINE (OvidSP), and CINAHL were searched from their inception to October 2023 and 6193 studies were initially identified. Following removal of duplicates, 3896 title and abstracts were screened for relevant characteristics. Of those, 3796 studies were excluded as they did not meet inclusion criteria. 100 papers were read in full for closer inspection of inclusion and exclusion criteria and 13 RCTs qualified for final inclusion in the systematic review.

Figure 1: PRISMA Flow Diagram of Included Studies



Study Characteristics

Selected characteristics of included studies are available in Table 1. Of the thirteen included RCTs, four were feasibility or pilot RCTs (Badr et al., 2015; Davis et al., 2020; Gregory & Gellis, 2020; Milbury et al., 2020). Eleven studies had two study arms, and two studies had three study arms (Demiris et al., 2019; Milbury et al., 2020). Sample sizes ranged from 37 to 514 participants. Five studies originated from the USA (Badr et al., 2015; Demiris et al., 2019; Gregory & Gellis, 2020; Milbury et al., 2020; Washington et al., 2018), two studies from Germany (Fegg et al., 2013; Kuhnel et al., 2020), two from Denmark (von Heymman et al., 2018; von Heymann et al., 2023), one from Australia (Davis et al., 2020), one from Canada (McLean et al., 2013), one from Nigeria (Onyechi et al., 2016); and one from Spain (Soto-Rubio et al., 2022).

Seven studies targeted the caregivers of cancer patients (Badr et al., 2015; von Heymann et al., 2018; McLean et al., 2013; Milbury et al., 2020; Onyechi et al., 2016; von Heymann et al., 2023; Washington et al., 2018) and the rest targeted caregivers of mixed palliative care patients including those with cancer (Davis et al., 2020; Demiris et al., 2019; Fegg et al., 2013; Gregory & Gellis, 2020; Kuhnel et al., 2020; Soto-Rubio et al., 2022).. A total of five studies were conducted in inpatient palliative care units or hospices (Davis et al., 2020; Demiris et al., 2019; Fegg et al., 2013; Kuhnel et al., 2020; Soto-Rubio et al., 2022) and the remaining eight recruited participants from outpatient or home-based settings (Badr et al., 2015; Gregory & Gellis, 2020; von Heymann et al., 2018; McLean et al., 2013; Milbury et al., 2020; Onyechi et al., 2016; von Heymann et al., 2023; Washinton et al., 2018).

Table 1 *Study and Sample Characteristics*

Author / Year / Country	Study Design and Primary Aim	Health Condition/Illness	Setting	Intervention N (Control N)	Relation to Patients (%)	% Female Intervention (Control)	Caregiver Ethnicity (%)	Outcome Measures and Time Points
Badr et al. (2015); USA	Pilot RCT (I v TAU)* To examine the feasibility, acceptability, and efficacy of a 6-session dyadic psychosocial intervention for advanced cancer patients and caregivers.	Advanced Lung Cancer	Outpatient Care	20 (19)	Partner – 51.3% Child – 30.8% Other – 17.9%	Total – 69%	NR	PROMIS; ZBI T1 – Preintervention T2 – Postintervention
Davis et al. (2020); Australia	Feasibility RCT (I v TAU)* To test the feasibility and preliminary efficacy of an Acceptance and Commitment Therapy (ACT) self-help intervention for carers of palliative care patients.	Mixed Palliative Care	Inpatient Palliative Care Unit	35 (20)	Partner – 40% Child – 27.3% Other – 29.1%	I – 77% C – 73%	NR	AAQ-II; VLQ; PG-13; HADS T1 – Preintervention T2 – 1-month follow up T3- 6-months post-loss follow up
Demiris et al. (2019); USA	3-Arm RCT (I1 v I2 v AC) To test efficacy of problem-solving therapy (PST) delivered face to face (FE2F) and via videoconferencing (VC) for hospice caregivers.	Cancer, Dementia, Cardiovascular disease, other	Hospice	171 /171 (172)	Partner – 25.3% Child – 57.3% Other – 16.7%	I_1 (F2F) – 73.1% I_2 (VC) -75.4% C – 76.7%	White – 88.3% Asian – 0.04% Hispanic – 1.46% African American – 0.04% Other – 2.63%	CQLI-R; GAD-7; PSI; CRA T1 – Preintervention T2 – Postintervention T3 – 40-day follow up
Fegg et al. (2013); Germany	RCT (I v TAU) To test the efficacy of Existential Behaviour Therapy (EBT) for informal caregivers of palliative care patients.	Cancer, Neurological disease, Other	Palliative Care Ward/Unit	69 (64)	Partner – 61.7% Child – 26.3% Other – 12%	I – 72.5% C – 67.2%	NR	BSI; SWLS; WHOQOL-BREF; PANAS T1 – Preintervention T2 – Postintervention T3- 3-month follow up T4 – 6-month follow up
Gregory & Gellis (2020); USA	Pilot RCT (I v TAU)* To examine the effects of Brief PST on caregiver quality of life, depression and problem-solving in family caregivers of hospice patients.	Cancer, Dementia, COPD, Heart disease, Other	Hospice Care at Home	18 (19)	Partner – 37.8% Child – 51.4% Other – 10.8%	I – 77.8% C– 84.2%	NR	PHQ-9; CQOLC; SPSI-R T1 – Preintervention T2 – Postintervention
Kuhnel et al. (2020); Germany	RCT (I v AC) To test the effectiveness of short-term EBT on psychological symptoms of informal caregivers of palliative care patients.	Cancer, Neurological disease, other	Palliative Care Unit	75 (82)	Partner – 39.5% Child – 4.5% Other – 56.1%	I – 68% C– 58.5%	NR	PHQ-9; GAD-7; GHQ-12; PANAS; SWLS; WHOQOL T1 – Preintervention T2 – Week 2 T3 – Week 4 T4 – 6-month follow up
McLean et al. (2013); Canada	RCT (I vs TAU) To evaluate the effects of Emotionally Focused Therapy (EFT) on marital functioning and psychosocial outcomes among couples with end-stage cancer.	Cancer	Outpatient Care	22 (20)	Partner – 100%	I – 24% C – 21%	NR	RDAS; BDI-II; BHS; CBS; RFCS T1 – Preintervention T2 – Postintervention T3 – 3-month follow up
Milbury et al. (2020); USA	3-Arm Pilot RCT (I v AC v TAU)* To test a couple-based meditation (CBM) intervention relative to a supportive-expressive	Cancer	Outpatient Care	26 / 24 (25)	Partner – 100%	I1 (CBM) – 58% I2 (SE) – 50% C – 48%	White – 78.7% Asian – 2.7% Hispanic – 12%	CES-D; IES; FACIT-SP T1 – Preintervention

	(SE) and a treatment as usual arm targeting psychospiritual distress in patients with metastatic lung cancer and their caregivers.						Black –6.7%	T2 – 1-month follow up T3 – 3-moth follow up
Onyenchi et al. (2016); Nigeria	RCT (I v AC) To examine the effects of rational emotive hospice care therapy (REHCT) on problematic assumptions, death anxiety, and psychological distress of family caregivers of cancer patients.	Cancer	Outpatient Care	26 (26)	NR	I – 84.6% C – 84.6%	NR	CPFCAQ; DAQ; K_{10} T1 – Preintervention T2 – Postintervention T3 – 1-month follow up
Soto-Rubio et al. (2022); Spain	RCT (I v WL) To explore the effects of a psychological counselling programme for family caregivers of end-of-life patients.	Cancer, Chronic Obstructive Pulmonary Disease, Frail Elderly Syndrome	Palliative Care Unit	74 (139)	Partner – 50.6% Child – 36.4% Other – 12.9%	NR	NR	HADS; ZBI-22 T1- Preintervention T2- Postintervention
Von Heymann-Horan (2018) Denmark	RCT (I v TAU) To examine the effects of dyadic psychological intervention on depression and anxiety levels of caregivers of palliative care patients.	Cancer	Palliative Care at Home	134 (115)	Partner – 78.3% Child – 13.7% Other – 8.0%	I – 63% C– 65%	NR	SCL-92 T1 – Preintervention T2 – Week 2 T3 – Week 4 T4 – Week 8 T5 – 6-month follow up
von Heymann et al. (2023); Denmark	RCT (I v TAU) To examine the effects of dyadic psychological intervention caregiver burden of caregivers of palliative care patients.	Cancer	Palliative Care at Home	134 (115)	Partner – 78.3% Child – 13.7% Other – 8.0%	I – 63% C- 65%	NR	ZBI T1 – Preintervention T2 – Week 2 T3 – Week 4 T4 – 6-month follow up
Washington et al. (2018); USA	RCT (I v TAU) To examine the impact of PST on family caregivers' anxiety, depression, and quality of life.	Cancer	Outpatient Care	42 (41)	Partner – 53.0% Child – 26.5% Other – 12.0%	Total – 68.7%	White – 92.8% Asian – 1.2% Native-American – 2.4% Black – 2.4%	GAD-7; PHQ-9; CQLI-R T1 – Preintervention T2 – Mid-intervention T3 – Postintervention T4 – 1-month follow up

Note: TAU, treatment as usual; NR, not reported; WL, waitlist control; ZBI, Zarit Burden Interview; AAQ-II, Acceptance and Action Questionnaire; VLQ, Valued Living Questionnaire; PG13, Prolonged Grief; HADS, Hospital Anxiety and Depression Scale; CQLI-R, The Caregiver Quality of Life Index; GAD-7, Generalised Anxiety Disorder Assessment; PSI, Problem Solving Inventory; CRA, Caregiver Reaction Assessment; BSI, Brief Symptom Inventory; SWLS, Satisfaction With Life Scale; World Health Organisation Quality of Life Scale; PANAS, Positive and Negative Affect Schedule; PHQ-9, Patient Health Questionnaire; CQOLC, Caregiver Quality of Life Index-Cancer; SPSI-R, Social Problem-Solving Inventory; GHQ-12, General Health Questionnaire; RDAS, Revised Dyadic Adjustment Scale; DI-II, Beck Depression Inventory; BHS, Beck Hopelessness Scale; CBS, Caregiver Burden Scale; RFCS, Relationship-Focused Coping Scale; CES-D, Center for Epidemiologic Studies Depression Scale; IES, Impact of Events Scale; FACIT-SP, Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being; CPFCAQ, Cancer Patients' and Family Caregivers' Assumptions Questionnaire; DAQ, Death Anxiety Questionnaire; K_{10}, Kessler Psychological Distress Scale; SCL-92, Symptom Checklist; CQLI-R, Caregiver Quality of Life Index.

* Studies are feasibility or pilot studies and results should be viewed critically.

Participant Characteristics

Selected participant characteristics of included studies are available in Table 1. A total sample of 1898 caregivers participated in the studies. One study did not report on caregiver gender (Soto-Rubio et al., 2022), however, 68.7% of the remaining 1685 caregivers were female. The main caregivers spouses/partners, adult children, parents or siblings, however, most of the main caregivers were spouses (54.1%). Two studies specifically targeted spouses (McLean et al., 2013; Milbury et al. 2020), and one study did not report on caregiver's relationship to the patient (Soto-Rubio et al., 2022). Only three studies reported on caregiver ethnicity (Demiris et al., 2019; Milbury et al., Washington et al., 2018), and most participants were white (88.1%).

Intervention Characteristics

Selected characteristics of included interventions are available in Table 2. Interventions included in the review showed heterogeneity in terms of intervention type, delivery method, format, and duration. Four interventions were based on Existential Therapy and aimed to help individuals adapt to their changing roles more flexibly (Fegg et al., 2013; Kuhnel et al., 2020; von Heymann-Horan et al., 2018; von Heymann 2023). Three interventions were based on Problem-Solving Therapy and focused on encouraging behaviour change in caregivers by addressing skills such as problem definition and decision making (Demiris et al., 2019; Gregory & Gellis, 2020; Washington et al., 2018). Two interventions were based on Acceptance and Commitment Therapy (ACT) and guided caregivers through experiential mindfulness techniques to develop self-compassion and gratitude, as well as allowing caregivers to reflect on their core values and engage in valued behaviour (Davis et al., 2020; Milbury et al., 2020). One intervention adopted an Emotionally Focused Therapy approach to address both the patient and caregiver's experience of terminal illness, to increase flexible communication, and strengthen attachment (McLean et al., 2013), while another intervention adapted Rational Emotive Behaviour Therapy to the cancer population, and covered strategies such as cognitive restructuring and reframing to help caregivers adjust to a terminal diagnosis (Onyechi et al., 2016). Two interventions adopted eclectic approaches; one covered teaching caregivers self-care and cognitive behavioural strategies to cope with depression and anxiety (Badr et al., 2015), and one equipped caregivers with communication and decision-making skills, as well as allowing a space to express and regulate emotions (Soto-Rubio et al., 2022).

In terms of intervention format, eight interventions were focused solely on the caregiver and were delivered on an individual basis (Badr et al., 2015; Davis et al., 2020; Demiris et al., 2019; Gregory & Gellis, 2020; Kuhnel et al., 2020; Onyechi et al., 2016; Soto-Rubio et al., 2022; Washington et al., 2018), one intervention was delivered to caregivers in a group format (Fegg et al., 2013), and four interventions targeted caregiver-patient dyads (McLean et al., 2013; Milbury et al., 2020; von Heymann-Horan et al., 2018; von Heymann et al., 2023). Most interventions were offered face-to-face, and of the remaining five interventions, two were offered over the phone (Badr et al., 2015; Davis et al., 2020); one was offered over videoconference (Milbury et al., 2020), and two gave the participants to either join over telephone, videoconference or in person (Demiris et al., 2020; Washington et al., 2018). In terms of time and frequency of the intervention, most of them were comparatively regular, where participants were offered weekly sessions ranging from 45 to 90 minutes. The total intervention times ranged from 2 hours to 22.5 hours. One intervention (von Heymann-Horan et al., 2018; von Heymann et al., 2023) offered caregivers two initial sessions followed by flexible sessions arranged based on need, thus, it was not possible to comment on total intervention time. Four interventions were relatively short-term and offered either one (Davis et al., 2020), two (Kuhnel et al., 2020), or three (Demiris et al., 2019; Washington et al., 2018) sessions.

Regarding the practitioner of interventions, five were delivered by psychologists or clinical psychology PhD students trained in the relevant therapeutic modality (Davis et al., 2020; Demiris et al., 2019; Kuhnel et al., 2020; McLean et al., 2013; Heymann-Horan et al., 2018; von Heymann et al., 2023), three were delivered by counsellors with relevant training (Badr et al., 2015; Milbury et al., 2020; Onyechi et al., 2016), one was delivered by a behavioural therapist with relevant training and supervision (Fegg et al., 2013), one was delivered by a clinical social worker (Gregory & Gellis, 2020) and one was delivered by a research nurse with training in the relevant therapeutic modality (Washington et al., 2018). One study did not report who the intervention was delivered by (Soto-Rubio et al., 2022). However, after close examination of the counselling intervention components and the theoretical background of the intervention, the reviewer agreed that the intervention fitted the psychological intervention definition, and the study was included in the review. Reporting standards for palliative care studies will be discussed in the discussion section.

Seven studies used treatment as usual as control (Badr et al., 2015; Davis et al., 2020; Fegg et al., 2013; McLean et al., 2013; von Heymann-Horan et al., 2018; von Heymann et al., 2023; Washington et al., 2018) and one study used a waiting list control (Soto-Rubio et al., 2022). Four studies used active control conditions of either "friendly calls" (Demiris et al., 2019), a caregiver education brochure (Gregory & Gellis, 2020), client-focused therapy sessions (Kuhnel et al., 2020) or counselling sessions (Onyechi et al., 2016). The remaining study employed a three-arm RCT design and used both active control which was a social support programme and treatment as usual as control (Milburry et al., 2020).

Outcome Measures

Outcome measures varied greatly among included studies with this heterogeneity impacting on grouping of outcomes within the review. Although all outcome measures used in studies are reported in Table 1, only measures of psychological distress (anxiety and depression), quality of life (QoL), and caregiver burden are of importance for this review. All studies used standardised self-report outcome measures. All studies except for three (Badr et al., 2015; Gregory & Gellis, 2020; Soto-Rubio et al., 2022) reported follow-up data ranging from 1-month to 12-months.

Five studies measured and reported quality of life (Badr et al., 2015; Demiris et al., 2019; Fegg et al., 2013; Gregory & Gellis, 2020; Kuhnel et al., 2020; Washington et al., 2018). The measurement tool used to assess QoL varied from the Caregiver Quality of Life Index-Revised (CQLI-R) (n=2); the World Health Organization Quality of Life Questionnaire (n= 2); the Satisfaction with Life Scales (SWLS) (n=1); and the Caregiver Quality of Life Index-Cancer (CQOLC) (n=1). Four studies measured and reported caregiver burden (Badr et al., 2015; McLean et al., 2013; Soto-Rubio et al., 2022; von Heymann et al., 2023), using either the Zarit Burden Interview (ZBI) (n=3) or the Caregiver Burden Scale (CBS) (n=1).

Two studies reported on psychological distress, without differentiating between anxiety and depression, using either the Hospital Anxiety and Depression Scale (HADS) (Davis et al., 2020), or the Kessler Psychological Distress Scale (K_{10}) (Onyechi et al., 2016). Seven studies measured anxiety (Badr et al., 2015; Demiris et al., 2020; Fegg et al., 2013; Kuhnel et al., 2020; Soto-Rubio et al., 2022; von Heymann-Horan et al., 2018; Washington et al., 2018). The measurement tools used to assess anxiety varied from the Generalised Anxiety Disorder Scale (GAD-7) (n=3); the Hospital Anxiety and Depression Scale (HADS) (n=1); the Symptom Checklist (SCL-92) (n=1); the Brief Symptom Inventory (BSI) (n=1); and the PROMIS anxiety scale (n=1).

Nine studies measured depression (Badr et al., 2015; Fegg et al., 2013; Gregory & Gellis, 2020; Kuhnel et al., 2020; McLean et al., 2013; Milbury et al., 2020; Soto-Rubio et al., von Heymann-Horan et al., 2018; Washington et al., 2018) using a variety of measures such as; the Patient Health Questionnaire (PHQ-9) (n=3); the Hospital Anxiety and Depression Scale (HADS) (n=1); the Brief Symptom Inventory (BSI) (n=1); Beck Depression Inventory (BDI-II) (n=1); the Center for Epidemiologic Studies Depression Scale (CES-D) (n=1); the Symptom Checklist (SCL-92) (n=1); and the PROMIS depression scale (n=1).

***Table 2** Selected characteristics of included interventions*

Author / Year	Therapeutic Modality	Treatment Arm	Control Arm	Delivered by	Delivery Method	Format	Duration of Intervention	Results				
								Caregiver Burden	**QoL**	**Psychological distress**	**Anxiety**	**Depression**
Badr et al. (2015)*	Eclectic (Cognitive Behaviour Therapy & Problem-Solving Therapy)	Novel dyadic psychosocial intervention consisting of 6 weekly counselling sessions. Self-help booklet consisting of six modules: self-care, stress and coping, symptom management, effective communication, problem-solving, and maintaining and enhancing relationships.	TAU	Trained interventionist with a master's degree in mental health counselling	Telephone	Individual	60min x 6	Y T2 (d=-2.5)	-	-	Y T2 (d=-1.3)	Y T2 (d=-1.8)
Davis et al. (2020)*	Acceptance and Commitment Therapy	Self-help booklet consisting of psychoeducation and experiential mindfulness exercises. One telephone call to support personal application of skills.	TAU	Clinical psychology PhD student with training and clinical supervision in ACT	Telephone	Individual	NR	-	-	N	-	-
Demiris et al. (2019)	Problem Solving Therapy (PST)	3 PST sessions focusing on adopting a positive attitude, defining the problem, creating alternatives, predicting consequences, and trying a solution.	AC (Standard hospice care and same number of "friendly telephone calls")	Psychologist and one social worker with 25h PST training	Face-to-face or Video-conference	Individual	45min x 3	-	Y T2 (d=0.17)	-	Y T2 (d=0.24)	-
Fegg et al. (2013)	Existential Behaviour Therapy (EBT)	6 EBT group sessions covering the following topics: mindfulness, bereavement, activating resources and finding meaning, self-care and stress management, personal values for reorientation.	TAU	Behavioural therapists with 20h training and regular supervision	Face-to-face	Group	22 hours	-	Y (effect size not reported)	-	Y (effect size not reported)	Y (effect size not reported)
Grergory & Gellis (2020)*	Problem Solving Therapy (PST)	5 sessions of Brief PST-Hospice focusing on adopting a positive attitude, defining the problem, creating alternatives, predicting consequences, and trying a solution.	AC (Caregiver education brochure)	Clinical social worker	Face-to-face	Individual	45min x 5	-	Y (effect size not reported)	-	-	Y (effect size not reported)
Kuhnel et al. (2020)	Short-term Existential Behaviour Therapy (sEBT)	2 sessions of sEBT covering mindfulness, psychoeducation on psychological meaning of resources, imaginative exercises, encouragement to express strengthening activities.	AC (Two sessions of client-focused therapy without mindfulness or resources)	Psychologists trained in behavioural psychotherapy	Face-to-face	Individual	45-60min x 2	-	N	-	N	N
McLean et al. (2013)	Emotionally Focused Therapy (EFT)	8 sessions of couple-based EFT focusing on impact of diagnosis, communication and decision-making	Treatment as Usual	Psychologist trained in EFT	Face-to-face	Dyadic	60min x 8	N	-	-	-	N

		skills, exploration of fears, role changes, and existential issues such as values.										
Milbury et al. (2020)*	Mindfulness and Acceptance and Commitment Therapy (ACT)	4 sessions of couple-based mindfulness therapy consisting of guided mindfulness techniques, self-compassion, gratitude, and reflection on core values.	AC (Four sessions of social support programme) Treatment as Usual	Licensed psychological counsellor	Videoconference	Dyadic	60min x 4	-	-	-	-	Y (d=0.74)
Onyenchi et al. (2016)	Rational Emotive Behaviour Therapy (REBT)	10 sessions of REBT adapted to the hospice care setting covering strategies such as cognitive restructuring, problem solving, acceptance, and reframing.	AC (Treatment as usual and counselling)	Guidance counsellors with training in REBT	Face-to-face	Individual	45min x 10	-	-	Y T2 ($\eta 2p$=0.95) T3 ($\eta 2p$=0.99)	-	-
Soto-Rubio et al. (2022)	Eclectic	8 sessions of counselling focusing on the identification of concerns, expressing and regulating emotions, establishing channels of communication, decision-making skills, and finding meaning in the caregiver role.	WL	NR	Face-to-face	Individual	90min x 8	Y T2 (d=3.93)	-	-	Y T2 (d=5.51)	N
Von Heymann-Horan et al. (2018)	Existential Therapy	2 initial sessions followed by flexible sessions arranged depending on need targeting psychoeducation, increasing flexibility and adapting to changing worldviews.	TAU	Psychologists with EPT training and supervision	Face-to-face	Dyadic	NR	-	-	-	Y T2 (d=-0.19) T3 (d=-0.22) T4 (d=-0.45)	N
Von Heymann et al. (2023)	Existential Therapy	2 initial sessions followed by flexible sessions arranged depending on need targeting psychoeducation, increasing flexibility and adapting to changing worldviews.	TAU	Psychologist with EPT training and supervision	Face-to-face	Dyadic	NR	N	-	-	-	-
Washington et al. (2018)	Problem Solving Therapy (PST)	3 sessions focusing on positive self-talk, identifying main problem, identifying potential solutions and developing an implementation plan.	TAU	Research nurse with PST training	Telephone / Videoconference	Individual	NR	-	N	-	Y (effect size not reported)	N

* Studies are feasibility or pilot studies and results should be viewed critically.

Effectiveness of Interventions

In two of the four studies that measured caregiver burden, caregivers in the intervention group showed statistically significant improvement in caregiver burden scores at post-treatment (Badr et al., 2015; Soto-Rubio et al., 2022). In these studies, effect sizes suggested a medium to large effect of interventions on caregiver burden outcomes. Both interventions adopted eclectic approaches covering cognitive-behavioural, problem-solving, communication and emotion regulation strategies, and were delivered individually to the caregivers. Neither study collected follow-up data which makes it difficult to comment on the long-term effectiveness of the interventions. In the remaining two studies there was no statistically significant change in caregiver burden (McLean et al., 2013; von Heymann et al., 2023).

In three of the five studies that measured quality of life, quality of life of caregivers in the intervention group improved significantly at post-treatment (Demiris et al., 2019; Fegg et al., 2013; Gregory & Gellis; 2020). Demiris et al. (2019) reported moderate-to-large effects of intervention on QoL. The remaining two studies, where a change in quality of life was observed, did not report effect sizes (Fegg et al., 2013; Gregory & Gellis; 2020). The two remaining studies did not report statistically significant change in quality of life at post-treatment (Kuhnel et al., 2020; Washington et al., 2018). Taken together, limited and mixed evidence makes it difficult to conclude on the effectiveness of psychological therapies on the quality of life of palliative caregivers.

Two studies reported on changes in caregivers' psychological distress. Rational Emotive Behaviour Therapy was effective in reducing psychological distress scores at post-intervention and 1-month follow-up compared to control (Onyechi et al., 2016). In contrast, the only other study that reported psychological distress scores did not report any significant changes at post-intervention, although at 6-month follow up caregivers showed significantly reduced psychological distress scores (Davis et al., 2020). It was difficult to conclude on the effectiveness of psychological therapies on caregiver psychological distress as evidence was limited and contrasting.

On four of the nine studies that measured caregiver depression, compared to control caregivers in the intervention group showed significantly reduced depression scores at post-intervention indicating evidence in support of eclectic (Badr et al., 2015), existential (Fegg et al., 2013), problem-solving (Gregory & Gellis, 2020) and ACT (Milbury et al., 2020) approaches. However, studies by Badr et al. (2015), Gregory and Gellis (2020), and Milbury et al. (2020) were pilot studies and did not report power calculations, thus, results should be viewed with care. In one study investigating the effectiveness of existential therapy, although no significant overall intervention effect for symptoms of depression were observed, caregivers in the intervention group experienced significantly lower symptoms of depression than caregivers in the control group at 8-week and 60-months follow up (von Heymann-Horan et al., 2018). Four studies found no significant differences on depression scores between the intervention and control group at any time point (Kuhnel et al., 2020; McLean et al., 2013; Soto-Rubio et al., 2022; Washington et al., 2018). Taken together, current evidence does not allow us to make conclusions about which psychological therapies may be most beneficial in alleviating caregiver depression symptoms.

In five of the seven studies that measured anxiety, caregivers in the intervention group showed significantly reduced anxiety at post-intervention indicating evidence in support of eclectic (Badr et al., 2015; Soto-Rubio et al., 2022), problem-solving (Demiris et al., 2019) and existential (Fegg et al., 2013; von Heymann-Horan et al., 2018) approaches. Four of these studies reported effect sizes which indicated that the interventions had a low-to-large effect on anxiety scores. Although Badr et al. (2020) reported a large effect size, they did not report power calculations, thus results should be viewed with care. In one study that collected follow-up data, compared with the control group, caregivers in the intervention group showed significantly reduced anxiety at post-intervention, 8-week and 6-month follow-up (von Heymann-Horan et al., 2018). Two studies found no significant differences on anxiety scores between the intervention and control group at any time point (Kuhnel et al., 2020; Washington et al., 2018). Taken together, limited and mixed evidence makes it difficult to conclude on the effectiveness of psychological therapies on reducing the anxiety of caregivers of palliative care patients.

Risk of Bias of Included Studies

All included studies were rated for risk of bias using The Cochrane Collaboration Risk of Bias tool (Higgins et al., 2016) (Figure 2). Two review authors independently assessed risk of bias of 46% of included studies. Initially, they independently assessed the RoB of one study each and met to compare how they each assessed different domains. This discussion allowed the independent reviewers to calibrate how they assess each domain, and this was used when assessing the remainder of studies.

Overall, both reviewers rated each domain in the RoB tool for each study the same, reaching consensus on all decisions.

Figure 2 'Risk of Bias' summary of included studies

Study ID	Weight	D1	D2	D3	D4	D5	Overall
Badr et al. (2015)	1	!	!	+	!	+	!
Davis et al. (2020)	1	+	!	+	!	+	!
Demiris et al. (2019)	1	+	!	+	+	+	!
Fegg et al. (2013)	1	!	+	+	!	+	!
Gregory & Gellis (2020)	1	+	+	+	+	+	+
Kuhnel et al. (2020)	1	+	+	+	!	+	!
McLean et al. (2013)	1	!	!	+	+	!	!
Milbury et al. (2020)	1	+	+	+	+	+	+
Onyechi et al. (2016)	1	!	!	+	+	+	!
Soto-Rubio et al. (2022)	1	!	!	+	!	+	!
von Heymann-Horan et al. (2018)	1	+	!	+	!	+	!
von Heymann et al. (2023)	1	!	!	+	-	+	-
Washington et al. (2018)	1	+	!	+	!	+	!

+	Low risk
!	Some concerns
-	High risk
D1	Randomisation process
D2	Deviations from the intended interventions
D3	Missing outcome data
D4	Measurement of the outcome
D5	Selection of the reported result

Seven studies described a robust method of randomization and allocation concealment and were judged as having low risk of bias (Davis et al., 2020; Demiris et al., 2019; Gregory & Gellis, 2020; Kuhnel et al., 2020; Milbury et al., 2020; von Heymann-Horan et al., 2018; Washington et al., 2018). The remaining studies provided insufficient information for us to reach a decision, so were assessed as having ‘some concerns’ (Badr et al., 2015; Fegg et al., 2013; McLean et al., 2013; Onyechi et al., 2016; Soto-Rubio et al., 2022; von Heymann et al., 2023).

Four studies were assessed as having low risk of performance bias because they reported adequate blinding processes (Fegg et al., 2013; Gregory & Gellis, 2020; Kuhnel et al., 2020; Milnury et al., 2020). Nine studies were judged to have ‘some concerns' because the studies did not provide an adequate description of the blinding procedures (Badr et al., 2015; Davis et al., 2020; Demiris et al., 2019; McLean et al., 2013; Onyechi et al., 2016; Soto-Rubio et al., 2022; von Heyamnn-Horan et al., 2018; von Heymann et al., 2023' Washington et al., 2018).

All studies were judged as having low risk of attrition bias because they reported attrition, and there were no significant differences between completers and non-completers. All studies except one (McLean et al., 2013) were assessed as having low risk of reporting bias.

Four studies were assessed as having low risk of detection bias as outcome assessors were blinded to group allocation (Demiris et al, 2019; Gregory & Gellis; McLean et al., 2013; Milbury et al., 2020; Onyechi et al., 2016). Seven studies were assessed as having 'some concerns' (Badr et al., 2015; Davis et al., 2020; Fegg et al., 2013; Kuhnel et al., 2020; Soto-Rubio et al., 2022; von Heymann-Horan et al., 2018; Washington et al., 2018). One study was assessed as having high risk of detection bias as it used an unvalidated outcome measure (von Heymann et al., 2023).

Discussion

Summary of Findings

To our knowledge this is the first review synthesising evidence from RCTs of psychological interventions aiming to improve the mental health, quality of life, and caregiver burden of caregivers of palliative care patients. Addressing family and caregiver needs is set as a priority in palliative care research (Hasson et al., 2020), however, only 13 RCTs evaluating interventions for caregivers of palliative care patients were included in this review, highlighting the need for further research in this field. However, compared to previous reviews both the quality and quantity of research on this topic has improved.

Interestingly, there was no overlap between the studies included in previous systematic reviews and meta-analyses (Candy et al., 2011; Chi et al., 2015; Harding & Higginson, 2003; Hudson et al., 2003) and the studies included in the current review. Although all reviews used similar definitions of palliative care and caregivers our detailed definition of “psychological interventions” meant that psychoeducational, behavioural, communication and skills training interventions delivered by non-psychology staff included in previous reviews were excluded from the current review. Furthermore, the exclusion of interventions that supported caregivers during bereavement meant that although based on psychological models and delivered by psychology staff, a small number of grief interventions included in previous reviews were not part of the current review. Interventions that were designed to support carers during bereavement were excluded in line with research and policy (Aoun et al., 2017; Breen et al., 2014) that encourage palliative care services to asses and support caregivers during the pre-bereavement period and to develop community referral pathways for bereavement care.

Overall, there was evidence of effectiveness of psychological interventions directed at caregivers of palliative care patients, as half of the interventions included in the review led to positive and significant improvements in caregiver mental health, QoL and caregiver burden. However, due to the limited amount of trial data, the variability in the types of interventions, how they were delivered and how they were evaluated, the review was limited in its capacity to answer questions such as: specifically which interventions provide greater potential benefit, how they are best delivered, and which caregivers may benefit the most. Results will be discussed in detail below.

Conclusions about study and participant characteristics

The relatively homogenous nature of the study samples must be noted as it may limit the generalizability of conclusions. Although all studies included in the review involved carers of patients with cancers, the majority of included studies specifically and solely focused on caregivers of patients with advanced cancer receiving palliative care. This is perhaps unsurprising, as although the WHO (2020) suggests that in addition to cancer, non-cancer illnesses should also be subject to palliative care, evidence for palliative care patients with cancer is far more advanced than the evidence for patients with non-cancer illnesses (Harrison, Kotwal & Smith, 2020). For example, in a meta-analysis of 43 RCTs of specialty palliative care interventions, 70% of the trials included patients with cancer (Kavalieratos et al., 2016). Studies have shown that the physical, psychological, social and spiritual needs of cancer and non-cancer patients may be similar (Bandeli, des Ordons & Sinnarajah, 2020; Jang et al., 2022). However, to our knowledge, there aren’t any studies that compare the needs of caregivers looking after patients with cancer and non-cancer illnesses. Taken together, our results indicate that more research looking at caregiver needs of non-cancer patients is needed before the questions of whether or not cancer and non-cancer caregivers can be pooled into the same sample in RCTs can be answered.

Significant majority of studies included in this review originated from North America, Europe and Australia. Only 23% of studies included in the review reported on caregiver ethnicity or race, whereas a recent systematic review has indicated that 32% of RCTs focused on palliative care patients report on participant ethnicity or race (Selvakumaran, Sleeman & Davies, 2024), showing that reporting standards for caregiver studies may not be up to standard. Among the studies that reported ethnicity most participants were white (88%). The homogenous sample in this review is a potential limitation but perhaps reflects reality, which is that palliative care services are rarely utilised by ethnic minorities (Jawed & Comer, 2024). Overall, the applicability of interventions covered in the review to other cultures and contexts requires further investigation. More explanatory studies that explore the psychosocial, cultural and spiritual needs of caregivers from minority backgrounds is important. Furthermore, adaptations in RCT designs such as multi-lingual or multicultural study materials and race-concordant staff (Sy et al., 2023) should be considered.

Conclusion about outcome measures

There was high heterogeneity in the outcome measures used to assess psychological wellbeing, caregiver burden, and QoL of caregivers which made it difficult to compare their effects on caregivers across the studies. The selection of appropriate outcome measures in palliative care research is problematic because of the diversity of available tools, which often have limited reliability and validity evidence in caregiving and palliative care contexts. For example, overall QoL is distinct from caregiver QoL. While overall QoL captures the general state of physical, mental, and well-being that can be attributed to any life situation, caregiver QoL focuses on the specific context of caring for a loved one (Martin, McEntee & Suri, 2021). Yet, overall QoL outcome measures are still widely used in caregiving studies included in this review (e.g., Fegg et al., 2013; Gregory & Gellis, 2020). Similarly, the majority of other outcome measures used to assess anxiety, depression, and caregiver burden were not designed originally to assess palliative caregivers. Several studies in the review used translated versions of outcome measures which were not tested for validity or reliability (Onyechi et al., 2016; von Heymann et al., 2023). Standardisation of reported outcome measures among palliative care studies is crucial for providing high quality evidence. For example, the National Palliative Care Research Centre has identified appropriate measurement and evaluation tools to use in palliative care research, however, none of the caregiver measures used in the included studies were part of those identified measures.

Conclusion about interventions

Although, results of this review do not support one intervention over the other there are important discussion points relating to interventions. Majority of the interventions were manualised and reported intervention strategies somewhat in detail. This was a strength as manualised treatments allows a template for treatment fidelity to be checked to determine whether an intervention is carried out in the way in which it was intended. However, nearly half of the studies did not check for treatment fidelity which limited the ability to attribute treatment effects to the specific intervention components. Intervention protocols for studies were not available. Importantly, one study (Soto-Rubio et al., 2020) did not report who the intervention was delivered by which is crucial in intervention trials. Accurate description of the intervention's content and delivery is crucial in terms of replicability and implementation of interventions. Future studies should report detailed intervention protocols and specific components, timing and delivery method of interventions. Such improvements will allow the examination of how specific intervention components lead to changes. Standardisation of reporting will also allow studies to be replicated in different settings, as well as aid the facilitation of interpretation of findings and comparison between interventions. Standardised templates for description of complex interventions such as TIDieR (Cotterrill et al., 2018) or CReDECI (Mohler et al., 2012) which are widely used in health research contexts, should expand to the palliative care research field.

Importantly, manualised interventions can be turned into digital health interventions that caregivers can access via technology platforms. A recent meta-review has revealed that digital health interventions in palliative care are mainly used for education, symptom management, decision making, and communication, and only a small fraction of them (4%) address caregiver support (Finucane et al., 2021). Low participation and high attrition rates in palliative care caregiver research can be attributed to overtaxed caregivers (Alam, Zimmermann & Hannon, 2020). Thus, allowing caregivers to access psychological interventions at their own time of need may be more beneficial and effective, and will allow for greater scalability of trials.

None of the studies involved stakeholders (e.g., patients, carers, or service providers) in any part of the research process. A key to increasing the relevance of the research undertaken is involving stakeholders to assist in prioritising, defining, and developing an intervention (Evans, Harding & Higginson, 2013). However, patient and carer involvement in palliative care research is less advanced compared to other areas of health and social care research (Chambers et al., 2019). Considering that addressing caregiver needs may not be straightforward as their needs may be broad ranging and may change during the period of caregiving and the bereavement phase, it is especially crucial to involve caregivers in research that explores their needs and what may be helpful or beneficial for them.

In terms of control conditions, psychological interventions were compared to an either active control, treatment as usual, or waitlist control conditions. However, control groups were often not well described, and it was unclear to which services participants routinely had access as usual palliative care treatment varies between settings (e.g., specialist palliative care unit, hospice, or outpatient settings). In contrast, nearly all of the remaining studies had a control condition that controlled for attention which was a as this allows to ensure observed changes are due to treatment effects.

Methodological Limitations

The most common limitations identified across studies were high attrition rates, short-term intervention or follow-up period, selection bias and small sample size. Long-term follow-up after intervention is an important yet often overlooked aspect of palliative care research. Palliative care is broad ranging and ideally starts at the diagnosis stage of a life-limiting condition, and depending on the nature and trajectory of the illness may be provided alongside other life-sustaining therapies to improve quality of life, but may also involve end-of-life care with a focus on making dying patients as comfortable as possible. As such the palliative care needs of patients and caregivers will be wide-ranging depending on the illness stage and trajectory (e.g., diagnosis stage vs. end-of-life stage). Thus, collecting long-term follow-up data following an intervention is important in identifying how that intervention may affect caregiver needs at different stages of the illness.

Recruitment and retention are difficult in palliative care studies, and high attrition rates in palliative care research has been reported in other reviews (Bouca-Bachado et al., 2017). Reasons for attrition were not reported in the majority of the studies. Furthermore, nearly half of the studies did not report power calculations, thus, they may have been underpowered to detect differences between groups. The use of tools to help reporting study outcomes, such as CONSORT or SPIRIT, could be a simple and efficient way of improving reporting quality.

Strengths and Limitations

The novel focus on psychological therapies for caregivers of palliative care patients was a strength of the study. A detailed search was conducted, and risk of bias was measured which were additional strengths. However, the current review only included RCTs to attempt to control for bias. However, recently, there have been debates on whether RCTs are the best method to use in palliative care research (Aoun & Nekolaichuk, 2014) and a systematic review of palliative care literature revealed that RCTs compromised only 6% of all studies, majority of which were focused on interventions for physical symptoms (Hui et al, 2012). Thus, the exclusion of non-RCT studies in this review may have resulted in the exclusion of important learning points. Future reviews may benefit from including multiple methodologies.

Recommendations for Clinical Practice

As discussed above due to the limited amount of trial data, the variability in the types of interventions, how they were delivered and how they were evaluated, the review was limited in its capacity to recommend one intervention over the other. Only four interventions showed effectiveness in all outcome domains that they were measuring (Badr et al., 2015; Demiris et al., 2019; Fegg et al., 2013; Gregory & Gellis, 2020; Milbury et al., 2). Individual eclectic therapy drawing on from CBT and PST strategies was effective in reducing caregiver burden, anxiety and depression of caregivers (Badr et al., 2015). Both longer- and shorter-term individual PST was effective in improving QoL, and redacting anxiety and depression of caregivers (Demiris et al., 2019; Gregory & Gellis; 2020). Existential behaviour therapy in group format was also effective in improving QoL, and reducing anxiety, and depression of caregivers (Fegg et al., 2020).

When looking at commonalities between these interventions it was evident that although none of them were purely CBT interventions, they all adopted cognitive and behavioural strategies aimed at increasing caregiver coping through behaviour change. All interventions aimed to increase social support by either enhancing already existing relationships or reflecting on communication skills. Interventions also involved increasing coping by introducing CBT-based problem solving skills and by activating already existing resources. In this sense all interventions were strengths-based and built on already existing resources, skills, and values caregivers had. Taken together, the evidence suggests that providing caregivers with a safe space to reflect on their current caregiver role and emotional wellbeing alongside offering them cognitive and behavioural strategies to improve social and practical coping may be beneficial.

Conclusion

Research into psychological therapies for caregivers seems to be in its infancy, and the review was unable to answer specifically which interventions provide greater benefit to caregivers. Nevertheless, on the basis of the literature presented we argue that caregivers should be part of the unit of care and their needs should be assessed alongside the patient. Although complex caregiver-specific or dyadic interventions are often not readily available (Northouse et al., 2012), palliative care teams often have multidisciplinary staff that can offer psychosocial support to caregivers. The results and suggestions of this review should serve as a roadmap for future research as addressing the gaps in caregiver research in palliative care requires systematic change.

Statements and Declarations

There was no funding associated with this review and the authors have no competing interests to declare.

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Chapter 2 Major Research Project

Staff Experiences of Delivering End-of-Life Care in Acute Hospital Settings:

A Qualitative Framework Study

Prepared in accordance with the author requirements for Qualitative Health Research

https://us.sagepub.com/en-us/nam/journal/qualitative-health-research#2.1

Plain Language Summary

Title Staff Experiences of Delivering End-of-Life Care in Acute Hospital Settings: A Qualitative Framework Study

Background End-of-life care aims to support those who are nearing the end of their lives. Many people nearing the end of their life spend time in acute settings such as hospitals. Yet, characteristics of an acute setting can be less favourable for good end-of-life care delivery, which can lead to poorer patient care. We need to understand staff experiences of caring for dying patients, and the barriers and challenges they face, so that we can suggest strategies to help improve end-of-life care in acute settings.

Aims This study aims to explore the experiences of multidisciplinary healthcare staff when caring for dying people and the barriers they face in an acute settings. This study also aims to use Normalisation Process theory, which examines how new practices get implemented in every day work, to understand how guidelines can be implemented to support end-of-life care in acute settings.

Methods The main researcher conducted semi-structured interviews with 14 multidisciplinary staff (medical staff, nursing staff, allied health professionals) delivering end-of-life care at the Glasgow Royal Infirmary. The interviews explored the views and experiences of healthcare staff when caring for dying people. We used thematic analysis to identify common themes and subthemes across the interviews. We then mapped these themes and subthemes onto the different components of NPT using framework analysis.

Main Findings and Conclusions Three overarching themes consisting of 13 subthemes captured staff perceptions of end-of-life care, barriers, and facilitators of “good” end-of-life care. Overall, staff found caring for dying people rewarding. Yet, at times it was difficult to deliver good EoL care because acute settings often had a focus on actively treating patients, which was seen as odds with end-of-life care. Using NPT, we proposed strategies to increase the confidence, knowledge and skills of staff when caring for dying patients such as having protected learning time, reviewing work structures, supporting collaborative team working, and enabling structured debrief opportunities. Limitations of the study were explored.

Abstract

Background Acute hospitals play a significant role in end-of-life (EoL) care delivery; however, characteristics of an acute setting can be less favourable for EoL care delivery, potentially leading to suboptimal care. Understanding staff experiences of delivering EoL care in acute settings is crucial in identifying barriers and facilitators of EoL care excellence, and to propose strategies to improve care delivery in such environments.

Aim This study aimed to explore the experiences of multidisciplinary healthcare staff delivering EoL care in an acute setting, and to use Normalisation Process Theory (NPT) to understand and describe the processes underpinning the implementation of EoL care in acute settings.

Design A qualitative methodology was adopted, and semi-structured interviews were conducted with 14 with multidisciplinary staff delivering EoL care at Glasgow Royal Infirmary. Thematic analysis was used to generate initial themes. The framework approach was utilised to map initial themes to the four constructs of NPT.

Results Inductive analysis generated three overarching themes consisting of 13 subthemes which captured staff perceptions of EoL care, barriers, and facilitators of ‘good’ EoL care. All subthemes were mapped onto the NPT framework. Results suggested that although staff valued EoL care, difficulties in team working, systemic issues, and care processes acted as barriers of implementation. Suggestions for enhancing generalist staff coherence, collective action, cognitive participation, and reflective monitoring were proposed.

Conclusion Enhancing acute staff’s coherence, collective action, cognitive participation and reflective monitoring is crucial in improving EoL care delivery in acute settings.

Introduction

End-of-Life Care in Acute Settings

Palliative care aims to improve the quality of life of patients living with life-limiting health conditions and their families, and involves the holistic delivery of physical, psychosocial, and spiritual care (World Health Organization, 2020). Although often used interchangeably, end-of-life (EoL) care is a distinct and important component of palliative care that aims to support those who are nearing the end of their lives.

In recent years, EoL care excellence has become a policy priority in many countries, and in the UK a person’s preferred place of care and death is a key feature of evidence-based national policy reform (e.g., Scottish Government, 2023). Despite national policies designed to encourage people dying at home, and many patients voicing a wish to be cared for and die at home or in a hospice (Gomes et al., 2013), the likelihood of dying in hospital is generally high with and around 50% of deaths in the UK occurring in hospital settings (Marie Curie, 2020). Taken together, research and data suggest acute hospital settings have an important role in delivering EoL care.

EoL care in hospitals is mostly provided by generalist staff with additional support from specialist palliative staff where available. Traditionally, acute hospitals operate within a biomedical model, where the focus is towards short-term treatment of injuries or episodes of illness. Thus, despite the commitment and willingness of generalist staff, characteristics of the hospital environment can be less favourable for EoL care delivery when compared to specialist palliative contexts such as hospices (Brereton et al., 2011; Dougherty et al., 2015; Royal College of Physicians, 2021).

Research highlights that patients and families express that limited communication about the dying process (Anderson et al., 2019; Walker et al., 2023), difficulty of coordinating shared decision-making (Virdun et al., 2017), lack of privacy and high staff and patient turnover (Black et al., 2018; Donnelly et al., 2018) in acute settings negatively impacts end-of-life care. Thus in a recent national audit of EoL care, although 80% of patients and caregivers felt that the hospital was the ‘right’ place for the person to die, a quarter of them rated the quality of care as ‘poor’ (Healthcare Quality Improvement Partnership, 2020). Additionally, in a recent multi-centred service evaluation in the UK covering 88 hospitals, 93% percent of patients had unmet needs, including physical symptoms (75%), and psychosocial or spiritual needs (86%) (Tavabie et al., 2023). Thus, enabling and supporting EoL care excellence in acute settings is a significant area of need.

Staff Experiences of Delivering EoL in Acute Settings

Research also highlights that providing EoL care within the constraints of an acute setting negatively impacts medical staff (Corrardi-Perini, Beltrao & Ribeiro, 2021; Maffoni et al., 2019). Healthcare staff providing palliative care in general settings experience more symptoms of burnout when compared to those in hospices (Ostacoli et al., 2010), and analysis of data show that the clinical setting in which staff work is the only factor that influences the level of burnout symptoms. Symptoms of burnout not only affect the wellbeing of staff members but are also associated with poorer quality of patient care (Hall et al., 2018). Since burnout is largely related to work conditions (Harrison et al., 2017), interventions directed at organisational level are more effective in reducing symptoms of burnout when compared to interventions directed at individuals (West, Dyrbye & Shanafelt, 2018; Hill et al., 2016). Therefore, identifying challenges faced by staff in EoL care in acute environments is crucial for the development of new standards of care.

Nurses play an important role in EoL care because of their close interaction with patients, families, physicians and other healthcare providers. Accordingly, nurse’s experiences of delivering EoL care in acute settings has been explored in various studies and has highlighted common barriers to patient care including ward busyness (Chan et al., 2018), lack of private rooms (Thompson, McClement & Daennick., 2006), the organisational emphasis on acute care tasks and the inappropriate use of active treatments (Gardiner et al., 2011). In contrast, experiences of other healthcare providers such as doctors and allied healthcare professionals have not been explored as thoroughly. Importantly, the UK NICE guidelines (National Institute for Health and Care Excellence, 2019) highlight the importance of multidisciplinary teams offering a holistic approach to EoL care. Therefore, it is important for future studies to explore the experiences of various professionals involved in delivering EoL care in acute settings.

Withdrawal of the Liverpool Care Pathway

The Liverpool Care Pathway (LCP) was used in the UK hospitals between 1990s and 2014 with the aim of introducing holistic hospice-style EoL care in acute settings (Twigger & Yardley, 2017). An official review of the LCP (Department of Health, 2013) highlighted the gaps between the goals of the LCP and its use in practice and has criticised the lack of focus on its process of implementation. These findings suggest that effective implementation of LCP could have been aided by understanding the local context and the role of different professional perspectives and work structures.

The Scottish Government issued guidance regarding ‘Caring for People in the Last Days and Hours of Life’ (Scottish Government, 2014) after the withdrawal of the LCP. The guidance highlights essential areas of care that teams should address when caring for dying people such as sensitive communication, multidisciplinary working, holistic care, and support for families and carers. In NHS Greater Glasgow & Clyde, these principles were utilised to aid the development of a tool known as the ‘Guidance at End of Life (GAEL)’ (NHS Greater Glasgow & Clyde, 2019). However, it is not yet known how this guidance has been implemented in real life settings, and how staff experience caring for dying people following the withdrawal of the LCP.

Implementation Research and Normalisation Process Theory

The withdrawal of the Liverpool Care Pathway (LCP) highlights the importance of implementation research in palliative care contexts. Previously determinant frameworks such as the Consolidated Framework for Implementation Research have been used in EoL and palliative care research to describe barriers and enablers to implementation (Coffey et al., 2021; Pinto et al., 2018). However, determinant frameworks are limited to description and categorisation rather than examining the mechanisms that underpin implementation (Nilsen, 2015). This makes it difficult to explain how and why implementation is likely to succeed or fail and to propose strategies to aid successful implementation.

In contrast, implementation theories go beyond description and provide explanations of different mechanisms that underpin implementation and allow the identification of practical steps in translating research into practice (Nilsen, 2015). One such implementation theory is Normalization Process Theory (May & Finch, 2009) which offers a framework that focuses on the implementation of interventions (the way in which practices are put into action), their embedding in routine practice (the process of practices becoming routine), and the processes by which interventions are integrated and normalized (the process of sustaining). NPT consists of four components that define distinctive processes. The first component, *coherence* refers to the extent to which stakeholders involved in implementation have a sense of clear and common purpose of the intervention. *Cognitive participation* refers to the degree to which stakeholders perceive the potential benefits of the intervention and the willingness to support the implementation. *Collective action* relates to the service level factors, which are involved in successful implementation and to the stakeholders' readiness to change their current practice. The fourth component, *reflexive monitoring* refers to an agreed plan of how the implementation would be assessed. NPT predicts that implementation processes need to satisfy these four components to become normalized in routine practice.

NPT was specifically developed to address and explore implementation in healthcare settings and has been used to examine implementation in various healthcare settings (Huddlestone et al., 2020; Scantlebury et al., 2017; Volker et al., 2017), including palliative settings (Bradshaw et al., 2021; Noble et al., 2018). Furthermore, a recent systematic review demonstrated that NPT was a consistent and generalizable framework for explaining implementation dynamics and processes within health research (Williams et al., 2023). Thus, NPT offers a suitable theoretical framework for examining the delivery of EoL care in acute settings.

Aims and Research Questions

Aims

The aim of this study is to; (a) provide a comprehensive description of experiences of multidisciplinary healthcare staff delivering EoL care in acute settings; (b) identify individual and contextual barriers and enablers surrounding implementation of EoL care delivery in an acute setting; (c) integrate our data using NPT.

Research Questions

- How do multidisciplinary health care staff working in acute settings make sense of EoL care delivery?
- Can staff experiences delivering end of-life-care in acute settings be understood within the NPT framework?

Design, Methods and Procedure

Design

This study adopted a qualitative design to explore individual experiences within the context and social reality of participants. The epistemological position behind this study followed a critical realist and post-positivist paradigms suggesting that the experience of participants and the researcher is influenced by the social, structural, and political context in which the study is conducted (Danermark, Ekstrom, Jakobsen, & Karlsson, 2002). NPT was used as a theoretical lens as it offers an explanation of individual and contextual processes for implementing, embedding, and integrating practices in everyday work. Semi-structured interviews with multidisciplinary healthcare staff were employed. This design facilitated in-depth exploration of staff experiences and perspectives of the barriers and enablers of implementing EoL care in acute settings.

Ethical Considerations

Data were anonymised and stored in a password protected NHS computer in line with the university’s ethics guidelines on confidential data. Only the research team had access to the data. Ethical approval was granted by the University of Glasgow MVLS ethics committee (Appendix 4) and the research proposal for this study was approved by the local NHS Research and Development Department (Appendix 5).

Setting and Participants

This study was conducted in a large teaching hospital in Glasgow, Scotland, with around 90 wards and a capacity of around 1000 beds. All multidisciplinary healthcare staff working in all hospital wards and teams were invited to participate in the study. Participants were required to have experience of caring for dying people as part of their role. Participants were recruited using a purposive sampling technique which is commonly used in implementation research (Palinkas et al., 2015). This ensured the recruitment of a range of perspectives within professional stake holders, including nursing, medical and allied health professionals, with different levels of experience as NPT posits that everyone has a role in successful implementation. Malterud, Siersma and Guassora's (2016) model was used to systematically reflect on the dimensions that impact the "information power" of a study. The adequacy of the sample size and information power was continuously evaluated throughout the study. After the completion of 14 interviews, no new themes were identified, and the research team agreed to end recruitment.

Procedure

Information about the study was emailed to relevant team leaders (e.g., Chief of Medicine, Chief Nurse) who were asked to circulate information to staff (see Appendix 6). The researcher also visited wards to introduce the study to staff, and left information flyers in staff areas. Interested participants were asked to contact the researcher either by email or phone. Participants were provided with a Participant Information Sheet (see Appendix 7) and a detailed verbal account of what the research involved, limits of confidentiality, anonymity, and the voluntary nature of participation. Prior to the interviews participants provided written informed consent (see Appendix 8). All semi-structured interviews were conducted by the lead researcher in either private NHS settings or remotely over MS Teams. The interview guide was developed to explore the perceptions, views and experiences of healthcare staff when caring for dying patients in acute settings. Initial questions explored individual experiences of caring for dying patients, then moved on to team working and processes, and finally allowed participants to reflect on wider systems-level factors. The NPT framework was used to prompt, guide, and structure questions of the interview guide and each question was mapped onto a different NPT construct (see Appendix 9 for Interview Guide). Participants were provided with a Debrief Form (see Appendix 10) at the end of the interview. Field notes were recorded after each interview. All interviews were audio recorded, transcribed verbatim and checked for accuracy. Data collection took place between November 2023 and February 2024.

Data Analysis

The initial inductive stage of analysis was conducted in line with Braun and Clarke's (2013) six phases of thematic analysis, as the aim of the study was to capture common patterns and experiences of EoL care delivery across different staff groups. This helped us to identify themes that might not be adequately captured in the deductive framework. The researcher initially immersed themselves in the data by re-listening to the interviews and reading the transcribed interviews and noting down how participants made sense of their experiences. The researcher then started coding by identifying features that were considered pertinent to the research question (see Appendix 11 for example coding). As the coding progressed, codes describing common experiences were translated into themes. Thematic maps helped the researchers visualise the links and relationships between themes. Once themes from each interview were identified, these themes were discussed with an independent researcher reaching a consensus regarding the composition of each overarching theme.

The deductive coding was completed using a five-stage framework analysis approach (Ritchie & Spencer, 2003), which involved developing a list of all the subthemes that led to the composition of the overarching themes. The researcher then attempted to map patterns and associations between themes to the four constructs of NPT.

Reflexivity Statement

I am a Trainee Clinical Psychologist working in NHS GG&C. As a researcher, I became interested in EoL care after having a family member receive EoL care in an acute setting and realising how patients, family members, and staff often shy away from talking about death. I do not have any experience working within the study setting or delivering EoL care and knew none of the participants. To familiarise myself with the study setting, I spent a day shadowing the Specialist Palliative Care Team within the study hospital and observed the roles and tasks of specialist doctors and nurses, as well as getting a sense of different ward settings, and meeting patients receiving palliative or EoL care. Potential sources of bias to data interpretation were discussed in research supervision before data collection. A reflective log was also kept during the data collection process to reflect on sources of bias during interviews with participants.

Results

The sample consisted of 14 participants, 12 of whom were female. Participants consisted of medical consultants (n=3), a senior registrar (n=1), “junior” doctors (n=2), senior charge nurses (n=2), charge nurses (n=2), staff nurses (n=2), a specialist occupational therapist (n=1), and a healthcare support worker (n=1). None of the participants who initially volunteered to participate dropped out of the study. The interviews lasted between 17 and 74 minutes.

Throughout the interviews it was clear that participants were passionate about caring for dying people to the best of their abilities. Across the interviews I was struck by how vividly participants recalled individuals that they cared for, remembering the names of the first patients they had cared for until death. They viewed their patients as individuals with interests, desires, fears; and at times saw connections to their own lives in the patients that they cared for. As participants gave me context and described their experiences in detail, I realised just how many layers of emotions caring for dying people bring up. What dominated the interviews was not the fear of closeness to death but the best bits of living – compassion, kindness, caring. When I asked participants how they found the interviews, they all said that they felt better for talking about death, even though many were apprehensive about it at first, showing that we make sense of our experiences and emotions through talking and we need to talk about death.

Inductive thematic analysis of staff experiences of EoL care delivery in acute settings produced 13 subthemes that contributed to the development of 3 subthemes (see Table 1).

Table 1 *Overarching themes and subthemes of thematic analysis and the number of participants that mentioned each subtheme*

Overarching Themes	**Subthemes**
Perceptions of EoL care	Staff views of good vs. bad death (14/14)
	EoL care delivery seen as rewarding (10/14)
	EoL care seen as at odds with acute care provision (12/14)
Barriers to “good” EoL care delivery	Delays in communication and decision making (13/14)
	Limited training in EoL care (9/14)
	Acute tasks take priority over EoL care (10/14)
	Inconsistent availability of guidance (9/14)
	Lack of integration between acute and community settings (10/14)
	Systemic issues (13/14)
Facilitators of “good” EoL care	Proactive rather than reactive EoL care (11/14)
	Cohesive team working (14/14)
	Availability of reflective space (14/14)
	Close links with specialist staff (12/14)

Perceptions of EoL Care

Staff views of good vs. bad death

Staff members had strong views of what constituted a “good” or “bad” death. A “good” death was conceptualised as one where the patient’s symptoms were well controlled, they had family members around, and were preferably in a side-room with privacy. In contrast, if a patient was distressed, alone and lacked privacy this was seen as a “bad” death. These views of what constitutes a good death shaped their individual EoL care delivery:

> “I don’t think as a society we talk enough about death and what constitutes a good death and a bad death. So, I try to move people towards a good death… And I like to think that’s what I would want for any member of my family. And if I’m in doubt… What would I want if this was my relative and I kind of use that as a bit of a moral compass.” (Consultant)

Most staff had experienced a loved one receiving EoL care and their experiences, whether negative or positive, shaped the EoL care they delivered. One Senior Charge Nurse said “I’ve lost a few family members. And they were all totally different. So, I remember how it was like, sitting there, and what I wanted for them.”

EoL care seen as rewarding

Caring for people at the end of their life was seen as a privilege: “…it's such a privilege to be able to be there, to be part of that” (Senior Registrar). Being able to offer good EoL care to patients and families was seen as rewarding: “I find it quite rewarding. I think obviously it can be quite a sad time…but it's rewarding when it can be done well” (Consultant). Importantly, nursing staff viewed EoL care as a continuation of the acute care they provided to patients: “I just think palliative care is very important. We do everything else, so why can’t we help someone have a peaceful death” (Senior Charge Nurse).

EoL care seen as at odds with acute care provision

The acute hospital setting was seen as having a curative focus which made it difficult to accept that treatments may not be working, and a patient may be approaching EoL: “…it’s almost a stigma I guess, where people come to hospital because they want to get better. So, people then don’t want to say, actually what if we can’t help you? What if we can’t make you better?” (Junior Doctor)

Medical staff often focused on active treatment as finding solutions was seen as ‘inherent’ in medicine: “… it is probably inherent in medical nature to always be looking for the treatment rather than not, so when someone goes to their doctor, they are probably looking for what can make them a bit better” (Consultant). Therefore, withdrawing active treatment could be perceived as ‘giving up’: “medical staff want to keep everybody going and don’t want to give up” (Senior Charge Nurse).

However, continuing active treatment was seen as being at odds with a “good” or dignified death: “…we have to accept that the best way we can help that person is not by flogging them with treatments that are not going to work, but by giving them as pain free and dignified death as we can” (Consultant). It could be emotionally difficult for nursing staff to follow the orders of medical staff and to continue with active treatment when they could see that a patient had further deteriorated:

> “Because as nurses we can see the rapid deterioration… Can we not let this lady die in dignity? They were already given a terminal diagnosis before being admitted to this ward. It’s not our job to save her. It’s our job to make her comfortable. I find that really hard sometimes.” (Charge Nurse)

Barriers to “good” EoL care

Delays in communication and decision-making

Often nursing staff first noticed signs of deterioration and raised the possibility of a patient dying, however, they looked to the medical team for confirmation and decision-making:

> “We as nurses do see our patients 24 hours a day. I feel that we are probably the first to pick up any sort of deterioration. We as nurses can’t make the decision to say they are approaching end of life…So, we then need to branch out to the medical staff or even palliative care to raise our concerns” (Staff Nurse)

Nursing staff often alerted junior doctors as they spent more time on the ward compared to consultants: “Other than the palliative care consultant team, it is quite unusual for very senior members of staff to be involved in end-of-life care” (Junior Doctor). However, junior staff often wanted guidance from senior members when it came to decisions around EoL care, which caused delays. Differences in accessing medical staff during working hours and out of hours was echoed by other staff members. During the working day, ward doctors who knew the patients responded relatively quickly to alerts from nursing staff. However, asking on-call doctors to attend to patients out of hours could be time consuming. It was felt because on-call doctors lacked a personal relationship with patients, they did not feel a sense of urgency in decision making, especially in regard to EoL care.

> “Sometimes you can wait for hours to get a doctor to come. Because it's not personal to them. Because they've not been looking after the patient. They've never met the patient half of the time. They've never met any of the relatives” (Senior Charge Nurse)

The ‘back and forth’ communication between nursing and medical staff caused delays in starting EoL care. Nursing staff expressed that they felt frustrated that despite seeing that a patient was deteriorating, they could not shift their attention to a holistic care approach. Therefore, they felt that a core component of their nursing role was to be an advocate for the patient getting the most appropriate care possible: “So, we really are the heart and soul, we're the advocates...” (Staff Nurse).

Acute tasks take priority over EoL care

Nursing staff felt that once EoL care was deemed appropriate and active treatment was withdrawn, medical staff did not have an active role in care delivery: “they see end-of-life care as if they have nothing else to do” (Senior Charge Nurse). The difficulty between balancing acute tasks and EoL care was echoed by medical staff: "…if someone's been labelled as end-of-life, it means that although there's symptoms that you can be treating, unfortunately they are not as high priority as someone that is potentially acute, deteriorating and receive active management" (Junior Doctor).

Due to the high demands of the acute setting, medical staff felt that they often struggled to recognise that a patient may be dying: "… I think we get so caught up in the acuteness of what we're doing that we don't always recognise that actually what the person needs is not lots of aggressive treatment but end-of-life care" (Consultant).

Limited training in EoL care

Staff members had limited training in EoL care. Other than medication management, EoL care was not a core component of medical training. Thus, staff felt that they lacked opportunities to build their knowledge of EoL care unless they took initiative to access further training: "Unless you go looking for it, you don't get much training on it" (Senior Charge Nurse). Limited knowledge meant that staff looking after dying patients had to rely on specialist advice from the hospital palliative care team.

The busyness of the acute setting was identified as a barrier to accessing further EoL care training: "…there could be better education around it but that does go back to time. Is there time to educate your nurses on the ward? It all comes back to the acuteness, the busyness, the staff shortages" (Charge Nurse).

Inconsistent availability of guidance

Some participants shared that the withdrawal of the LCP was seen as a loss, and they were unsure whether new guidance was available:

> "When you had the Liverpool Care Pathway it was good because, it went through everything to make sure you've been through all aspects (of care)… At least you had some things that was more set in place then. I don't know if we actually do the same thing the now, only just don't go through the checklist."
>
> (Senior Charge Nurse)

Staff members mainly referred to the Scottish Palliative Care guidance, especially for support around medication planning and administration. Staff often relied on the hospital palliative care team as it was difficult to keep up to date with new guidance due time constraints:

> "… you don't have much time, so I use what I know…when that doesn't work, there's normally someone from palliative care that can give you advice rather than you having to go and search for it. I guess in some ways that's fortunate, but maybe means that I'm not aware of other stuff that's out there too."
>
> (Junior Doctor)

It was also felt that more senior medical staff were less up to date with guidelines as they did not take an active role in EoL care, which was felt to be a barrier for junior staff: “…having senior staff who are quite out of touch with the guidelines is a big barrier because you can’t go to them for advice because you know that their advice is going to be phone the palliative care team” (Junior Doctor).

Lack of integration between acute and community care

Lack of social care provision in the community and limited hospice spaces were barriers to patients being discharged into the community. The withdrawal of funding for the Hospital Based Complex Clinical Care (HBCCC) which allowed patients with complex care needs to be looked after in care homes with support from specialist staff in the community meant that patients who were not imminently dying but could not manage at home had to remain in hospital.

> “We are limited in terms of what support we can offer patients to have the opportunity to die elsewhere if hospital isn’t their preferred setting… if they can’t manage at home with four carer visits and the odd district nurse visit, then they need to be in the acute hospital setting until death.” (Consultant)

Transferring a patient to the community required multidisciplinary liaison between the acute, specialist palliative care, and community teams, as well as social work, which could be time consuming. Discharging a patient with necessary support was easier if they were already known to community teams and had social care provision set up. Otherwise, delays in liaison and arranging care, especially during out of hours, meant that discharges from the acute setting were delayed:

> “What service you get is so time of day and day of the week dependent. If it is a Friday night, I'm probably going to have to admit them to hospital until Monday before I can get any of those services in place for them, when what all they really want to do is go home.” (Consultant)

Staff also felt that they did not always have up to date knowledge of what support was available in the community and therefore struggled to support families. It was felt that families were left on their own to research and secure care for the patient: “and we just kind of hand it over and expect other people to sort it, and these people are still dying, and we kind of hand it over to chance” (Senior Registrar). Improving links with community services was also seen as important “I think it is useful for us to know what can happen at home because then we can help families to come to those decisions” (Junior Doctor).

Systemic issues

The physical environment of acute wards was seen as a barrier to “good” EoL care: “It’s busy, it’s crowded, there is no space, and you’re trying to give them time and space that you can’t give them” (Consultant). Working within time pressures could be emotionally difficult for staff members who felt that they could not deliver the EoL care they wish “This is all personal to me, I feel guilty that I can’t split myself into two” (Senior Charge Nurse).

The limited availability of private side rooms meant that some dying patients had to be cared for in open wards, which could be difficult, not just for the dying patient and their family, but also other patients: “After someone passes away we sometimes need to talk to the other patients, because they know what happens. So that can be difficult, because it’s an open ward” (Senior Charge Nurse). Hospital rules meant that patients and families could not make the surroundings more personal or homely which was seen as a core component of holistic EoL care: “We’ve got a lady who has got flowers for her 90th birthday, but if infection control came through, they would be whipped away like a lot of other things we used to do to make people’s rooms a bit nicer” (Senior Registrar).

Facilitators of “good” EoL care

Proactive rather than reactive EoL care

Knowing about patient wishes were important for delivering good EoL care. Most patients that ended up in acute settings had long-term or comorbid health conditions. Staff felt that their deterioration could often be anticipated, and anticipatory care planning could have happened at an earlier stage allowing for better EoL care: “people could have had more productive discussions about it… so suddenly a long process gets condensed into a short period of time and of course that is very difficult for caregivers” (Consultant).

Junior staff felt that having conversations around resuscitation and ceilings of treatment could be difficult. Less experienced staff often shied away from these conversations:

> "I remember as a junior running into multiple arrest calls on night shifts because we just weren't as proactive at thinking about what was appropriate for patients and what wasn't. Now it would be rare for me not to have had a discussion about whether or not resuscitation is the right thing for them." (Consultant)

Cohesive team working

Recognition of dying and holistic EoL care was seen as a team activity. Staff valued having contrasting opinions and experiences when making decisions around EoL care:

> "We try to select our colleagues over time so that we have got people that both think similarly and differently to us. So that we can have a productive discussion, so that never do we feel a decision is made either half-heartedly or without scrutiny" (Consultant).

When team members shared similar values, this allowed for cohesive working and informal peer support which was important for staff wellbeing. In contrast, when multidisciplinary teams did not work cohesively this could negatively affect staff: "It can be frustrating at times if I feel like I’m not getting the best results for my patients because, it’s not just a nurse that’s involved in the care” (Staff Nurse).

Availability of reflective space

Staff appreciated that caring for dying people could be emotionally challenging and could lead to moral injury. Having space to reflect on difficult cases was seen as important: “I came away and I couldn’t get her out of my mind… and I couldn’t sleep, I kept seeing her. I was fine after talking to the girls (nurses), but it does affect you” (Healthcare Assistant). However, formal structured debrief opportunities were only available after major or unexpected incidents such as cardiac arrests, and there was an absence of regular interprofessional and structured debriefing: “You don’t get a formal chance to talk about these things that you could have done better or worse unless you kind of make that happen yourself. And it is very unusual that there’s anyone senior involved in that either” (Junior Doctor). Structured debrief was not only seen as important for staff wellbeing but also played a crucial role in moving from individual reflection to wider team learning:

> “I don’t think we recognise the impact on staff that end-of-life care in acute hospitals has, what everyone does with those feelings… We would never talk about a case, either good or bad, to learn from. We don’t reflect on cases of caring for dying people. And yet there us so much learning that we could do. How do we make things better at a ward or team level… But we just don’t. And

> I think that’s interesting because it might identify what we could start sorting out” (Senior Registrar)

Structured debrief was also seen as an appraisal tool especially in the absence of systematic audit and feedback processes to inform and improve EoL outcomes. Although certain wards where deaths occurred more regularly, such as the ICU, mortality reviews or patient and family questionnaires were used to appraise EoL care, many staff looked for subjective markers of patient or family comfort to appraise their EoL care delivery.

> “I’ve had some families ask me by name so that to me is a bit of feedback. I must have done something right. It’s not really something that you can quantify. You can’t ask the patient was that all right?”

Close links with specialist staff

The specialist hospital palliative care team was seen as valuable support in terms of treatment planning and guidance. Staff felt that they could easily reach out to them and that they would respond in a timely manner. Junior staff were quicker to involve palliative care in EoL care discussions, whereas more experienced medical staff felt confident making proactive EoL decisions without the support from specialists: “Earlier in my career I might have asked for help sooner than I maybe do now. I feel more comfortable managing certain scenarios that I would have previously asked for input with” (Consultant).

However, it was felt that recognising dying, and holistic EoL care delivery was everyone’s responsibility: “We can all recognise when someone is dying and we can all act on that, and start to do the things that need to be done to make things more comfortable, to rationalise medicines, to have those conversations…” (Senior Registrar). Improving information and knowledge sharing between generalist and specialist staff was seen as an important way of increasing the confidence of generalist staff: “Maybe if each nurse had a dedicated learning day to go around with the palliative care team and see what it is exactly they do and how they look after their patients” (Staff Nurse).

Discussion

Summary of Findings

The aims of the study were to explore the experiences of multidisciplinary healthcare staff delivering EoL care and to identify contextual barriers and facilitators surrounding the implementation of EoL care delivery in acute settings. Three overarching themes consisting of thirteen subthemes captured a mix of barriers and facilitators of EoL care implementation in acute settings.

Overall, staff had personal ideas of “good” and “bad” death which guided their EoL care delivery. Although different cultures and individuals may have different views of a “good” death, dying with independence and comfort, minimised suffering are commonly considered important in achieving a good death across cultures (Demir et al., 2017; Kastbom, Milber & Karlsson, 2017). In line with this, what participants considered a “good” death echoed those identified in previous research (Luxardo et al., 2014; Trankle, 2014). Importantly, although at times EoL care was seen at odds with acute care provision, staff valued delivering good EoL care.

Through interviews participants identified contextual barriers to good EoL care delivery in acute settings: delays in communication and decision making, limited training in EoL care, acute tasks taking priority over EoL care, inconsistent availability of guidance, lack of integration between acute and community settings and systemic issues. Staff voiced that at times due to the demands of acute tasks they were late in recognising dying and the back and forth communication between medical and nursing staff could cause further delays. Patients in the acute setting are often more complex, with more disciplines involved and more clinical uncertainty about prognosis. In an acute setting cure and care can appear incompatible, especially in an environment where staff are under daily pressure to meet treatment targets. Taken together, this meant that EoL care would be commenced late, and only when agreement was reached that a patient was dying, which has been echoed in other research (Chan et al., 2020; Nobel et al., 2018; Reid et al., 2013).

Limited training in EoL care was another significant barrier identified by staff. Numerous previous studies have also shown that healthcare staff in generalist acute settings do not feel adequately prepared to provide EOL care (Friedenberg et al., 2012; Holms, Milligan, & Kydd, 2014; Travers & Taylor, 2016). Interestingly, a recent study has demonstrated that nurses with additional training in EoL care report fewer barriers toward EoL care in acute settings (Chan et al., 2020), indicating the importance of training in developing confidence in good EoL care delivery. Systemic issues such as ward busyness, staff shortages, lack of private spaces, and treatment targets that were identified as barriers in this study. Similar findings have also been reported as an important barrier to providing quality EOL care in other countries such as Thailand (Mesukko, 2010), Canada (Tung et al., 2019), Australia (Raymond, Lee, & Bloomer, 2017) and the UK (Lund et al., 2015).

Our results indicated that there was inconsistent availability of EoL-care specific guidance. One of the starting points of this study was to explore how staff made sense of the GAEL guidelines and how the guidelines shaped their EoL care delivery. Interestingly, the GAEL was not mentioned by staff. Instead, staff often relied on the Scottish Palliative Care Guidelines for support with anticipatory medication prescribing, diet and fluid intake guidance and discharge planning. However, actions to address the more holistic needs of patients and families, such as psycho-social-spiritual support were based on individual staff values. It may be that the holistic care aspects of the guidance are less available or accessible compared to the medical management aspects. Accordingly the recent Palliative and End of Life Care Strategy (2023) highlight the importance of improving holistic psychosocial care for dying patients and their families in acute settings. Interestingly, an analysis of UK health policies since 2010 has showed that of the fifteen policy documents included twelve referred to palliative or EoL care but details about what should improve or mechanisms to achieve these improvements were sparse (Sleeman et al., 2021). Thus, the use of implementation theories is helpful in identifying mechanisms of change that need to be addressed to improve EoL care in acute settings.

Overall, these identified barriers all relate to the he fundamental conflict between the perceived goals of the acute care setting which is the short-term treatment of injuries or episodes of illness and that of individualised and holistic EoL care. Importantly, in a recent systematic review synthesising experiences of non-specialist healthcare providers delivering palliative care in acute settings, twenty-nine out of the thirty-seven included studies mentioned this fundamental conflict (Nevin, Hynes & Smith, 2020). These results indicate that embedding non-specialist EoL care in everyday acute hospital provision necessitates a major change in core assumptions about the organisation and delivery of acute care.

In contrast, facilitators of good EoL care were a having proactive approach to EoL care, cohesive team working, availability of reflective space and close working links with specialist palliative care staff. Our findings further affirmed that good EoL delivery is not only about symptom relief, but also timely and proactive involvement of patients and their families in EoL care planning and communication. Additionally, our findings highlight the importance of the availability informal peer support achieved through cohesive team working and more formal reflective space, which have been shown to significantly reduce moral injury (Cartolovni et al., 2021; Hegarty et al., 2022).

What can we learn from NPT?

Understanding the challenges faced by generalist healthcare staff caring for dying patients, as well as the factors that support their EoL care delivery is an important first step in designing approaches to achieve changes in practice. However, without a structured theoretical framework, such as NPT, translating staff experiences into strategies to support the implementation of EoL care in acute settings is difficult. Thus, in the deductive stage of analysis the themes and subthemes identified through the inductive analysis were mapped onto the four constructs of NPT (Table 2). This framework provided us a systematic description and explanation of how staff work in face of EoL care, as well as allowing us to propose strategies to embed EoL care in acute settings.

***Table 2** Key barriers, facilitators, and proposed strategies using the NPT framework*

NPT Construct	Key Facilitators	Key Barriers	Proposed Strategies
Coherence	Staff views of good vs. bad death EoL care delivery seen as rewarding	EoL care seen as at odds with acute care provision Limited training in EoL care	Protected study time to support development of EoL care knowledge and skills
Cognitive participation	Cohesive team working	Delays in communication and decision-making	Define duties and responsibilities of healthcare staff in terms of EoL care Foster an interprofessional approach to EoL decision

			making (i.e., regular multidisciplinary ward rounds)
Collective action	Proactive rather than reactive EoL care Close links with specialist staff	Lack of integration between acute and community care Acute tasks take priority over EoL care Systemic issues	Review work structures to support prioritisation of EoL care (i.e., prioritise dying patients on ward rounds) Interprofessional case-based discussions (i.e., with community settings) Interprofessional learning activities to support EoL practice in collaboration with specialist palliative care team Protected time for keeping up to date with guidance
Reflexive monitoring	Availability of reflective space	Inconsistent availability of guidance	Create opportunities for structured team debrief Enhance opportunities for audit and feedback

Coherence – Making Sense of EoL Care

Staff viewed EoL care as rewarding and being aligned with their values. Nursing staff viewed EoL care as a continuation of the acute care they provided to patients. This view helped them legitimise EoL care delivery in acute settings and allowed them to shift the focus of care from a more traditional biomedical model to a more holistic approach that also considered spiritual and family support. However, medical staff at times felt that EoL care was at odds with their role in acute settings which had a focus on active treatment with the goal of patient recovery. Furthermore, lack of training in EoL care principles meant that some staff were unsure about what their role was when it came to EoL care.

Again, there were contrasting views between nursing and medical staff when it came to diagnosing dying. Due to spending extended time with patients, nursing staff felt comfortable in recognising the signs of dying. In contrast, the acuteness of the setting meant that medical staff who were focused on active treatment often disregarded signs of dying. As many EoL care patients had chronic conditions, as well as an acute illness that exacerbated their chronic condition at the time of admission, for medical staff there was a sense of uncertainty with the duality of treating the acute illness while also holding the possibility that a patient may be dying. Nursing staff felt more comfortable once the decision to withdraw active care was made by the medical team, and they could focus on holistic comfort care. Overall, participants knew and valued good EoL care, however it was difficult for them to integrate EoL care principles into already established acute care practices.

Cognitive Participation – Getting Involved in EoL Care

Staff valued cohesive team working, however, at times it was difficult to achieve fully integrated multidisciplinary working that is required for good EoL care delivery. EoL care roles were not parallel with acute care roles. EoL care, unlike acute care, was seen as being nurse-led. This meant that nurses saw their role as being an “advocate” for the patient and felt empowered to prompt medical staff to make decisions about EoL care. Yet, nursing staff were not able to commence EoL care without input from medical staff about the treatment plan. Communication difficulties between nursing and medical staff delayed the start of EoL care and created a sense of tension between the two professions.

Usual patterns of working, such as seeking reassurance and guidance from senior staff, differed between acute and EoL care. Depending on specialty and individual confidence in delivering EoL care, some senior medical staff avoided direct engagement with the practical complexities of good EoL care, and instead delegated responsibilities to more junior staff. This meant that, although junior staff felt like they needed support from seniors, they could not consult them for guidance, and instead sought advice from the specialist palliative care team. This meant that the involvement of specialist palliative care was not only limited to complex cases.

Collective Action – Implementing EoL Care

When caring for dying patients several systemic issues acted as barriers. The physical environment of the hospital was not considered ideal for good EoL care delivery. Due to competing acute care demands, staff often were not able to have proactive EoL discussions with patients and families. This meant that, EoL care was delivered too late, or reactively, once signs of deterioration were identified. A reactive rather than proactive response to EoL care could also be attributed to shift patterns and staff resourcing. For example, getting hold of staff that were not based on wards, such as on-call medical staff during out of hours, meant that there were delays in EoL care delivery. Similarly, despite playing a crucial role in liaising transfer of EoL patients to the community, as AHPs were not based on wards they would often be invited to contribute after an EoL care decision was made, rather than being collaboratively involved in the decision-making process.

Furthermore, pressures from senior management around bed spaces and the push for discharges were noted. However, the lack of longitudinal and continued care between acute and community settings meant that patients were dying in hospital. Close working links with specialist hospital palliative care team meant that staff could easily access specialist support and guidance around treatment and discharge planning.

Reflexive Monitoring – Improving EoL Care

Crucial to the implementation success was the potential for staff to learn from their experiences, however barriers to effective staff reflection were evident. Firstly, although staff valued having space to reflect, structured multidisciplinary debrief opportunities were limited to unexpected and major incidents. Thus, although staff individually reflected on their practice and changed their practice based on such reflections, without the opportunity for team debriefing, these learning points did not generalise to team level EoL care delivery.

Secondly, although staff often referred to the Scottish Palliative Care guidance for support around medication management, guidance for more holistic care was missing.

For example, AHPs did not have EoL-specific guidance or guidelines and therefore, adapted their usual working practices and assessments to the EoL context. Due to the inconsistent availability of best-practice guidance staff were unsure what to compare their practice to. Lastly, other than wards where death occurred frequently, most teams did not have systematic audit and feedback processes that are required for improved practice and outcomes. Thus, in the absence of objective markers they looked at subjective markers to appraise their practice.

Implications for Practice and Proposed Strategies

This study provides empirical evidence from multidisciplinary healthcare practitioners caring for dying patients in acute settings. To achieve EoL care excellence in acute settings the following learning strategies informed by NPT constructs are proposed. The proposed strategies closely paralleled what participants shared would be helpful to improve their individual and team-level EoL care practice.

To increase coherence, generalist staff need support to develop their EoL care knowledge and skills. This might be in the form of protected study time so that staff can attend online training or other CPD activities. Accordingly, all study participants shared that they would benefit from protected study time and refresher courses to enhance their EoL knowledge and skills and to be able to keep up-to-date with relevant guidance. Participants also shared that they would benefit from shadowing opportunities or better skill and knowledge sharing between specialist and generalist staff. For example, a UK study (Selman et al., 2015) has shown that even a two-day

EoL course designed for generalist staff could increase staff confidence in EoL communication, teamwork, and holistic care. Increased confidence in EoL care knowledge will also assist staff to be able to hold two approaches (active care vs. comfort care) during transition periods and will allow staff to see EoL care as not a failure of acute care provision but an extension of it.

To support cognitive participation, teams may benefit from defining duties and responsibilities of staff in terms of EoL care. Learning experiences where a team collaboratively work through a case example may help create a shared understanding of individual staff roles and responsibilities. For example, simulation-based learning experience where nurses get the opportunity to engage with real-life scenarios in palliative care have shown to increase teamwork (Skedsmo et al., 2023). Thus, such practices can be adapted to the acute EoL care context.

Collective action can be strengthened through reviewing work structures and staff working processes. For example, a multidisciplinary approach to EoL care can be fostered through regular ward rounds where non-ward-based staff also attend. This was echoed by the non-ward-based participants who shared that regularly attending ward rounds alongside other AHPs would improve communication around discharge and care planning. Work structures may be reviewed to prioritise EoL care, for example, by prioritising the discussion of dying patients on ward rounds. Similarly, regular interprofessional case discussions with community teams may be helpful. Staff may also benefit from improving links with community or specialist palliative care teams via assigning link workers, or EoL “champions.” Nearly half of the participants shared that they would want to have a better understanding of what was offered in the community and develop better working links with community services to better inform and guide their patients and families around decision-making. Recently as part of the SEECare UK service evaluation (Tavabie et al., 2023), specialist palliative care teams visited wards for a day to identify patient needs against the relevant guidelines and criteria, and if needed to suggest an immediate intervention to better serve the area of unmet need. Although it was not part of the aims of the study, specialist involvement led to educational interventions, review of local policies, and helped with team functioning. Thus, regular involvement from specialist teams can be used to support generalist staff working processes.

To foster reflexive monitoring, staff will benefit from regular structured team debrief opportunities to review and amend EoL practices. Importantly, all participants shared that they would value and benefit from regular structured multidisciplinary debrief and reflective practice opportunities. Historically death review processes that have strong focus on adverse events rather than evaluating the quality of EoL care have been used in acute settings. However, more recently new audit tools specific to the EoL context have been developed (Heufel, Kourouche & Curtis,2023), which may be helpful in introducing meaningful quality improvement processes into acute settings.

Strengths and Weaknesses

The use of NPT as an analytic framework enabled us to understand how EoL care practices were normalised and embedded in acute settings, the identification of barriers and enablers to this process, and suggest recommendations for learning strategies to support EOL care excellence. Yet, at times there seemed to be an overlap between the different NPT constructs which has been echoed by other researchers (Atkins et al., 2011; Franx et al., 2012). However, initially using an inductive analysis approach allowed us to engage with the data without forcing themes to NPT constructs. Furthermore, we chose to map themes relating to the 'attitudes and perceptions' of healthcare staff onto the coherence construct of NPT, as staff attitudes and perceptions were crucial in how staff made sense of their work. However, a criticism of NPT may be that it focuses on how the work is being done, rather than the social and cognitive features that play role in implementation. In contrast, other implementation theories such as Theory of Planned Behaviour (Ajzen, 1991) place a stronger emphasis on how participant attitudes or intentions affect the work being done, which may add additional strengths to a study.

The study took place in a single acute care setting in one health board which may limit the broader applicability of its findings. Potential transferability is enhanced by the inclusion of professionals from different backgrounds and experience levels working in different acute care wards. The use of semi-structured interviews also generated rich descriptions. The purposive sampling method of study in this might have led to further biases as the participants who volunteered in this study might hold specific views about EoL care delivery. Although attempts were made to minimize researcher's bias, given the critical realist position of this study, it is possible that other researchers might have interpreted the data differently.

Conclusion

Overall, although generalist multidisciplinary staff value EoL care, the interviews highlight the barriers they face when caring for dying patients. Embedding EoL care in everyday acute hospital provision requires a major change in core assumptions about the organisation and delivery of acute care. However, enhancing acute staff's coherence, collective action, cognitive participation and reflective monitoring, is crucial for improving EoL care in acute settings.

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Appendices

Appendix 1: PRISMA 20202 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	p. 8
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	p. 9
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	pp. 10-14
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	p. 14
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	pp. 15-17

Section and Topic	Item #	Checklist item	Location where item is reported
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	p. 15
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	p. 15 Appendix 2
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	pp. 17-18
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	pp. 17-18
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	p. 17
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	p. 17

Section and Topic	Item #	Checklist item	Location where item is reported
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	p.18
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	p.18
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Table 1 Table 2
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	N/A
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	p. 18
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	p.14
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/A

Section and Topic	Item #	Checklist item	Location where item is reported
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	pp. 18-19
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	p. 19
Study characteristics	17	Cite each included study and present its characteristics.	Table 1 Table 2
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	pp. 32-34
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Table 2
	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	p. 29-32

Section and Topic	Item #	Checklist item	Location where item is reported
Results of syntheses	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	pp. 32-34
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	pp. 33-41
	23b	Discuss any limitations of the evidence included in the review.	pp. 33-41
	23c	Discuss any limitations of the review processes used.	pp. 33-41
	23d	Discuss implications of the results for practice, policy, and future research.	pp. 33-41
OTHER INFORMATION			

Section and Topic	Item #	Checklist item	Location where item is reported
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	N/A
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	N/A
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	N/A
Competing interests	26	Declare any competing interests of review authors.	p.41
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

Appendix 2: Search Strategy

EMBASE Search Strategy

1. exp Palliative Care/
2. palliat*.tw.
3. Terminally Ill/
4. Terminal Care/
5. (terminal* adj6 care*).tw.
6. ((terminal* adj6 ill*) or dying or (close adj6 death)).tw.
7. (terminal* adj6 disease*).tw.
8. (end adj6 life).tw.
9. hospice*.tw.
10. ("end-stage disease*" or "end stage disease* or end-stage illness" or "end stage").tw.
11. "advanced disease*".tw.
12. ("incurable illness*" or "incurable disease*").tw.
13. or/1-12

14. (family or families or parent$2 or mother? or father? or friend? or relative? or spous$2 or partner? or husband? or wife or wives or son? or daughter? or offspring? or sibling? or brother? or sister?).tw. and (care* or caring).mp.

15. caregivers/

16. (carer* or caregiv* or care giv*).tw.

17. exp family/

18. or/14-17

19. exp Psychotherapy/

20. Adaptation, psychological/

21. Relaxation therapy/

22. ((cognitive or cognition) adj3 (behav$ or treatment$ or technique$ or therap$ or intervention$ or restructur$ or reapprais$)).mp.

23. (behav$ adj3 (treatment$ or therap$ or intervention$ or activ$ or technique$ or modif$ or change$ or adapt$ or condition$)).mp.

24. (accept$ adj5 commitment).mp.

25. (autogenic adj (train$ or relax$)).mp.

26. (mindful$ or awareness or mood$).mp.

27. (psychotherap$ or psychological$).mp.

28. (group$ adj3 (therap$ or psychotherap$)).mp.

29. (talk$ adj3 (therap$ or intervention$)).mp.

30. counseling/

31. counsel$.mp.

32. or/19-31

33. Clinical Trial/

34. Randomized Controlled Trial/

35. controlled clinical trial/

36. multicenter study/

37. Phase 3 clinical trial/

38. Phase 4 clinical trial/

39. exp RANDOMIZATION/

40. Single Blind Procedure/

41. Double Blind Procedure/

42. Crossover Procedure/

43. PLACEBO/

44. randomi?ed controlled trial$.tw.

45. rct.tw.

46. (random$ adj2 allocat$).tw.

47. single blind$.tw.

48. double blind$.tw.

49. ((treble or triple) adj blind$).tw.

50. placebo$.tw.

51. Prospective Study/

52. or/33-51

53. Case Study/

54. case report.tw.

55. abstract report/ or letter/

56. Conference proceeding.pt.

57. Conference abstract.pt.

58. Editorial.pt.

59. Letter.pt.

60. Note.pt.

61. or/53-60

62. 52 not 61

63. 13 and 18 and 32 and 62

64. limit 63 to human

MEDLINE Search Strategy

1. exp Palliative Care/

2. palliat*.tw.

3. Terminally Ill/

4. Terminal Care/

5. (terminal* adj6 care*).tw.

6. ((terminal* adj6 ill*) or dying or (close adj6 death)).tw.

7. (terminal* adj6 disease*).tw.

8. (end adj6 life).tw.

9. hospice*.tw.

10. ("end-stage disease*" or "end stage disease* or end-stage illness" or "end stage").tw.

11. "advanced disease*".tw.

12. ("incurable illness*" or "incurable disease*").tw.

13. or/1-12

14. (family or families or parent$2 or mother? or father? or friend? or relative? or spous$2 or partner? or husband? or wife or wives or son? or daughter? or offspring? or sibling? or brother? or sister?).tw. and (care* or caring).mp.

15. caregivers/

16. (carer* or caregiv* or care giv*).tw.

17. exp family/

18. or/14-17

19. exp Psychotherapy/

20. Adaptation, psychological/

21. Relaxation therapy/

22. ((cognitive or cognition) adj3 (behav$ or treatment$ or technique$ or therap$ or intervention$ or restructur$ or reapprais$)).mp.

23. (behav$ adj3 (treatment$ or therap$ or intervention$ or activ$ or technique$ or modif$ or change$ or adapt$ or condition$)).mp.

24. (accept$ adj5 commitment).mp.

25. (autogenic adj (train$ or relax$)).mp.

26. (mindful$ or awareness or mood$).mp.

27. (psychotherap$ or psychological$).mp.

28. (group$ adj3 (therap$ or psychotherap$)).mp.

29. (talk$ adj3 (therap$ or intervention$)).mp.

30. counseling/

31. counsel$.mp.

32. or/19-31

33. Randomized Controlled Trials as Topic/

34. randomized controlled trial/

35. Random Allocation/

36. Double Blind Method/

37. Single Blind Method/

38. clinical trial/

39. clinical trial, phase i.pt.

40. clinical trial, phase ii.pt.

41. clinical trial, phase iii.pt.

42. clinical trial, phase iv.pt.

43. controlled clinical trial.pt.

44. randomized controlled trial.pt.

45. multicenter study.pt.

46. clinical trial.pt.

47. exp Clinical Trials as topic/

48. or/33-47

49. (clinical adj trial$).tw.

50. ((singl$ or doubl$ or treb$ or tripl$) adj (blind$3 or mask$3)).tw.

51. PLACEBOS/

52. placebo$.tw.

53. randomly allocated.tw.

54. (allocated adj2 random$).tw.

55. or/49-54

56. 48 or 55

57. case report.tw.

58. letter/

59. historical article/

60. or/57-59

61. 56 not 60

62. 13 and 18 and 32 and 61

63. limit 62 to humans

PsycINFO Search Strategy

1. exp Palliative Care/

2. palliat*.tw.

3. Terminally Ill/

4. Terminal Care/

5. (terminal* adj6 care*).tw.

6. ((terminal* adj6 ill*) or dying or (close adj6 death)).tw.

7. (terminal* adj6 disease*).tw.

8. (end adj6 life).tw.

9. hospice*.tw.

10. ("end-stage disease*" or "end stage disease* or end-stage illness" or "end stage").tw.

11. "advanced disease*".tw.

12. ("incurable illness*" or "incurable disease*").tw.

13. or/1-12

14. (family or families or parent$2 or mother? or father? or friend? or relative? or spous$2 or partner? or husband? or wife or wives or son? or daughter? or offspring? or sibling? or brother? or sister?).tw. and (care* or caring).mp.

15. caregivers/

16. (carer* or caregiv* or care giv*).tw.

17. exp family/

18. or/14-17

19. exp Psychotherapy/

20. Adaptation, psychological/

21. Relaxation therapy/

22. ((cognitive or cognition) adj3 (behav$ or treatment$ or technique$ or therap$ or intervention$ or restructur$ or reapprais$)).mp.

23. (behav$ adj3 (treatment$ or therap$ or intervention$ or activ$ or technique$ or modif$ or change$ or adapt$ or condition$)).mp.

24. (accept$ adj5 commitment).mp.

25. (autogenic adj (train$ or relax$)).mp.

26. (mindful$ or awareness or mood$).mp.

27. (psychotherap$ or psychological$).mp.

28. (group$ adj3 (therap$ or psychotherap$)).mp.

29. (talk$ adj3 (therap$ or intervention$)).mp.

30. counseling/

31. counsel$.mp.

32. or/19-31

33. Treatment Effectiveness Evaluation/

34. exp Treatment Outcomes/

35. Followup Studies/

36. random*.mp.

37. "comparative stud*".mp.

38. (clinical adj3 trial*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]

39. (evaluat* adj3 stud*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]

40. ((singl* or doubl* or trebl* or tripl*) adj3 (blind* or mask*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]

41. exp Randomized Controlled Trials/ or exp Randomized Clinical Trials/

42. or/33-41

43. 13 and 18 and 32 and 42

44. limit 43 to human

CINAHL Search Strategy

S47	S14 AND S21 AND S33 AND S46
S46	S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45
S45	TX allocat* random*
S44	(MH "Quantitative Studies")
S43	(MH "Placebos")
S42	TX placebo*
S41	TX random* allocat*
S40	(MH "Random Assignment")
S39	TX randomi* control* trial*
S38	TX ((singl* n1 blind*) or (singl* n1 mask*)) or TX ((doubl* n1 blind*) or (doubl* n1 mask*)) or TX ((tripl* n1 blind*) or (tripl* n1

	mask*)) or TX ((trebl* n1 blind*) or (trebl* n1 mask*))
S37	TX clinic* n1 trial*
S36	PT Clinical trial
S35	(MH "Clinical Trials+")
S34	S14 AND S21 AND S33
S33	S22 OR S23 OR S24 OR S25 OR S26 OR S28 OR S29 OR S30 OR S31 OR S32
S32	TI counsel* OR AB counsel*
S31	(MH "Counseling")
S30	TI ((talk* N3 (therap$ or intervention*))) OR AB ((talk* N3 (therap$ or intervention*)))
S29	TI ((group* N3 (therap* or psychotherap*))) OR AB ((group* N3 (therap* or psychotherap*)))

S28	TI ((psychotherap* or psychological*)) OR AB ((psychotherap* or psychological*))
S27	TI ((mindful* or awareness or mood*)) OR AB ((mindful* or awareness or mood*))
S26	TI (accept* N5 commitment) OR AB (accept* N5 commitment)
S25	TI ((behav* N3 (treatment* or therap* or intervention* or activ* or technique* or modif* or change* or adapt* or condition*))) OR AB ((behav* N3 (treatment* or therap* or intervention* or activ* or technique* or modif* or change* or adapt* or condition*)))
S24	TI (((cognitive or cognition) N3 (behav* or treatment* or technique* or therap* or intervention* or restructur* or reapprais*))) OR AB (((cognitive or cognition) N3 (behav* or treatment* or technique* or therap* or intervention* or restructur* or reapprais*)))

S23	(MH "Adaptation, Psychological")
S22	(MH "Psychotherapy+")
S21	S17 OR S18 OR S19 OR S20
S20	(MH "Family")
S19	TI ((carer* or caregiv* or care giv*)) OR AB ((carer* or caregiv* or care giv*))
S18	(MH "Caregivers")
S17	S15 AND S16
S16	TI ((care* or caring)) OR AB ((care* or caring))
S15	TI ((family or families or parent$2 or mother? or father? or friend? or relative? or spous$2 or partner? or husband? or wife or wives or son? or daughter? or offspring? or sibling? or brother? or sister?)) OR AB ((family or families or parent$2 or mother? or father? or friend? or relative? or spous$2 or

	partner? or husband? or wife or wives or son? or daughter? or offspring? or sibling? or brother? or sister?))
S14	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13
S13	TI (("incurable illness*" or "incurable disease*")) OR AB (("incurable illness*" or "incurable disease*"))
S12	TI "advanced disease*" OR AB "advanced disease*"
S11	TI (("end-stage disease*" or "end stage disease*" or "end-stage illness" or "end stage")) OR AB (("end-stage disease*" or "end stage disease*" or "end-stage illness" or "end stage"))
S10	TI hospice* OR AB hospice*
S9	(MH "Hospice Patients")
S8	TI (end N6 life) OR AB (end N6 life)

S7	TI (terminal* N6 disease*) OR AB (terminal* N6 disease*)
S6	TI (((terminal* N6 ill*) or dying or (close N6 death))) OR AB (((terminal* N6 ill*) or dying or (close N6 death)))
S5	TI (terminal* N6 care*) OR AB (terminal* N6 care*)
S4	(MH "Terminal Care")
S3	(MH "Terminally Ill Patients")
S2	TI palliat* OR AB palliat*
S1	(MH "Palliative Care")

Appendix 3: COREQ Checklist

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	p.64
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	p.65
Occupation	3	What was their occupation at the time of the study?	p.65
Gender	4	Was the researcher male or female?	N/A
Experience and training	5	What experience or training did the researcher have?	p.65
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	p.65
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	p. 65
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	p.65
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	p.62, 64, 65
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	p. 63
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	p. 63
Sample size	12	How many participants were in the study?	p. 66
Non-participation	13	How many people refused to participate or dropped out? Reasons?	p. 66
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	p. 64
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	p. 64
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	p. 63, 66
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Appendix 8 p. 64
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	p. 64
Field notes	20	Were field notes made during and/or after the inter view or focus group?	p. 64
Duration	21	What was the duration of the inter views or focus group?	p. 66
Data saturation	22	Was data saturation discussed?	p. 63
Transcripts returned	23	Were transcripts returned to participants for comment and/or	N/A

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	p. 64
Description of the coding tree	25	Did authors provide a description of the coding tree?	p.64 Appendix 10
Derivation of themes	26	Were themes identified in advance or derived from the data?	p. 64
Software	27	What software, if applicable, was used to manage the data?	N/A
Participant checking	28	Did participants provide feedback on the findings?	N/A
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	p. 67-80
Data and findings consistent	30	Was there consistency between the data presented and the findings?	p. 80-9
Clarity of major themes	31	Were major themes clearly presented in the findings?	p. 67-80
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	p. 67-80

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Appendix 4: Ethical Approval

Appendix 5: NHS GG&C R&D Approval

Appendix 6: Information Flyer

https://osf.io/2ntby

Appendix 7: Participant Information Sheet

https://osf.io/dt3ua

Appendix 8: Consent form

https://osf.io/k2my6

Appendix 9: Interview Guide

https://osf.io/p9qng

Appendix 10: Debrief form

https://osf.io/8zsdh

Appendix 11: Example coding

P3: So, do you know what I find more difficult? We deal with a lot of very poorly people and a lot of them come in, you know, we deal with out of hospital, cardiac arrests and things like that, and that's almost easier than the hard ones **are the ones that come in and talking to you.**	**What is difficult is the ones that come in and talking to you** **Gives example**
So, I remember a gentleman who was in his 90s. He cleaned his oven every Sunday. And on this particular Sunday, his oven exploded, and he came in with significant full burns. But completely alert totally with it, talking to us, but just with his age and the percentage of burns that he had the **decision was we couldn't treat this, and it was going to be about palliation for this gentleman.** And the anaesthetist and plastic surgeons went out to speak to his family, and **no one had told him,** and he was completely wide awake and with it. **And I'm like, someone needs to tell him, and I'd spent quite a bit of time talking to him, so I'm like I'm. I'll do it. And his family at first were a bit horrified.** And I'm like, well, no, he's fully with it. **He deserves to know.** So, I had a chat and told him, and he just said to me, can you make it quick? And I'm like, bless him because I'm like, I **can't promise that, but I can promise you we'll make it as comfortable as we can**, but	**Been unable to treat and communicating to conscious and alert patient** **No one told him (but informed family)** **Communicating end of life to elderly patient – others horrified** **Patient's wishes**

they're always harder. It doesn't matter even so much the age. It's when they are awake. I've told a lot of families that their relative is dead or dying somehow. **It's hard to telling the person, I think.**	**Very emotive story, clear imagery, compelling** **Difficult having EoL/ACP/DNR conversations**
R: Absolutely. Gosh, that story, I think I felt it here when I heard it and I think something about that communication must bring up that emotional side. Yeah. And you know understandably end of life care and death and dying is going to bring up distressing or difficult emotions. How do you manage that?	
P3: Do you know **I probably compartmentalise** quite a lot, but I still show my emotions. I think it's **human** to do that and I think if you don't then that's probably the sign that I need to stop working now, I think. And that and they're always little bits of things that get there. **But so, you just acknowledge it and move on.**	**Compartmentalise – coping?** **Human to show emotions** **Acknowledging emotion and moving on**
But we've now, I'm part of a team, we've now set up a debrief service within the emergency department, it's fairly new. So, we do both the **hot debrief** that, just like the people there can do that they've got prompt cards for. But also, then we've set up a **cold**	**Part of a team, access to debriefing** **Hot versus cold debrief**

debrief service so that anyone can request that who's been involved, and they can **request it anonymously.** So, we've not actually had any requests for any for quite a while. We did a few and then we've not had any requests for a while. And one of the **nurses that's involved, she's done a brilliant job.** So, like, literally, they can just scan a QR code that's up various places in the department anonymously. And then it would be facilitated by one of us within the **debrief team who wasn't involved with dealing with the patient.** So, we've done a few of those for some people that have been particularly emotional and challenging in one way or another, and I think that's very useful because sometimes even **just to let people talk about it** and but also acknowledge that you've got feelings about it and that that's OK. And sometimes also, **people worry about little things they did or didn't do,** and did it make a difference? So, I quite like to be able to say, particularly to more junior members of medical staff **stop worrying about that, you've been too hard on yourself, it would have made no difference whatsoever.** **R:** Yeah, that sounds like an incredibly	**Anonymised access to cold debrief** **Nurse involvement in debrief service** **Debrief team** **Letting people talk – staff support in EoL** **Worry about practice** **Feedback and reassurance**