Social Support in Palliative Care

A Realist Exploration of Hospice Day Services

Thesis submitted in accordance with the requirements of the University of Liverpool for the degree of Doctor of Philosophy by Natasha Mary Bradley

December 2020

Abstract

Hospices offer psychosocial support for people with incurable illness, and those approaching death or bereavement. This project uses mixed methods and realist evaluation principles to extend understanding of social support in palliative care. It aims to describe practice and function of social support in hospice day services, to develop appropriate methods for future effectiveness and cost-effectiveness research.

A systematic review summarises available quantitative evidence on effectiveness of palliative care interventions that facilitate social support. There is some evidence of short-term benefits to patients in psychological and physical domains, however consistent difficulties in method are reported, and social support is underexplored as an outcome of intervention.

An online survey of hospice day service managers in the UK & ROI establishes an overview of services that facilitate social support for people living in the community with life-limiting illness. These are: multi-component interventions, activity groups, formal support groups, befriending, and informal social activities. The survey documents a diverse and evolving sector that is active in facilitating social support.

A longitudinal cohort study observed patient outcomes using validated measures of perceived social support, loneliness, depression, and health-related quality of life. Participants (n=30) are recruited across four locations, but attrition is high. The outcome measures appeared acceptable to patients, and sensitive to change. Improvement is observed in emotional support (a subscale) and in loneliness (n=19).

Qualitative investigation included nineteen interviews with hospice service-providers. Analysis using realist principles provides explanation of how patient and hospice context might interact to produce beneficial mechanisms that lead to outcomes beyond the hospice. Reciprocity and honesty within the group could be enabled through autonomy and familiarity. These processes could reduce and improve acceptance of change and mortality.

This thesis proposes an initial programme theory that can be extended or developed. It suggests how, in some contexts, social opportunities lead to changes in emotions and behaviour, that might ultimately increase personal and practical resources to cope with illness and death. Hospices might seek to foster beneficial social support, and collective opportunities to acknowledge mortality.

Acknowledgements

This thesis was made possible by the wisdom of my supervisors, the generosity of devoted hospice staff, and the incredible support from family and friends. I am truly grateful for the enthusiasm of so many people who gave their time and energy towards developing this project and encouraging this researcher.

I wish to dedicate this thesis to the memory of my grandmother, Jean Johnson. Her life started this journey, and many others.

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Chapter 1: Introduction

This chapter is an introduction to the thesis, intended to set the scene for subsequent chapters by providing a brief outline of relevant concepts and an overview of chapters. By summarising existing work on the effectiveness of palliative care, this chapter demonstrates the key concerns of this research project. In particular, that hospice care is explicitly holistic, responding to psychosocial concerns as well as symptomatic and spiritual aspects, yet effectiveness research has often overlooked the relevance of non-clinical needs in determining palliative care experience, patient outcomes, and healthcare costs. The definitions used by this thesis for key terms are collected in appendix A.

1.1 Overview of Chapters

Chapter 1: Introduction to the Thesis

This initial introductory chapter describes in depth the field of practice into which this research investigation was held. The chapter introduces modern hospice day services and explains their position of interest for researching social support in palliative care. The literature reviewed identifies limitations of the existing research and demonstrates some of the challenges inherent to palliative care research.

Chapter 2: Literature Review

The literature review chapter presents a more detailed review of research and concepts describing the significance of social support for health and wellbeing - generally in the population, and specifically in palliative care. The aims and rationale of the research project are articulated at the end of this narrative review, exploring the significance of social support and the complexity of beneficial intervention.

Chapter 3: Systematic Review

The systematic review was carried out to identify the available quantitative evidence on the effectiveness of social support interventions in palliative care. Several categories of intervention were reported, but existing evidence is limited by sparse investigation, recruitment and attrition challenges, and inappropriate outcome measures. The initial systematic review was published in January 2018 and informed research design for this project. The review was updated in October 2020.

Chapter 4: Methods

The methods chapter explains and justifies the methodological approach of this thesis and the methods for data collection and analysis of each component. As a mixed methods study, this chapter is also important to explaining how the different strands of work fit together and relate to a realist evaluation framework.

Chapter 5: Survey

The online survey was conducted to gain an overview of service provision by contacting hospices in the UK & ROI to ask how they facilitate social support for people with life-limiting illness living in the community. Responses are used to describe the sample and to produce a typology of services identified. The knowledge gained informed purposeful sampling of research locations for subsequent stages.

Chapter 6: Patient Reported Outcome Measures

Patients were recruited who were about to start attending a social service at one of four hospice locations. Patient reported outcome measures used the domains of perceived social support, depression, loneliness, and health-related quality of life. This chapter reports on the use of this method, sample recruited (n=30), and analyses change over time for participants with more than one timepoint (n=19).

Chapter 7: Qualitative Findings

Qualitative interviews were held with nineteen staff delivering or designing social support interventions at nine hospices across England. This chapter presents an analysis of qualitative interviews that is underpinned by the principles of realist evaluation, leading to the construction of context-mechanism-outcome configurations as partial explanatory devices to understand these interventions.

Chapter 8: Discussion

The discussion chapter summarises empirical results and draws on relevant literature to develop an initial programme theory for social support in palliative care, and to further the conceptualisation of social support as essential to meet universal human needs.

Chapter 9: Conclusion

The final chapter concludes the thesis by articulating key findings and recommendations for practice, research, and policy.

1.2 Palliative Care: Practice and Outcomes

1.2.1 Palliative care in the UK

The objective of palliative care is to prevent and relieve the suffering of patients with life-limiting illness and their families, by responding simultaneously to physical, psychological, spiritual, social, cultural, and situational needs (Krikorian et al, 2011). Hospices are prominent providers of palliative care, supporting people with a palliative diagnosis and the people around them to cope and live actively until death. Hospices provide services to more than 225,000 people in the UK each year (Hospice UK, 2018). Palliative care in cancer has been shown to reduce symptom burden and resource utilization for some patients, while improving quality of life; and evidence is emerging for non-malignant disease (Rocque & Cleary, 2013).

Most hospices in the UK and ROI are independent charities working within and alongside the local health and social care system. On average, adult hospices in the UK receive 32% government funding and rely on fundraising and legacies for income (Hospice UK, 2018). Although inspected by the same regulatory bodies as statutory services, hospices are generally self-determining - hospice activity can vary according to the ethos of each hospice as well as local patient need and the characteristics of a local area (e.g. staffing, transport, availability of other services). Different hospices offer different services to different patients for different reasons - site-level variations in practice are well-established (Spencer & Daniels, 1998) and continuing to flourish (Payne et al, 2017).

The practice of hospice care is distinct from traditional medicine because of its holistic philosophy of care, set apart from biomedical intervention with a curative intent. Saunders (1964) described suffering near the end of life which arises from unmet physical, psychological, social, and spiritual need - a pain from all sides, for which the phrase ‘total pain’ was coined and ultimately became foundational to hospice philosophy. Supportive care of palliative patients today requires these domains of quality of life to be considered in addition to those related to disease self-management and preparedness for death (McCaffrey, 2016).

Each hospice differs in their interpretation of a holistic approach, and might emphasise one domain over another, but there are often numerous services offered to meet the varied needs of different patients (Higginson 2000). Professional activity usually involves multidisciplinary teams, and inter-agency collaboration working to co-ordinate care (Fernando & Hughes, 2019). Most patients access hospice services without an inpatient stay – they receive hospice care within their own homes or attend the hospice for a few hours or a whole day (Hospice UK, 2016). Only a minority of hospice services involve staying overnight, with the majority (83%) occurring as homecare, outpatient services and hospice day care.

Access to palliative care has been a long-standing challenge. Gradually, service provision to those with non-cancer diagnoses has grown, but it is not yet suggested that access to palliative care is equitable between malignant and non-malignant conditions. Access to hospice care appears to be starkly determined by socioeconomic and demographic factors (Allsop et al, 2018) and trends suggest the gap between most deprived and least deprived areas is widening over time (Sleeman et al, 2016). As an upstream intervention, public health palliative care might achieve better dying for everyone, not just for groups who are traditionally more likely to access hospice care. Advocates for public health palliative care argue that achieving equity in care at the end of life requires us to understand dying and caregiving as social problems that have medical aspects, rather than medical problems with social aspects (Abel & Kellehear, 2016). Increasingly diverse service models are being reported in the literature that reflect hospice support being embedded with other hospice goals, such as the ‘opening up’ of hospice care.

1.2.2 Hospice day services

The first hospice day care centre for people living with incurable cancer and chronic disease was opened by St Luke’s hospice in Sheffield in 1975 – by the turn of the century, there were over 220 day hospices in the UK (Spencer & Daniels, 1998). Through holistic care and social opportunities, hospice day care seeks to provide opportunities for rehabilitation within the constraints of illness, addressing holistic quality of life as well as symptom control and continuity of care, preserving dignity and enabling individuals to continue living at home (Spencer & Daniels, 1998; Thompson, 1990). Hospice day care offers social support in a secure and supportive environment that allows engagement in meaningful activities, which is thought to reduce isolation and dependency (Seale, 1991). Benefits are also suggested to extend to the family, who gain informational and emotional support as well as respite opportunities (Corr & Corr, 1992).

Hospice day care can improve symptom control and continuity of care, potentially reducing avoidable declines and care costs, and providing a transition environment to introduce hospice care to patients with declining function (Vandaele, Chambaere & Devisch, 2017). Hospice day care is purported to be cost-effective by reducing the use of more expensive healthcare services, but underlying expenditures such as building and staffing costs could be equally expensive regardless of the setting of care. Arguments of cost-effectiveness are undermined if day care ultimately acts as an additional (rather than replacement) service - it is possible that day care may increase requirement for inpatient hospice care at the end of life if it succeeds in its goal to be an introduction to services, leading to a 'climate of expectation' for future inpatient care (Spencer & Daniels, 1998).

However, defining research methods appropriate to assess these assumptions is not straightforward. An initial challenge comes in identifying and agreeing an appropriate outcome – one that is both measurable and aligned with the goals of the intervention. As described above, hospice day services have a broad purpose that may mean different things in different facilities. Differences in activities, client groups, organisational structure and available therapies reflect a variety of service provision such that it has been suggested that day care leans either towards the medical needs or social needs of patients (Horobin, 1987 – cited in Spencer & Daniels, 1998). The medical or social focus of care could be influenced by input from different members of a multidisciplinary team and/or the needs of the community (Spencer & Daniels, 1998).

An investigation of palliative day care in the UK (Goodwin, 2003) concluded that social outcomes should be included in the evaluation of such services. Goodwin argued that health-related quality of life is not a true representation of quality of life and inclusion of social domains in outcome measurement is necessary when aims are explicitly social. However, a panel of experts participating in a recent Delphi study of quality indicators for palliative day services did not include any social structures, processes, or outcomes (McCorry, 2018). This could be interpreted as a matter of difference in stakeholder perception or reflect a genuine distinction (re)emerging between 'medical' and 'social' hospice services.

Community engagement within public health palliative care can build capacity for care within the community and improve death awareness - increasing the availability of nonprofessional support for those living with life-limiting illness and their families. Enriching community assets in this way could free up material resources to extend professional input to everyone with specialist palliative care needs (Abel & Kellehear, 2016). A survey of UK hospices found public health projects to be a priority for most respondents, who described work with schools, engaging with community groups, raising awareness of end-of-life care issues, and compassionate community initiatives to all be successful approaches to public health in palliative care (Paul & Sallnow, 2013). The specific details of these interventions and the extent to which patients themselves benefit remains unclear. However, initiatives characterised by community members and patients coming together seems likely to have social relevance at the interpersonal as well as the societal level.

An alternative perspective comes from rehabilitative palliative care, which aims to empower the patient to cope and remain active in society for as long as possible, often using exercise and education to achieve person-centered goals in time-limited group interventions. Here, the focus is on the individual and their functional ability – yet groupwork is a feature. Malcolm and colleagues (2016) emphasise that being in an exercise group with other patients is important for patient experience, and possibly the success of a rehabilitative intervention – patients gain comradeship and a sense of achievement that builds their self-esteem and confidence beyond the confines of the programme. Peer support in rehabilitative palliative care is understood as relating to shared experiences and verbal encouragement, that create understanding and a sense of normality between group members (Rutkowski et al., 2018). Although patients attend the hospice for a different purpose, the social value of being able to get out of house for an exercise class is remarkable (Malcolm et al, 2016).

This review of literature emphasises that day services provided by hospices often have a range of components offered, with different intended outcomes, and variations between sites and between patients. It is therefore a complex intervention (MRC, 2019). Clinical or nursing staff and symptom-focused treatment are commonly provided, alongside some form of group involvement or social interaction with other people (including but not necessarily limited to other patients), and thus the opportunity to gain social support. However, the richness of this area in practice and the significance of social support to patients is not consistently acknowledged.

1.2.3 Patient outcomes

There is evidence supporting the effectiveness of specialist palliative care in improving patient outcomes in palliative care. In a meta-analysis of randomised controlled trails of palliative care interventions across patient populations, Kavalieratos and colleagues (2016) reported palliative care intervention to be associated with improvement in quality of life and symptom burden for the patient (outcomes for caregivers and regarding healthcare expenditure were more mixed). A more recent meta-analysis in advanced cancer reported patients randomised to outpatient specialist palliative care to have higher quality of life (n=1398) and improved survival (n=646) compared to controls (Hoerger et al, 2019).

The association between specialist palliative care intervention and positive patient outcomes is clearest when palliative care is delivered early (Gaertner at al, 2017; Qureshi et al, 2019). Early palliative care includes comprehensive assessment and response to patient symptom burden and mood disturbance, assistance with decision-making, and increases in social support, which might improve wellbeing and potentially impact survival (Irwin, 2013). A single-site randomised trial (n=107) reported patients recently diagnosed with metastatic lung cancer had better quality of life and mood, less aggressive end-of-life care, and had a longer median survival time than controls (Temel, Greer, et al, 2010). Results of randomised controlled trials of early palliative care in advanced cancer have shown positive outcomes for quality of life and symptom intensity, but evidence for depression and survival is more mixed (Haun et al, 2017). Integrating outpatient palliative care into oncology shows associations with improved patient quality of life, symptoms, and mortality (meta-analysis of 10 studies, n=2385 – Fulton et al, 2018).

Randomised trials indicate outpatient palliative care to be beneficial, but participant samples to be homogenous: even within a meta-analysis, participants are generally white and in their sixties, with many recruited from the same region in the US (Hoerger et al, 2019). This is concerning, because some trials have reported palliative care outcomes to be moderated by gender, age, and diagnosis; so that evidence is stronger for male patients, younger patients, and lung cancer (Nipp et al, 2018). Evidence for survival benefit of psychosocial intervention in cancer appears strongest for participants who are unmarried and over 60 (Mirosevic et al, 2019). Large reductions in depression and small reductions in anxiety have been reported from randomised trials of psychotherapy in palliative care – in this case, evidence is stronger for younger patients (Fulton et al, 2018). Gender differences in anxiety and fatigue in advanced cancer have also been reported (Siemens et al, 2020). Randomised controlled trials in palliative care have been limited by poor recruitment, attrition, confounding variables, and small sample sizes, which all have potential to bias findings (Higginson et al, 2013). The underlying mechanisms by which age, gender, and other sociodemographic characteristics can influence patient experience and effectiveness of palliative care intervention are largely unknown (Nipp et al, 2018). Publication bias is likely (Fulton et al, 2018) and effects may be overstated when attrition and missing data are poorly managed (Hussain et al, 2016).

Qualitative investigation has consistently reported beneficial psychosocial experiences for patients attending palliative day care, but research testing the psychosocial outcomes of palliative care intervention has been somewhat sparse (Bradley et al 2010, Bradley et al 2018, Stevens et al 2010). Group therapy in the context of incurable illness appears effective in reducing stress (Amir et al, 2017). Both a therapeutic narrative intervention and palliative day care appear to reduce patient depression in advanced cancer, with effects lasting several weeks (Lloyd-Williams et al, 2013). Providing a supportive environment for emotional expression and cognitive reflection can have a lasting impact on depression in palliative care (Lloyd-Williams et al, 2018).

Those newly diagnosed with advanced cancer experience low quality of life due to their symptoms and their fears for the future (Siemens et al, 2020) – early interventions that improve symptom management and improve coping skills might have the potential to reduce their distress before it escalates to a crisis. The potential ramifications of unresolved distress are extensive, as such proactively addressing distress in practice could reduce the societal costs of illness (El Alili et al, 2020).

1.2.4 Healthcare costs

Palliative care might be able to improve patient care *and* reduce healthcare expenditure, *if* it is successful in preventing avoidable hospital admissions, reducing futile treatments or invasive diagnostics, and increasing uptake of advanced care planning. Palliative care is associated with patient and caregiver satisfaction, advanced planning, and lower healthcare utilisation (Kavalieratos et al, 2016). A recent systematic review reported that palliative care received in any setting reduces healthcare utilisation in advanced cancer – with early intervention again appearing most robust in impact, this time on cost (Yadav et al, 2020).

Receiving palliative care in the last year of life does appear to make emergency hospital visits less likely (Bone et al, 2019); however, this review is dominated by studies from the US which has a markedly different healthcare system than the UK. For example, cancer patients (n=754) in the US who attended an outpatient symptom management program were less likely than matched controls to visit the emergency department or receive aggressive end-of-life care as measured by hospitalisation, intensive care unit admission, or chemotherapy in the last two weeks of life (Conlon et al, 2019). They were almost 20% less likely to die in hospital. Controlling for age, sex, comorbidity, disease duration, disease site, urban/rural residence, income quintile and year, this is a large and robust study; but its transferability is limited because description of the intervention itself has been neglected.

A population-level matched cohort study in Belgium reported that those receiving palliative home care (whether multidisciplinary, nurse- or physio-led) had markedly fewer hospital admissions, intensive care stays, emergency visits, invasive healthcare procedures, and hospital deaths than matched controls receiving usual care (n=8837 in each group, matched by patient characteristics including clinical and socioeconomic variables; Maetens et al, 2018). Despite having more contacts with their primary care clinician, total healthcare costs in the intervention group were estimated to be €1617 lower than in usual care (Maetens et al, 2018). Similarly, a matched cohort study in Ontario, Canada showed that multidisciplinary community-based specialist palliative care teams targeting symptom management, patient education, care coordination, and ongoing conversations about care preferences was associated with a mean reduction in total care costs of $512 compared to controls receiving usual care. The savings were almost entirely driven by avoiding hospital costs (Seow, Salam-White & Bainbridge, 2019). Finally, a population-based study in Emilia-Romagna, Italy explored the effectiveness of palliative home or inpatient hospice care also reported that palliative care was associated with fewer hospital deaths, emergency department visits, hospital admissions, intensive care stays and operations; and increased access to opiate pain relief (De Palma et al, 2018).

A retrospective cohort study in Leeds, UK (n=2479) indicated that cancer patients who received palliative care prior to death were less likely to die in hospital, less likely to have an emergency admission to hospital in the last 4 weeks of life, less likely to receive 'late' chemotherapy and more likely to receive strong pain relief in the last year of life (Ziegler et al, 2018). Furthermore, the timing and frequency of palliative care was associated with these outcomes – those receiving palliative care a longer time before death were more likely to avoid hospital death, have opioid access, and end chemotherapy, suggesting that sufficient time is needed for palliative care to achieve favourable outcomes at the end of life (Ziegler et al, 2018). This study is a valuable contribution using administrative clinical data to demonstrate that access to palliative care services is associated with better patient outcomes, however the study was unable to include symptom prevalence or severity and so it is not clear that palliative care *caused* better outcomes. This design does not consider potentially confounding psychosocial variables or features of the socioeconomic context beyond postcode. Access to palliative care is not equitable, and we know little about the 35% of patients dying of cancer in Leeds during the study period that did not receive palliative care (Ziegler et al, 2018).

Yi, Johnston, Ryan, et al, 2020 conducted a retrospective survey of care costs in England, Ireland & US (n=767). Analysis of UK responses (all London – n=245) demonstrated that 83-86% of identified care costs in the last 3 months of life were associated with hospital care. Costs in specialist palliative care or hospice settings and in community care were low. Furthermore, hospices and palliative care units had by far the greatest satisfaction reported by carers (compared to care homes, hospitals, and home deaths). The findings of this study suggest that it is not cancer or multimorbidity driving high care costs at the end of life, but older age, economic deprivation, and poor experiences of home care.

Analysis of patient records in London indicated costs of state-funded care in the last year of life for adults over 50 to be £7,450, of which £4,218 was to unplanned hospital care (Jayatunga et al, 2019). Cost-savings associated with specialist palliative care consultation are largely driven by reduced length of hospitalisation, with reduced intensity of treatment also contributing (May et al, 2017). Financial costs in health and social care settings in the last year of life are concentrated in emergency and inpatient hospital care (Jayatunga et al, 2019) and the estimated cost saving per patient saving by avoiding a hospital death is estimated to be

£958 (Dixon, Matosevic & Knapp, 2015) - this is before considering the additional psychological cost of a distressing and avoidable hospital death. It is therefore optimistic for both the treasury and the empath that palliative care initiated more than 4 weeks before death is associated with avoiding emergency hospital admission at the end of life (Ziegler et al, 2018).

A systematic review of reviews concluded that palliative care appears to show benefits to patients, irrespective of the setting, and that some models of palliative care may reduce healthcare expenditure (Brereton et al, 2018). However, there is very little research evaluating the cost-effectiveness of different palliative care models (Mathew et al, 2019). Furthermore, the majority of studies discussed above evaluate outcomes of input from a specialist palliative care clinician, oncologist, or team of healthcare professionals into the illness journey of identified palliative patients, with interventions taking place within home, hospital, or inpatient end-of-life settings. This professionalised and clinical focus does not correspond to the holistic emphasis of palliative care as defined by the World Health Organisation or the broad practice of hospice care in the UK, which is characterised by intervention complexity and variability, with a high degree of volunteer input and peer interaction.

Non-symptomatic healthcare domains such as shared decision-making, respect, emotional support, spiritual support, and care coordination make important contributions to perception of care quality at the end-of-life, potentially even more so than symptom management (Kricke et al, 2019). Discussion and exploration with patient on the goals of care, and guidance on planning for change, might ultimately be what helps the patient avoid hospitalisation. Therefore, these social processes may be at least as relevant for cost-saving as the avoidance of unnecessary diagnostic tests and pharmaceuticals (May et al, 2017). Feasibility work has indicated that a nurse-led multidisciplinary intervention in advanced heart failure in the UK (inc. care coordination by an assigned specialist, holistic assessments of patient and carer, and additional training for healthcare professionals) led to a better patient experience, fewer nights in hospital, more advanced care planning documentation, and possible cost savings overall (Johnson et al, 2018).

1.3 Conclusion

This chapter introduces the holistic philosophy that underpins palliative care. Day services provided by hospices often have a range of components offered, with different intended outcomes, and variations between sites and between patients. It is therefore a complex intervention (MRC, 2019). Clinical or nursing staff and symptom-focused treatment are commonly provided, alongside some form of group involvement or social interaction with other people (including but not necessarily limited to other patients), and thus the opportunity to gain social support. Yet the richness of this area in practice and the significance of social support to patients is not consistently acknowledged.

The aims of palliative care interventions are multiple, and potentially contested. However, due to population changes and the socio-political context, it is vital that we improve understanding of mechanisms that support patients to continue living at home and avoid hospital (Brereton et al, 2019; Hasson et al, 2020). Health-related benefits have been identified in palliative care - particularly for hospital and home-based care - but these interventions might not be comparable to the complex interventions offered by hospice day services. It remains unclear what outcomes should be considered as primary when health-related improvements are not expected. Identifying mechanisms through which hospices might reduce avoidable health and care costs could indicate high-value components of their services- yet there are stark gaps in knowledge about the important non-clinical mechanisms by which palliative care can change a patient's trajectory (Irwin, Greer, et al, 2013).

In the next chapter, literature is reviewed indicating multiple routes by which social support in palliative care might be impactful on patient experience and outcomes. It is argued that the emotional, social, and physical world are intractably enmeshed in people's real lives - a perspective which aligns well with the hospice movement's holistic philosophy of care.

Chapter 2 : Literature Review

The chapter is a narrative discussion of relevant research that introduces relevant literature and concepts, leading to the rationale for this research project exploring social support in palliative care.

‘Social support’ refers to the resources we gain through interaction with others, including tangible, emotional, or informational support, and companionship. In patients, social support is associated with psychological health and illness experiences, but the effectiveness of intervening to provide social support has been difficult to establish. People living with life-limiting illness are at risk of loneliness and social isolation, which may restrict their ability to engage in health behaviours and contribute to distress near the end of life. Hospice day services aim to meet unmet social needs of palliative care patients, but interventions are poorly described, and outcomes are unclear.

2.1 Significance of Social Support

Social support is defined as resources gained through interpersonal interactions and relationships. The phrase refers to functions that people fulfil for each other’s benefit, in that social support can be instrumental, informational, or emotional (House and Kahn, 1985); however social support as a concept goes beyond the simple receipt and reciprocation of transactions for obvious functions. Social resources are derived through time spent together in companionship, contributing to feelings of belonging and trust in future support. A subjective sense of inadequate social support can be described as loneliness. Extensive research in the general population has indicated that social domains including actual and perceived social support are associated with quality of life and an array of physical, behavioural, psychological, and societal outcomes.

2.1.1 Physical health

We are a social species. Our desire for social connection is considered an essential biological need tied to our survival (Holt-Lunstand, 2018). The severity of social isolation for humans is clear when we consider its impacts at the biological level. Extensive experimental work has demonstrated negative impacts of social isolation on cognitive and cardiovascular function (White et al 2015). Detrimental effects of social isolation for the immune system, neuroendocrine axis, and autonomic nervous system have been shown to accumulate as a pro-inflammatory state at the cellular level, increasing the risk of cardiovascular and cerebrovascular disease (both incidence and severity) (Friedler & Crapser, 2015).

The presence of social support, the absence of positive social relationships, and the subjective feeling of loneliness have each been demonstrated to be predictive of future morbidity and mortality via large meta-analyses (Cacioppo & Cacioppo, 2014; Leigh-Hunt et al., 2017; Holt-Lunstad et al, 2010; Holt-Lunstad et al, 2015). Social disconnection is linearly associated with increased mortality risk, whether its due to social isolation or loneliness (Steptoe et al, 2013; Tanskanen & Anttila, 2016). Whilst is not straightforward to draw conclusions on causality from observational data, prospective longitudinal work has demonstrated social disconnection to precede poor health and mortality; as such there is strong evidence that levels of social isolation and integration are predictive of morbidity and mortality risk (Holt-Lunstad, 2010; Yang, et al., 2016). Furthermore, the increased mortality risk exists on a continuum so that the socially isolated are most affected, but those who experience mild to moderate social isolation are increasingly at risk (Tanskanen & Anttila, 2016).

Social isolation and loneliness are consistently related to poorer health outcomes and all-cause mortality, but direct associations between loneliness and physical health outcomes are less clear than those linking social isolation and physical health (Leigh-Hunt et al., 2017). Synergistic interactions observed between loneliness and social isolation on mortality suggests that higher isolation increases the effect of loneliness, and higher loneliness increases the effect of isolation, so that both are important for predicting physical health (Beller & Wagner, 2018). However other observational research has reported that objective social isolation is associated with increased mortality only in situations where the person also experiences subjective loneliness (Holwerda et al, 2012).

Social surroundings determine health through interacting behavioural, psychological, and biological processes: consider how those with abundant social contact might participate in health behaviours with greater ease, seek and access help more promptly when required, and benefit from increased opportunities for interpersonal coping (White et al 2015). However large prospective epidemiological research indicates that social aspects are important beyond their influence on health behaviour and income. For example, social engagement is associated with mortality in older men (US, n=5925) and this association remained when controlling for smoking, alcohol, exercise, weight, disability, comorbidity, and socioeconomic factors – thus social engagements appears protective, independent of behavioural factors and disability (Ramsay, Ebrahim, Whincup et al, 2008).

Social integration and social support have been observed to reduce activation of the brain's threat responses in neuroimaging studies (Ditzen & Heinrichs, 2014). Threats of social exclusion or rejection activate neural circuits evolved for detecting threats to our survival - social perceptions can trigger downstream hormonal and cellular processes as if in response to physiological threat, changing immune and sleep function (Eisenberger & Cole, 2012). The influence of social support on the cardiovascular, neuroendocrine, and immune systems does not appear to be mediated by anxiety, distress, depression, or altered mood in general (Uchino et al, 2012). Social exclusion and loneliness both predict pain in the general population (Allen et al, 2020). However, it is not a simple case of 'more is better' - relationship conflict, negative social interactions, unwanted social support, and ambivalent social relationships can also negatively impact health (Holt-Lunstad, 2018; Holt-Lunstad & Uchino, 2019; Shor et al., 2012; Seeman, 1996).

2.1.2 Mental health and wellbeing

Objective social support is associated with physical and mental health over time, including mortality; but the belief that the right support is and will be available appears to be more relevant for mental health and wellbeing (Thoits, 1995). Loneliness appears strongly associated with mental health – loneliness is an independent risk factor for depression, controlling for potential confounds including social isolation, demographics, and marital status (Cacioppo et al, 2010).

A conceptual distinction between perceived and received social support is not straightforward because social network characteristics influence the availability of social ties, and the receipt of social support over time influences the perception that social support is available for the future. However, it is important to note that the actual count of social ties or supportive acts may not represent the experience of social support for that person – it is the subjective experience of social disconnection, rather than an objective lack of social contact, that could be most debilitating (Luo et al, 2012). Similarly, meaningful connections to other people are more influential for loneliness and health outcomes than the actual number of individuals in a social network or amount of time spent with others (Segrin & Passalacqua, 2010).

Unpacking causality between social domains and mental health outcomes suggests a reciprocal relationship (Courtin & Knapp, 2017). The presence of depression can influence the perception of social support in older people with multimorbidity (Wicke et al, 2014). However, the subjective experience of social disconnection has been shown to be a stronger predictor of psychological distress year-on-year than vice versa (Saeri et al, 2018). Although associations between loneliness and mental health disorders are longitudinally bidirectional in community-living elderly, experiences of loneliness can predict a later degradation of social network, but not vice versa (Domenech-Abella, 2019). In a sample of relatively health community-dwelling older adults (n=237), social support appeared to buffer the impact of depressive symptoms on life satisfaction, controlling for perceived stress and self-rated health (Adams et al, 2016). Loneliness and depressive symptoms have a synergistic effect that can decrease wellbeing in older age groups (Cacioppo et al, 2006).

The presence of a supportive, confiding relationship that reduces feelings of loneliness is protective against the psychological impacts of stressful life events and chronic difficulties (Cohen and Wills, 1985 ; Segrin & Passalacqua, 2010). Perceived emotional support is directly associated to health outcomes but also serves an indirect role in buffering the physical and mental consequences of stress (Thoits, 1995). This stress-buffering hypothesis is well-established, but it is simplistic because social ties can be a source of stress in themselves - particularly the demands associated with obligatory relationships, whereas responsibilities in voluntary relationships might be more manageable/escapable and therefore less stressful (Thoits, 1995).

Social isolation has been linked to a diverse range of contextual precedents and behaviours that might contribute to poorer mental and physical health. Eg: social isolation is associated with having a cold home during winter, which increases mortality risk for older people (Sartini et al, 2018). Social support appears to protect against functional decline over time – including informal interactions, organised activity, and group leisure, but perhaps not paid work (Gao et al, 2018). Loneliness might also mediate the relationship between social support and poor health, via perceived stress and health behaviours (especially treatment adherence and poor sleep) (Segrin & Passalacqua, 2010). Loneliness appears to mediate the effect of interpersonal stress on psychological distress (Aanes, Mittelmark & Hetland, 2010). Social strain within the family is associated with depressive symptoms, and again, loneliness mediates this relationship (Santini, et al, 2016).

2.1.3 Health management

The access and availability of social resources shapes a person's capacity, responsibility, and motivation to aim for better health (Coventry et al, 2014). It appears that a rich social network can contribute to the management of chronic health conditions – social involvement, such as being a member of multiple voluntary and community groups, is associated with better self-management and health over time in people with long-term health conditions (Reeves et al, 2014).

Social support influences individual's behaviour, including healthy or unhealthy daily habits, and their attitudes towards help-seeking. People with many supportive relationships have more opportunities to obtain tangible and timely assistance when they need it, including help to get to healthcare appointments and to make decisions about their health (White et al, 2015). Social support enables treatment adherence through several mechanisms – indirectly through support in mastering new skills, and more directly through motivation to adhere to the treatment plan, although the perceived credibility of the support-giver can be crucial (Maula et al, 2020).

Social support is significantly related to treatment adherence in hypertension (Magrin, 2015); however, this association is not present for marital status or living arrangements. It appears that families support self-management generally but can sometimes present family-related barriers to self-care, which are associated with lower disease self-efficacy for long-term conditions (Rosland et al, 2010).

Social isolation and loneliness are particularly problematic for people experiencing changes in mobility, limitations in physical function, and/or decreasing economic or social resources (Courtin & Knapp, 2017). Emotional loneliness is associated with low self-efficacy, less positive state of mind, and less initiative taking to improve health in older adults (Nieboer, Hajema and Cramm, 2020), as well as increasing frailty (Mehrabi & Beland, 2020).

It is possible that poor physical health contributes directly or indirectly to feelings of loneliness. Perissinotto, Stijacic and Covinsky (2012) identified that loneliness predicts mortality, and increased difficulty in activities of daily living in older people (n=1604, US) but could not rule out a bidirectional relationship, in which poor functioning leads to loneliness (Perissinotto et al, 2012). Tanskanen and Anttila (2016) found those with the poorest health reported the highest levels of loneliness, raising the possibility that self-rated health could be a mediator by which loneliness impacts mortality (n=8650, Finland). In their model, loneliness was independently predictive of mortality, but not when social isolation was accounted for.

These findings corroborate work by Steptoe and colleagues (2013), (n=6550, UK), who found poor health at baseline to be more strongly related to loneliness over time than to social isolation, but the association between loneliness and mortality was not significant when baseline health, functional limitation, and depressive symptoms were also considered. This evidence is an indication that subjective loneliness (and therefore its consequences) could be characteristic of people who have substantial health and mobility problems (Steptoe et al, 2013). However other reports suggest that low social support increases risk of re-hospitalisation, independent of physical and mental health (Valkorta et al, 2018).

Loneliness is a risk factor for the development of depression, fatigue, and pain in both patient and non-patient participant groups (Jaremka et al, 2014). Conversely, absent or decreasing loneliness predicts good self-rated health in the future (Nummela, Seppanen & Uutela, 2011). Epidemiological reviews suggest that loneliness does appear a consequence of chronic physical ill-health, but that it also acts as a risk factor for poor health, poor sleep, mental health symptoms and cognitive decline (Lim, Eres & Vasan, 2020).

Evidence can be limited by complexity of relationships between concepts, a lack of longitudinal work, and low diversity in participant samples - but social support does appear important self-management and shared decision-making around health (Graven & Grant, 2014). Taken together, the consequences of social domains for mental health, health behaviour, and health and service utilisation indicate that social isolation and loneliness contribute a substantial and increasing cost to society (Mihalopoulos et al, 2020).

2.2 Social Support in Life-Limiting Illness

The research reviewed so far presents an evidence-based argument for social support to be considered an upstream intervention target for health intervention, because of its impacts on mental health, morbidity, and mortality (Leigh-Hunt er al, 2017). The absence of supportive relationships is likely to lead to loneliness and poor mental health; the absence of any relationships can be catastrophic. Our mental health, physical health, and social health are truly interconnected, and as such people living with declining function could be at risk of declines in other domains.

Social isolation and loneliness are consequential for health in most people, but they might have profound potential for suffering in the advanced illness patient. There are multiple routes by which the tangible and intangible resources obtained as social support might enable or disable a person living with illness. This section focuses on patient populations - particularly those living with life-threatening or incurable disease - to explore what is known about social support, and the potential ramifications of loneliness and social isolation.

2.2.1 Social support for coping with life-limiting illness

Quality of life is a multidimensional construct that goes far beyond health-related: older people value social contacts as much as health status when defining what quality of life means to them (e.g. Farquhar, 1995). A metasynthesis of the experience of lung cancer patients concluded that being ‘healthy with cancer’ means living with connection to everyday life activities – “health is thus regarded as a social more than a medical concept” (p. 91, Salander & Lilliehorn, 2016).

What would it mean to be coping well, living life to its fullest, with life-limiting illness? Research describing positive coping strategies in advanced illness frequently emphasise the social aspects of coping. Social networks provide access to relationships and resources which support the individual practically and emotionally in managing their condition (i.e. social support). Patients may have increasing needs for tangible support to manage both their health and their healthcare regime. The social context also provides motivation to engage with health behaviours towards functional goals and mental wellbeing. Palliative care patients actively draw supportive resources from people in their immediate family, the wider community or religious group, and interactions with healthcare professionals (Warmenhoven et al, 2016).

Relationships play a substantial role in shaping people's experiences of illness – with strong social support related to better treatment adherence and active coping methods. Emotional support is very commonly reported as a coping strategy in patients with incurable cancer (n=350) and is associated with better quality of life and reduced psychological distress compared to other coping strategies (Nipp et al, 2016). Social support, especially emotional support, predicts patient self-care confidence and self-reported symptom management in heart failure patients (Fivecoat, Sayers & Rigel, 2018). Perceived social support is significantly related to both treatment adherence and health-related quality of life in end-stage kidney disease (Varghese, 2018). An observational study of advanced cancer patients entering palliative care (n=85) showed that those seeking social support and positive reappraisal were less likely to experience hopelessness and depression, whereas avoidant coping was associated with increase anxiety (Sorato & Osaorio, 2015)

A person with a social network containing both strong and weak ties is better equipped to take on the self-monitoring and skill acquisition tasks required to manage long-term illness (Reeves et al, 2014). This may mean that hospital admissions, re-admissions, and emergency department visits are more common for patients without access to social support (Valkorta et al, 2018). Social isolation is associated with hospital readmission in chronic diseases such as heart failure (meta-analysis, n=6488, Gorji, Fatahian & Farsavian, 2019). Prevalence for living alone and lack adequate social support was high amongst patients with more frequent hospital readmissions, but the mechanisms by which social isolation might increase risk of hospitalisation are unclear (Gorji et al, 2019).

Self-management strategies of patients with advanced cancer are highly dependent on their social context and enabled by peer support particularly (van Dongen, 2020). Pre-cancer coping strategies can be stretched by the challenges of illness, but patients can develop new approaches that foster pragmatism, acceptance, and communication with others - learning effective everyday 'non-clinical' coping strategies from peers appears particularly beneficial for psychological wellbeing (Walshe et al, 2017). Patients sharing informational support - 'tips' for managing symptoms, treatment, and the health system - might be helpful for patients trying to reappraise their situation and take control of their illness experience (Harrop et al, 2017). Peer support in advanced cancer can convey hope and the possibility of change, whilst also helping people communicate with partners and relatives (Walshe & Roberts, 2018).

Peer support for patients might be an acceptable and effective intervention in cancer care, but research has been dominated by recently diagnosed people or cancer survivors (Meyer et al, 2015). In advanced cancer, many studies of peer support are cross-sectional or descriptive, typically reaching participants who are well-educated and middle-aged, often women. Questions remain on what forms of peer support are effective across patient populations (Walshe & Robers, 2018). Sociodemographic characteristics, functional ability, and psychological health all shape self-management ability, but our understanding of collective processes of self-management in advanced illness is limited (van Dongen, 2020).

2.2.2 Mismatches in required and received support

Social support is important for coping with illness, but it appears that availability of social support can decrease over time when living with illness. Longitudinal investigation has observed parallels in physical and social distress of patients with malignant and non-malignant disease (Kendall et al, 2016; Lloyd et al, 2016; Fettes et al., 2020). Changes in mobility, pain, and other symptoms obstruct the ability to participate in usual activities which drives decline across quality of life domains over time spent with breathlessness (Currow et al, 2020). Patients living with recurrent breast cancer describe four routes by via which declines in social support might occur (Thornton et al, 2014):

- Patients stemming their support requests over time.
- Relationships misunderstanding the nature of the disease.
- Social network erosion over the passing years.
- Low mood due to illness and treatment interferes with relationships.

A thematic synthesis of thirteen qualitative investigations into advanced cancer concluded that social relationships are an important source of support that helps maintain a connection to life, but that these relationships can become inadequate during the illness experience, and may be limited by a wider stigma around illness and death (Garcia-Rueda et al, 2016). Patients strive to maintain normality, engaging in efforts to preserve their identity so as to avoid being seen as their diagnosis. Incurable illness represents an irreparable change to the body, and as the self changes, so does the reality of interaction with other people; losses of equality in relationships might be especially challenging for patients (Williams, 2004).

Patient loneliness and fears of becoming a burden might stem from a context of present and future threats to personal autonomy (Lloyd et al, 2016). Patients describe keeping worries to themselves due to guilt about burdening other people, wanting to give the impression of managing independently, and/or experiencing shame about illness or bodily changes - this reluctance to disclose alters the experience of relationships, both inside and outside the family (Salander & Lilliehorn, 2016). Observable symptoms of illness (and stigmatising responses of other people) can trigger self-stigmatisation, leading to increased passivity in relationships and decreased societal participation (Miller & Walker, 2001). Low mood can further diminish patient capacity to cope, reducing their confidence or motivation to engage with self-management and health behaviours, including the active seeking of social support (Coventry et al, 2014).

Partners, family and/or friends can play an important role in adapting to illness and maintaining normality, but they do not possess authentic knowledge of what it is like to live with the illness and are thus limited in their ability to provide emotional support (Meyer, Coroui & Korner, 2015). Furthermore, people in close relationships with a terminally ill person have their own emotional and cognitive reactions to the illness, which might not match the support needs of the patient – for example, well-intended optimism about prognosis can inadvertently thwart communication of fears and worries for the future (Pistrang & Barker, 2005). These interpersonal mismatches manifest as social constraints, which suppress potential for adapting to illness by inhibiting emotional support; whilst also straining the core relationships that are themselves an importance source of identity and belonging (Lepore and Revenson 2007). Those who are constrained in talking about their illness (or other trauma) are less able to process their experiences – thus the psychological benefits of social coping are moderated by the responses of others (Lepore, 2001).

Social networks can be adaptive and responsive to illness - for some patients they provide increased ‘illness work’ that offset health service utilisation cost (Reeves et al, 2014). However, the availability of social resources within an individual’s network or community may be limiting in whether patient is willing to request or accept help. Older patients may lack a supportive network outside of families and feel reluctant to burden close relatives with more requests for help whilst striving to maintain individual independence (Corbett et al, 2020). People living with an incurable illness might be aware of the burden that chronic illness places on society and wish to minimise their own dependency (Miller & Walker, 2001). Those who live alone might prioritise their autonomy during decision-making and their willingness to accept help, leaving them vulnerable to low support and a fragile independence later in life (Haslbeck et al, 2012). People who are stuck at home may experience an additional layer of social disconnection and perceptions of dependency (Bradley et al 2010).

People living with illness experience trajectories of loss and adaptation across physical, psychological, social, and existential domains (Lloyd et al, 2016). These domains are linked – people experiencing symptoms and fatigue can find it challenging to maintain social networks, loneliness and social isolation reinforces loss of function, which further limits the individual's ability to obtain appropriate social support (Gale, Westbury & Cooper, 2017). A meta-analysis of twelve studies (n=1449) demonstrated that individuals with a cancer diagnosis experience increased loneliness and a lack of social support as a function of time since diagnosis (Deckx et al, 2014). Changes in the support networks of carers are also observed (Leonard, 2013).

The psychological impact of living with illness can be substantially shaped by increasing social isolation (Disler et al, 2014). Patients who rarely or never receive social support report more depressive symptoms and worse health-related quality of life (Arabyat & Raisch, 2019). Loneliness appears to influence and be influenced by depression and functional limitations over time (Luo et al, 2012). Loneliness moderates the relationship between depression and pain observed in a sample of community-dwelling elderly patients with a limited prognosis (n=312) (Chan et al, 2014). Loneliness might therefore be a useful indicator for the quality of social connectedness and the risk of increasing depression in palliative care patients (Teo et al, 2018).

2.2.3 Patient loneliness in palliative care

This section considers research on patient loneliness and how this may relate to suffering towards the end of life. Exploration of the lived experience of individuals with life-limiting illness has identified common factors that may contribute or alleviate to suffering, with the social world of the individual commonly significant. Loneliness is not a single universal construct - as a direct or indirect cause of illness and its experiences, patient loneliness can theoretically be experienced in different ways and across all relationships (ie with themselves, loved ones, their own social network, healthcare professionals, surroundings, spirituality, and the wider world around them) (Krikorian et al, 2012). Personal inauthenticity, interpersonal avoidance, negative healthcare interactions, and the societal stigma of cancer contribute multiple ‘layers’ of loneliness to the experience of living with and beyond cancer (Rague-Bogdan et al, 2017).

People with life-limiting illness are confronted with ‘existential givens’ through the limitations that illness has placed on their life – they might feel profoundly aware of the finitude and vulnerability of their existence (Vos, 2014). Existential suffering in palliative care patients can be related to anxiety caused by mortality, distress about separating from loved ones, and feelings of isolation and meaninglessness (Grech & Marks, 2017). Suffering in cancer is an intensely personal experience that is socially and culturally located – it might be characterised by alienation, helplessness, and loss of meaning: “suffering persons feel separated from or abandoned by their source of comfort and strength” (p. 980, Best et al, 2015). The ‘source’ is different for different people – it could be important relationships, God or spiritual beings, a sense of connectedness to a community, or a social role in society.

Meaning in life is constructed through our surroundings, most immediately and unchangeably through our bodies, from which we cannot escape – yet the body itself is endlessly changing, and a fact of its existence is that one day it will fail us. Illness is a confrontation with changeability and death, which can lead people to a different awareness of the contingency and chance in their own meanings in life - this might feel threatening, or freeing, or both (Vos, 2014). Physical pain can restrict access to the world, so that health related suffering becomes reinforced by loneliness and fear of the future (Gillsjo, 2020). Loneliness is associated with greater depression and lower patient help-seeking intentions in palliative care (Teo et al, 2018).

Threats to autonomy, relationships, and temporality might become overwhelming towards the end of life; but a patient might cope by redefining what their situation means to them or expressing their identity through relational communication (Prince-Paul, 2008). Emotional support represents the expression of emotions and so can allow for the detection of needs and subsequent resolution of distress (Krikorian et al, 2011), conversely emotional loneliness has been described as contributing hopelessness and unbearableness to the experience of living with an incurable illness (Baarsen, 2009).

People coping with existential challenges of approaching death may find interpersonal relationships to be a key component of experiencing meaning in life (Haug et al, 2016). Those who are dying 'off-time' in their life course (younger than their peers), or with low social or economic status might be less likely to have these validating relationships available; and people with terminal illness in financial distress can experience additional social constraint and a loss of equality in social exchanges (Williams, 2004). Patients who perceive themselves being a burden or causing hardship for other people can have feelings of shame and worthlessness that are inhibit communication and might underpin a wish to hasten death (Ohnsorge et al, 2014).

If suffering is disconnection, could connection represent the transcendence of suffering? Although quite the lofty question, the literature reviewed on coping would suggest that social connections do represent a route through suffering. Spiritual leaders and palliative care practitioners agree - human connection is internationally perceived as an essential component of spiritual care (Selmen et al, 2017). Love and supportive relationships are recognised as a primary source of strength with which to bear suffering in advanced illness (Ruijs et al, 2012). Having a sense of connection to something beyond our immediate self is considered in existential psychotherapy to be a resource against existential isolation (Yalom, 1980). Relationships are not the only source of this connection (see also spirituality, nature, art); though social and relational considerations do appear prominent in meaning for people at the end of life (Haug 2016, Ardelt & Edwards, 2016). Existential concerns among patients are relevant to healthcare practice, but understandings of how to address these concerns and relieve existential suffering is often limited to formal therapeutic encounters, which are not available for all patients (Henoch & Danielcon, 2009).

2.3 Intervening to Provide Social Support

Social support can preserve purpose, by allowing threats to be redefined with new meaning and hope (Krikorian et al, 2011). From their study of patient loneliness, Krikorian and colleagues' implications for patient care advise maintaining social network contact, and arranging relationships with other patients to provide confidential connections as a route to lessening the pain of patient loneliness. Peer support for patients has been evaluated within cancer support groups and one-to-one interventions (Hu et al, 2019; Meyer et al, 2015), but less is known about social support interventions in palliative care.

This section reviews available research indicating social support to be a valuable component of complex palliative care interventions. Qualitative research has reported on the social aspects of hospice day care from patient and stakeholder perspectives, but outcome measurement has been lacking. There are risks of intervening to provide social support, which means that intervention without rigorous evidence should be approached with caution. The subsequent section concludes this chapter with a rationale for research.

2.3.1 Social support in hospice day care

When exploring patient satisfaction with hospice day care, opportunities for group discussion and quiet time to chat are highly valued by patients (Kernohan et al, 2006). Patients can experience emotional loneliness at home, which is relieved by spending time with people they perceive to be in a similar situation (Hopkinson and Hallett, 2001). Patients comment on the ease with which they are able to communicate in the day care environment, particularly on topics of illness and death, often but not always using humour to share feelings or initiate conversation (Langley-Evans & Payne, 1997). This commonality between patients encourages supportive sharing, and a sense of belonging to a group or community (Hyde et al, 2011). Patients with chronic obstructive pulmonary disease accessing specialist palliative care (n=8) describe how opportunities to engage in honest emotional expression and reciprocal social altruism has led to increased confidence and sense of social inclusion – for some people, getting out for the day and into a new physical environment is a psychosocial achievement in itself (Hayle et al, 2013).

From a mixed-diagnoses sample attending palliative day care (n=37), Hyde and colleagues (2011) identified three themes representing the experiences of attending palliative day care: unhurried and accepting staff members; relationships with other patients in which they were able to "be real" with one another; and the sense of community/belonging in the group. This sense of community developed through similar circumstances and shared experiences, as well as eating together, and participating in occupational group activities. The authors conclude social interaction and relationships to be at the core of palliative day care (Hyde, Skirton & Richardson, 2011). Kennett & Payne (2005) also emphasise the beneficial effect of the supportive community achieved through group activity in palliative day care. Creative activities offer enjoyment and personal achievement, but are not an end in themselves, rather they are a vehicle for increasing communication and a sense of belonging in this patient community (Kennett & Payne, 2005).

Caution is needed when interpreting these evaluations, which typically focus on one hospice day care service and have sparse description of the specific activities and characteristics of the intervention or participants included. In patient evaluations, especially those led by hospice staff, those with 'better' quality of life or positive service experiences are most likely to be recruited - thus their experiences may be disproportionately reflected in literature and we know less about those with poorer quality of life or negative experiences of hospice care (Kennett & Payne, 2005). Participant concern for the continuance of the service can perhaps restrain the communication of any criticism they might have otherwise (Kernohan, 2006). However, it is noted that previous qualitative research has identified homogeneity in the conclusions reached – a systematic review concluded that patients perceive palliative day care to increase social support, reduce isolation, provide activities, and encourage communication (Bradley et al, 2010). Subsequent work reported the two most common reasons for healthcare professionals to refer to palliative day care were for social wellbeing and as introduction to hospice services (Bradley, 2011).

Why would the social support within hospice services be so valued by patients, even when other supportive relationships are available? Lobb (2013) suggests conversation itself to be beneficial, even without observable life change, because social comparisons are useful appraisal tools for people dealing with uncertainty. Shared experiences within cancer support group context provides a sense of community and increase personal agency (Ussher et al, 2006). Authentic, first-hand knowledge of what it is like to live with illness provides space for more honest communication about the illness experience (Meyer et al, 2015). Interacting with people ‘in the same boat’ is in contrast to frustrating and disempowering interpersonal experiences elsewhere; and might also benefit existing relationships by providing alternative space for emotional communication (Kennett & Payne, 2005). The benefits of patient-to-patient social interaction could be related to stigmatisation experienced elsewhere – as equals in their patient status, individuals feel relieved of expectations surrounding illness, for example that they will ‘battle with cancer’ (Wilson & Luker, 2006). As such, empowering and sometimes challenging interactions within the group allow for emotional expression and an increasing sense of personal control, which might enable more positive relationships with family and friends as well as medical professionals (Ussher et al, 2006).

Some groups might not be primarily aimed at facilitating social support, but the social support derived in the setting is clearly relevant to the patient and the outcomes of intervention; this has been discussed in groups focused on creativity (Kennett & Payne, 2005) and physical activity (Malcolm et al, 2016). Social activities held by some hospices are expanding and diversifying, aiming to increase patient choice and service responsiveness, with the long-term view that increasing social opportunities might enable patient self-management (Hartley, 2016). However, patients might feel overwhelmed by the plethora of services on offer, and group experiences are not necessarily enjoyable to all patients (Al-Abdin et al, 2019). With caveats of generalisability in mind, it appears that social support within the hospice day care is significant to some patients in attendance.

2.3.2 Outcomes of social support

Qualitative work has highlighted perceived benefits of palliative day care services form the perspectives of stakeholders (mostly patients). Meeting other people with similar experiences, sharing emotional and informational support, and being free to act how you feel – these are social experiences that support psychological adjustment to change. However, quantitative evidence and meaningful definition of these processes is lacking (Bradley et al, 2010). Evidence for outcomes has been limited by small sample sizes, high attrition rates, and the infrequent use of validated outcomes that are aligned to the goals of the intervention. The subjective, social component of attendance is valued by attendees, but there is little robust evidence on what effect this has for quality of life or symptom management (Stevens, 2010).

However, patients with depression have been observed to benefit from attending hospice day care (Lloyd-Williams et al, 2011) and there is increasing interest in the potential for peer support to improve care outcomes including advanced care planning (Bekelman et al, 2018; Fisher et al, 2018). Providing a supportive environment for encouraging emotional expression and cognitive reflection in a narrative intervention can have a lasting impact on depression (Lloyd-Williams, 2018). Life and legacy reflection may foster an inner source of strength for future use in the forthcoming stresses of progressive illness (Juliao et al, 2017; Steinhauser et al, 2017). An enhanced sense of meaning after group intervention appears to mediate improvements in quality of life and decreased depression after group psychotherapy in advanced cancer (Rosenfeld et al, 2018).

Social support resources might be ‘visible’ or ‘invisible’ (DItzen & Keinrichs, 2014) and participants themselves might not report the psychosocial processes contributing to benefit. A mixed methods evaluation of a group self-management program in Parkinson’s disease reported that analysis of outcome measures suggested improvements in self-management were associated with changes in social support (Pappa et al, 2017). Participants valued the opportunity to be part of a supportive community and benefited from having shared experiences with peers. They described improvements in communication in their existing relationships but did not acknowledge increased support arising as a result of the intervention. These participants reported high satisfaction with their existing networks and did not perceive a need for increasing social support, feeling that increased ‘visible’ support corresponded to increasing dependency (Pappa et al, 2017). However, achieving the intended outcomes of the group did seem related to the ‘invisible’ support of shared experiences and associated communication opportunities. This indicates the patient’s internalised expectations of illness and dependency could influence the acceptability, patient experience, and evaluation of a group intervention.

It remains unclear what the ‘magic ingredient’ is that makes an intervention acceptable to service-users: personal motivation to participate in the social intervention appears important, if not essential, for benefit (Windle et al, 2011). Reviews of group interventions indicate that productive engagement is more effective than passive activity (Gardiner, Geldenhuys & Gott, 2018). Simply being in the room for social activities or group interventions will not elicit the benefits of a genuine sense of connectedness to the group or its aims (Saeri et al, 2018). Positive group experiences might increase self-efficacy and endorse healthy changes in behaviour; over time this can lead to increased social connectedness and access to community support, which might reduce reliance on formal health services – but demonstrating this chain of outcomes is challenging (Johnston et al, 2012). Different psychosocial mechanisms may be relevant in different contexts, appropriate control groups difficult to define, and intended outcomes can be challenging to capture (Lloyd-Williams et al, 2011).

Furthermore, there is inconsistency in the extent that social support arising within a group intervention is considered relevant by researchers and evaluators. For example, group mindfulness training in metastatic cancer with patients and caregivers showed positive outcomes but did not appear to acknowledge that social support processes may be relevant in addition to the meditation activities (Johns, 2020). In contrast, a palliative rehabilitation program focusing on physiotherapy explicitly references the role of social support from both team and peers in contributing to positive outcomes (Feldstain, 2017). Reviews on mental health in advanced illness can focus on the individual, without acknowledging the importance of their social surroundings in contributing to or alleviating distress (Lehto et al, 2018). More than half of interventions to promote self-management in cancer survivors include access to group interaction (Cuthbert et al, 2019), but the significance of this social support as a component contributing to outcomes is often not explicitly considered.

The ‘social’ problems considered within palliative care are sometimes reduced to those relating to state welfare, financial management, and the appropriateness of current housing. Although these areas are unmistakeably essential when needed, the social world matters to palliative care patients, both within and beyond the walls of an intervention. Hospices recognise unmet social need in the patients they support, and as such provide day services that meet social objectives such as increased social interaction, decreased isolation, personal growth, a sense of control over the illness experience, and reassurance about the future (Payne, 2006). Despite this, and the holistic philosophy of the hospice sector more generally, effectiveness research has focused on health-related quality of life at the expense of social domains ('the social has been sidelined' – Payne).

There is robust evidence that social connections have an influence on health. Isolation and loneliness are widely recognised as public health issues - it appears that improving social connectedness in the present could improve mental health/wellbeing now and in the future (Saeri et al, 2018). However, there is a disconnect between what is known about the importance of naturally existing relationships and the effect of interventions to alleviate loneliness (Perissionotto, 2019). Efforts to describe or evaluate an intervention to provide social support in *any* population are relatively sparse and mechanisms are not well understood (Courtin & Knapp, 2017). Outcome evidence supporting social intervention is limited, and cost-effectiveness work largely absent (Windle, Francis & Coomber, 2011). Participant samples tend to be relatively healthy white adults (usually women under 70), who do not live in poverty or as a minority; as such there are concerns that socially isolated or lonely people may not be being reached appropriately by existing interventions (Windle et al 2011).

2.3.3 Risk of detrimental support

It is important to note that social support is not necessarily beneficial – there is risk of detrimental social support because we don't know what counts as useful. Tangible and intangible aspects of the context can determine whether social support has the potential to alleviate or contribute to suffering. Loneliness might be increased by situations in which the person perceives that they have little control over their social interactions or feels they are instrumental to another person's goal (Caccioppo & Caccioppo 2014). Well-intended help might inhibit personal growth in confidence. For example, Fivecoat and colleagues (2018) observed that lower levels of instrumental social support in heart failure patients led to a greater growth in self-care confidence over time, suggesting the potential negative effects of social support in lowering the receiver's sense of self-efficacy. Perceived emotional support, rather than instrumental support, is associated with increasing confidence in heart failure patients (Fivecoat et al, 2018). Detrimental social interactions can result in a reluctance to disclose emotional experiences, leading to lower quality of life despite the presence of social support (Kohler et al, 2019).

In accordance, a social support model for stress during chronic illness and bereavement emphasises that social support is stress buffering *only* when the support meets personal needs and situational demands – the provision and receipt of social support can exacerbate stress when it is not aligned to the person and the situation (Karantzas & Gillath, 2017). Both non-supportive social interactions and social isolation produce physiological stress and lower immune function. Depression, chronic stress, and loneliness have synergistic effects that promote inflammation, heightening future stress responses and worsening health (Jaremka, Lindgren & Kiecolt-Glaser, 2013). Thus, intervening in a way that inadvertently increases loneliness could be genuinely harmful.

It appears that interactions with others can be positive or negative depending on context and perspective taken (Smith & Christakis, 2008). For those aiming to provide positive support to those coping with incurable health conditions, it is crucial to avoid unwanted or unhelpful types of support (ie negative social interactions). It is how social support is perceived, rather than the quantity or content of interactions, that determines the influence on coping behaviours and treatment adherence (Rivers & Sanford, 2020).

Not all relationships are supportive and those characterised by indifference are far less likely to be beneficial. Importantly, negative or ambivalent relationships (i.e. relationships containing both negativity and positivity) can be detrimental to health and wellbeing (Holt-Lunstad & Uchino 2019). Social support received from an ambivalent source during a stressful situation is perceived as unsupportive, increasing the biological stress response - i.e. ambivalent relationships are less effective at helping people cope with stress and can become stressors in themselves (Gramer & Supp, 2014). Perception of provider ambivalence during a supportive interaction may be particularly stressful (Uchino et al, 2013).

Effective peer support interventions in breast cancer are typically non-hierarchical and appear to benefit quality of life, stress, and health behaviours. However, the risk of bias of included studies is unclear, and adverse effects on quality of life, distress, and depression following from unstructured or unmoderated peer support have also been identified (Hu et al, 2019). We should be wary of rushing to provide ‘just any’ social ties - social conflict, even from well-intended actors, can result in rumination, poorer adherence to health behaviours, and other negative coping strategies (Holt-Lunstad & Uchino 2019).

Interventions that provide social support sometimes aim to increase interaction or receipt of social resources without attending to the subjective aspects of social relationships, such as relationship quality or perception of support (Holt-Lunstad, 2018). The intervention is likely to be time-limited, whereas the relevance of the social world is enduring, and it is possible that some interventions could turn people away from existing network members and encourage dependency on a time-limited resource. This raises the question – how do we know if (and when) social support in palliative care is worthwhile?

2.3.4 Risk of reinforcing inequality

An early review highlighted issues of access to hospice day care, including referrals, admission and discharge procedures, number of places, and practicalities of transport (Spencer & Daniels, 1998). At the time, individuals with non-malignant disease were far less likely to receive specialist palliative care, with cancer patients comprising 95% of the hospice population at the start of the 1990s (Doyle, 1993). People with chronic obstructive pulmonary disease remain less likely to receive palliative care than those with lung cancer (Butler et al, 2020). Intervening at the right time can reduce hospitalisation towards the end of life, but many non-cancer decedents still lack access to early palliative care (Sleeman et al, 2016; Qureshi et al, 2019).

There is a pervasive social gradient in the place of death and access to palliative care in high-income countries: people with lower socioeconomic position (as measured by area deprivation or education level) are less likely to receive palliative care, are more likely to be hospitalised late in life, and are more likely to die in hospital (Davies et al, 2019). There is strong evidence that male gender, minority ethnic group status, and rural residence are factors that increase the likelihood of attending the emergency department in the last year of life (Bone et al, 2019). In the UK, dying at home is clearly associated with financial situation (as measured by area deprivation, income, and occupation); whereas evidence on the effect of rurality/urbanisation on place of death is more mixed (Neergaard et al, 2019). Comorbidity and deprivation increase risk of hospital death (Higginson et al, 2017). By explicating relevant human and environmental factors, a synthesis of qualitative work concluded that socioeconomic differences in achieving preferred place of death reflect differential availability of social support and care resources (Turner & Flemming, 2019).

Referral to palliative care occurs later for Black, Asian and minority ethnic groups in the UK (Chidiac et al, 2020). There are persistent diagnostic and socioeconomic inequalities reported in the receipt of palliative care and location of death (Mondor, Wodchis & Tanuseputro, 2020). In a systematic review, Parajuli and colleagues (2020) posited that provider-based barriers in communication that could underpin enduring sociodemographic differences in palliative care and hospice utilisation for cancer patients (identified as relating to gender, ethnicity, marital status, area characteristics and socio-economic status). In agreement, Mayeda and Ward (2019) reported that patients from minority groups are prevented from accessing palliative care services by challenges such as language literacy, knowledge about their health, and access to information.

Experiences with life-limiting illness is shaped by structural, interactional, and personal factors that provide practical advantage to self-management and resilience to physical limitations (May et al, 2017). Patients who do not feel connected with healthcare providers struggle to be taken seriously or to be informed about available care choices - as such they cannot participate as equals in decision-making (Noordman et al, 2017). Not receiving sufficient healthcare information increases the risk of psychological distress in palliative care (Larkin, 2008). As such, traditional models of healthcare service appear insufficient to address enduring inequalities (Mayeda & Ward, 2019).

Research suggests the relationship between social context and health is non-linear: advantage and disadvantage accumulates in a cascading process so that people with the most social disadvantage exhibit the most pronounced risk of poor health (Umberson & Montez, 2011). Processes of social support are influenced by broader social processes operating in society (e.g. intergroup discrimination, stigma) meaning that those who are socially disadvantaged are likely to become increasingly isolated. The health detriments for those experiencing social isolation may therefore reflect accumulating effects across physiological stress responses, psychological self-esteem, and health behaviours (Berkman & Glass, 2000). The effectiveness of interventions that empower individual patients is likely to be limited for patients who are most disadvantaged at the structural and interactional level (May et al, 2017) – but these are the patients research suggests are most in need of support.

There is a justifiable motivation to respond to loneliness and social pain near the end of life – indeed, foundational hospice philosophy and the World Health Organisation's definition of palliative care would mandate it. Some groups are more likely to be socially isolated (e.g. poorer and older groups) and as such should receive higher priority. However, existing interventions to provide social support appear ineffective in reaching socially isolated people (Windle et al, 2011). Palliative diagnoses are exaggerated in groups those from low socioeconomic status (Williams, 2004), yet under-represented in hospice care – there is a risk that this is alienating the people most in need of support, and thus deepening inequality around death by providing extra resources to those who least need them (Reimer-Kirham, 2016).

This section outlines risks to intervention. But there are also risks of not intervening to provide social support in palliative care – social constraint, isolation, despair, and avoidable suffering towards the end of life, disproportionately experienced by those with the least resources to cope. Ultimately, better evidence is needed to inform practice and evaluation.

2.4 The Need for Better Evidence

Social isolation and subjective loneliness make it harder to cope with life-limiting illness – without support, these patients are more likely to experience depression and pain, declines in mobility, crises requiring emergency admission, unfortunately leading to an unwanted death in hospital. However, continued inequalities of access to palliative care means that patients most likely to die in hospital are not necessarily reached by existing interventions to improve end-of-life outcomes. Patients can experience social constraints in their daily lives and may have unmet emotional and informational support needs placing them at risk of suffering. Impact on healthcare outcomes has not been ascertained, but there is indication that social support in palliative care can improve depression (Lloyd-Williams et al, 2018).

Hospices are one of the principal providers of palliative care in the UK. However, rigorous evaluation of hospice care has been slow to develop, in part due to the challenges of research in a palliative population. Whilst seeking to provide effective, caring, and holistic support to a growing number of people with finite resources, many hospices are diversifying their offering, and the contribution of social support to patient resilience is increasingly acknowledged. Variation in service provision could be beneficial if meeting the needs of the local population, but service models are not well-documented, and outcomes are unclear. It is possible that hospice services will be able to respond to enduring issues of access, but demand for palliative care is continuing to rise, and evidence is lacking to guide service development. Routes to demonstrating effectiveness are vague and 'best practice' is therefore challenging to identify.

Due to rising annual deaths, population projections report that palliative care provision in the community needs to at least double by 2040 to avoid a steep rise in hospital deaths (Murtagh et al, 2013). Furthermore, people are dying at older ages, increasingly from chronic conditions and long-term illnesses (Sleeman et al, 2016). Effective treatments allow people to live longer, with many advanced cancer patients experiencing a chronic and uncertain disease trajectory (Lobb et al, 2013). People with a limited life expectancy (due to advanced chronic conditions including frailty, dementia, organ failure, multi-morbidity, and cancer), represent more than 1% of the population, and up to a third of health service spend (Gomez-Batiste, et al, 2017). In response to these pressures, a broadening of perspective form patient-centred care to the development of community resources for care is advocated as urgently necessary (Abel et al, 2013).

Alongside increasing multimorbidity and patient complexity, population changes have implications for the ability of a society to provide care. Family composition and support availability in a country is shaped by cultural demands and demographic composition. Societal inequality directly and indirectly affects loneliness – at the individual level, socioeconomic resources shape quality of living and opportunities to build supportive relationships; and at the community level, inequality drives mistrust, reducing social integration and increasing perceptions of deprivation (De Jong Gierveld, Val Tilburg, & Dykstra, 2018). Social isolation, as measured by people living alone or reporting that they have no one to talk to, appears to be increasing in the United States, Europe, and the United Kingdom (Steptoe, Shankar, Demakakos & Wardle, 2013). Societal levels of loneliness in Europe appear to be increasing over time when measured longitudinally, and this increase is highest for older people (reviewed in De Jong Gierveld, Val Tilburg, & Dykstra, 2018). The societal consequences of social isolation and loneliness are demonstrable for all-cause mortality, cardiovascular disease, and reduced mental health (Leigh-Hunt et al, 2017).

Social domains have relevance to patterns of healthcare utilisation and advanced care planning, and as such effective social intervention might have relevant outcomes for the health and social care system. Early palliative and supportive care addressing the social network could be seen as an upstream intervention to the social determinants of suffering towards the end of life (Kellehear, 2009). It is important to align psychosocial interventions with ‘early’ palliative care to have potential for greatest duration of benefit - high levels of distress towards the end of life may indicate a lack or failure of adequate intervention to address earlier in the disease trajectory (Rodin, 2013). There is an urgent need to identify effective approaches that address inequality of access to palliative care, including models of care that meet the needs of non-cancer patients living in the community (Brereton et al, 2019; Hasson et al, 2020).

2.4.1 Research rationale

This chapter reviews evidence indicating social support to be significant for people living with life-limiting illness. Loneliness and isolation are not static experiences - they vary with time, in that people move in and out of loneliness and/or social isolation (Valkorta, Kanaan, Gilbody, Hanratty, 2016). The associations of social connectedness to physical health exist across the full spectrum of risk, rather than being a phenomenon of individuals experiencing severe isolation and profound loneliness (Steptoe, Shankar, Demakakos & Wardle, 2013). Therefore, interventions that are able to increase social connection could have a positive effect on health outcomes for those in attendance.

There are useful lessons to be derived from interventions in related populations, and particularly from their rigorous evaluation. However, the rigour of these evaluations is often refutable, and the significance of context insufficiently understood. Within a palliative care context, the hospice sector is active in providing social support as part of several different service models, but evidence regarding effectiveness and cost-effectiveness is lacking.

The key philosophy of palliative care is maintaining and improving quality of life. Developing research in the field requires consideration of two problems associated with the concept of quality of life: how quality of life can be maintained and improved, and how this can be meaningfully measured. Spencer and Daniels (1998) argued that identification of appropriate outcome measures was an important limitation in the development of research in hospice day care, and that descriptive evidence was valuable information on the context for which evaluative studies can be designed. Hospices are supporting more people, for longer time periods, with less resources. There is an increasing urgency that more is done with less, without consensus on what it is that needs to be done.

There has been progress in the evaluation of psychosocial palliative care, but the role of the social has sometimes been overlooked. Until recently, relatively few studies had considered the mechanisms of social supports impact on health beyond a dyadic level (Smith & Christakis, 2008). Research on the role of social support in chronic and life-threatening illness typically focusses on support within the family unit – less research exists that focuses on broader social support or peer support derived from an intervention (Graven & Grant, 2014). Graven and Grant (2014) highlight the limitations of copious cross-sectional research, calling instead for longitudinal designs, more diverse participant samples, and a concentration on causality. Research must be rigorous and trustworthy, from which decisions can be informed that might ultimately reduce suffering for more patients.

Research is needed that compares different models of palliative care and explore which components of a multicomponent intervention are effective in producing beneficial patient (or caregiver) outcomes in different contexts (Kavalieratos, Corbelli & Zhang, 2016). Unpicking effectiveness requires research to explore components and mechanisms indicated by previous work to be relevant – i.e. a deeper understanding of what is happening on the ground might be necessary (Stevens, 2010). Comparative research including different service models may support exploration and explanation; and focussing on one aspect of a multicomponent intervention might be useful to gain insight into the broader picture. Research must understand service models and the intended outcomes, so that conversations on the effectiveness and cost-effectiveness of different approaches can be approached with pragmatism (Hasson et al, 2020).

2.4.2 Research aims

This project aims to explore social support in palliative care by clarifying the meaning and significance of social support as a component of hospice interventions. In doing so, the project will improve understanding of this field of practice.

The appropriateness and effectiveness of different models of palliative care is likely to be shaped by contextual features of the patient and the intervention, with some components of the intervention more pertinent than others – this means that an understanding of complexity within these interventions is required (Brereton et al, 2018; MRC, 2019).

This work will be a mixed methods exploration of hospice settings. The project will identify possible explanatory mechanisms by which social support obtained in hospice day services might contribute to patient outcomes. It will report on the feasibility of a longitudinal observational study using patient reported outcome measures and contribute to methodological development towards effectiveness and cost-effectiveness evaluation of these complex interventions.

Chapter 3 : Systematic Review

Effectiveness of Palliative Care Interventions Offering Social Support to People with Life-Limiting Illness

3.1 Introduction

Social wellbeing is long recognised as a component of optimum health (World Health Organisation, 1946). Social support is a resource gained through interpersonal interactions that may comprise emotional support, companionship, information/advice and tangible assistance (Uchino, 2004). Adequate social support is necessary for both physical and mental health, and can protect against the negative outcomes of long-term stress (Hostinar, 2015). Inadequate support confers increased mortality risk comparable with high-profile risk factors such as smoking and obesity (Holt-Lunstad, Smith, & Layton, 2010). Social isolation is associated with reduced wellbeing and increased depression (Golden et al., 2009), cognitive decline (Gow, Pattie, Whiteman, Whalley, & Deary, 2007), increased pain intensity (Lopez-Martinez, Esteve-Zarazaga, & Ramirez-Maestre, 2008) and mortality (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015).

Palliative care aims to improve quality of life for patients with life-limiting illness and their families (Hui et al., 2013), providing support for patients to live as actively as possible (World Health Organisation, 2002). The social world of an individual has potential to contribute to, or alleviate, suffering in life-limiting illness (Garcia-Rueda, Valcarcel, Saracibar-Razquin, & Solabarrieta, 2016). Pain, fatigue, and other symptoms can limit opportunities to engage with others, so that declining physical function is paralleled by increasing social restriction (Lloyd, Kendall, Starr, & Murray, 2016). Friends and family members may struggle to accept the diagnosis and feel unable to relate to patient experiences (Wilson & Luker, 2006). Social relationships may also be limited by stigma around illness and death (Garcia-Rueda et al., 2016).

However, social support is also associated with better outcomes in advanced cancer (Applebaum et al., 2014) and other incurable diseases (Tomaka, Thompson, & Palacios, 2006). Obtaining emotional support from others, a common coping mechanism in advanced cancer, is associated with better quality of life and reduced anxiety and depression (Nipp et al., 2016). People coping with the existential challenges of approaching death can find interpersonal relationships to be a key component of experiencing meaning in life (Haug, Danbolt, Kvigne, & DeMartinis, 2016), and social comparisons with people in a similar situation may be helpful when trying to establish a new sense of normality in the presence of advanced illness (Lobb et al., 2013). Therefore, psychological stressors that accompany life-limiting illness might be alleviated through experiences of social support (Crunkilton & Rubins, 2009). Patients and referring clinicians agree that additional social support is helpful (Bradley, Frizelle, & Johnson, 2010, 2011); thus informal relationships cultivated in palliative care are valuable to stakeholders, but do appear under-acknowledged by research (Wilson & Luker, 2006).

A broad range of palliative services can facilitate social support, including home visits or remote support delivered via telephone or internet. However, opportunities to get out of the house and engage with others in a dedicated environment are thought to be particularly beneficial for wellbeing in palliative patients, by relieving both physical and psychosocial isolation (Bradley et al., 2010; Stevens, Martin, & White, 2011). Palliative day care offers psychosocial support alongside clinical services – patients in the UK report motivations to attend palliative day care because of potential gains in social support (D. Goodwin, Higginson, Myers, Douglas, & Normand, 2002; Kernohan, Hasson, Hutchinson, & Cochrane, 2006). Peer relationships developed in face-to-face group therapies or support groups are also highly valued by patients (Taylor-Ford, 2014). Therefore, this review focuses on solely on interventions taking place outside of the home.

3.1.1 Review aims

Previous reviewers have noted a scarcity of quantitative evidence in the evaluation of palliative care (Aoun & Nekolaichuk, 2014), particularly so for interventions with social goals that can be challenging to define and measure (Bradley et al., 2010; Stevens et al., 2011). The evidence base for economic evaluation is especially poorly developed (Gardiner, Ingleton, Ryan, Ward, & Gott, 2016). Quantitative evidence can be vital to demonstrate effectiveness and make pragmatic decisions about resource allocation in the context of an aging population and increasing healthcare demands (Woodthorpe & Foster, 2016). There is moderate evidence that complex interventions can improve quality of life in palliative care, but it is unclear which components of these interventions confer benefit (Catania et al., 2015).

Existing research indicates provision of social support may be a crucial component of psychosocial interventions in palliative care. This systematic review aims to summarise available evidence on the effectiveness and cost-effectiveness interventions taking place outside of the home that facilitate social support for palliative care patients, by including studies using at least one quantifiable, validated patient outcome measure.

An initial systematic review was carried out at the beginning of this project to inform its design, reported here and with a paper published in the European Journal of Cancer Care. The review was updated in October 2020 – see addendum from page 75. The systematic review was carried out an early stage in the thesis project, its prioritisation was deemed important to ascertain gaps in the evidence base and identify challenges reported by previous research.

3.2 Method

The review was conducted according to PRISMA guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009). A review protocol was not registered. The primary reviewer (NB) conducted searches, data extraction and quality appraisal. A representative sample of 10% of identified titles and papers were independently checked by a second reviewer (MLW) to reduce risk of bias. Any discrepancies during the process were discussed with the entire team (NB, MLW & CFD).

3.2.1 Search strategy

The literature was searched up to 30th January 2017 using electronic databases of AMED, CENTRAL, CINAHL Plus, EconLit, PsycINFO, PubMed (including MEDLINE), Social Care Online and Web of Science. MeSH terms for palliative care were used in CENTRAL, NHS EED and PubMed. Key journals were searched using Scopus, recent volumes were additionally hand searched. Grey literature was included using Google Scholar and Open Grey. The reference lists and citations of all included studies were manually searched.

A search string was developed from the PICOS (population, intervention, comparison, outcome, study design) model (Centre for Reviews and Dissemination, 2009) without limitation on comparison condition or study design:

(palliative OR “end of life” OR “advanced cancer” OR terminal OR incurable OR “life-limiting” OR “life-threatening”) AND (social* OR communit* OR outreach OR respite OR daycare OR “day care” OR “day centre” OR “day service*” OR “day setting*” outpatient OR group OR service* OR engagement OR support* OR ambulatory) AND (psycholog* OR Psychosocial OR emotional OR wellbeing OR well-being OR isolation OR loneliness OR quality OR qol OR qaly OR health OR economic* OR benefit* OR cost* OR value OR effect* OR efficien* OR outcome* OR impact OR mortality OR function* OR “service use” OR “resource use”)

3.2.2 Inclusion criteria

Palliative care interventions were considered to offer opportunities for social support if they facilitated face-to-face interactions with multiple other people, outside of the individual’s home. Participants are adult outpatients (at least 18 years old and currently living in the community) with a diagnosis of life-limiting (incurable) illness, including but not limited to cancer. Group activities, structured group interventions and settings such as palliative day care were included. Publications were included that reported at least one validated, quantifiable patient outcome measure, in any domain; including perceived social support, quality of life, psychological distress, symptoms etc. Mixed methods papers were included. Only English language papers were included due to resource limitations. There was no other restriction on comparators or study design.

3.2.3 Exclusion criteria

Interventions for children, long-term care residents, or palliative inpatients were not included in this review, as issues of social wellbeing are expected to differ in these populations. Interventions consisting entirely of clinical appointments, individual tasks or home-based activity were excluded. Publications were excluded that were purely descriptive or used only qualitative evaluation.

3.2.4 Quality appraisal

The quality of included papers was appraised using a structured checklist approach designed for disparate data (Hawker, Payne, Kerr, Hardey, & Powell, 2002). The flexibility of this checklist in assessing diverse study designs was considered advantageous for this review. Quality assessment considered nine domains: abstract, introduction, method, sampling, analysis, ethics and bias, results, transferability, and implications. Each domain was scored out of 4, with higher scores indicating better quality, giving a maximum score of 36.

3.2.5 Data extraction

Data was extracted summarising: study design, sample characteristics, outcome measures, results, and methodological difficulties reported. This included results of subsequent analysis and additional publications from the same study. A meta-analysis was not appropriate due to very high heterogeneity of included studies - thus results are presented as a narrative summary.

3.3 Results

Searches returned 6247 papers after removal of 3651 duplicates. 18 papers were identified from additional sources (hand searching reference lists, citation checking and key journals). A total of 6149 papers were excluded based on title and abstract, the vast majority of these were not relevant to this topic. 116 papers were read in full and assessed for eligibility. Sixteen studies met the criteria and are included in this review (PRISMA flowchart – Figure 1, and table 1 for details).

3.3.1 Study characteristics

Studies were required to employ quantitative methods, of which three utilised mixed methods. Included studies were from the USA (n=5), UK (n=4), Australia (n=2), Canada (n=2), Ireland (n=1), Poland (n=1) and Sweden (n=1). Participant allocation was frequently randomised (n=10), with other studies designed as non-randomised comparative studies (n=4) or as pilot studies without a comparator group (n=2). See table 1 for included studies. Most studies (n=12) used only participants with advanced cancer, frequently breast cancer (n= 6).

Other studies used mixed diagnoses (n=4) with advanced cancer constituting 68-96% of participants and other diagnoses including lung disease, progressive neurological disease and kidney disease. A wide age range was apparent across studies, from 25 years (Kissane et al., 2007) to 94 years (Leppert et al., 2014).

Outcome measures used were diverse, with 30 different tools utilised across sixteen studies. Only one study (Edmonds, Lockwood, & Cunningham, 1999) used a validated outcome measure to elicit information on social support - the Duke-UNC Functional Social Support Questionnaire (DUFSS) (Broadhead, Gehlbach, de Gruy, & Kaplan, 1988). Two studies reported on social subscales of outcome measures (Kissane et al., 2007) (Rummans et al., 2006). The Profile of Mood States (POMS or POMS-SF) was the most commonly used outcome measure (n=7). Quality of life was measured with nine different tools by studies reporting this outcome (n=12).

Three categories of interventions were identified, as defined by the original authors. The detail of interventions tend to be poorly described, but there is likely to be considerable overlap in components between these three categories. Group therapeutic interventions (n=7) included supportive-expressive group psychotherapy and group cognitive-behavioural therapy. Specialist palliative day care (n=5) offer clinical or nursing support in a dedicated environment, alongside group discussion and creative or therapeutic activities. Group practical interventions (n=4) typically include multi-disciplinary educational components and group discussion.

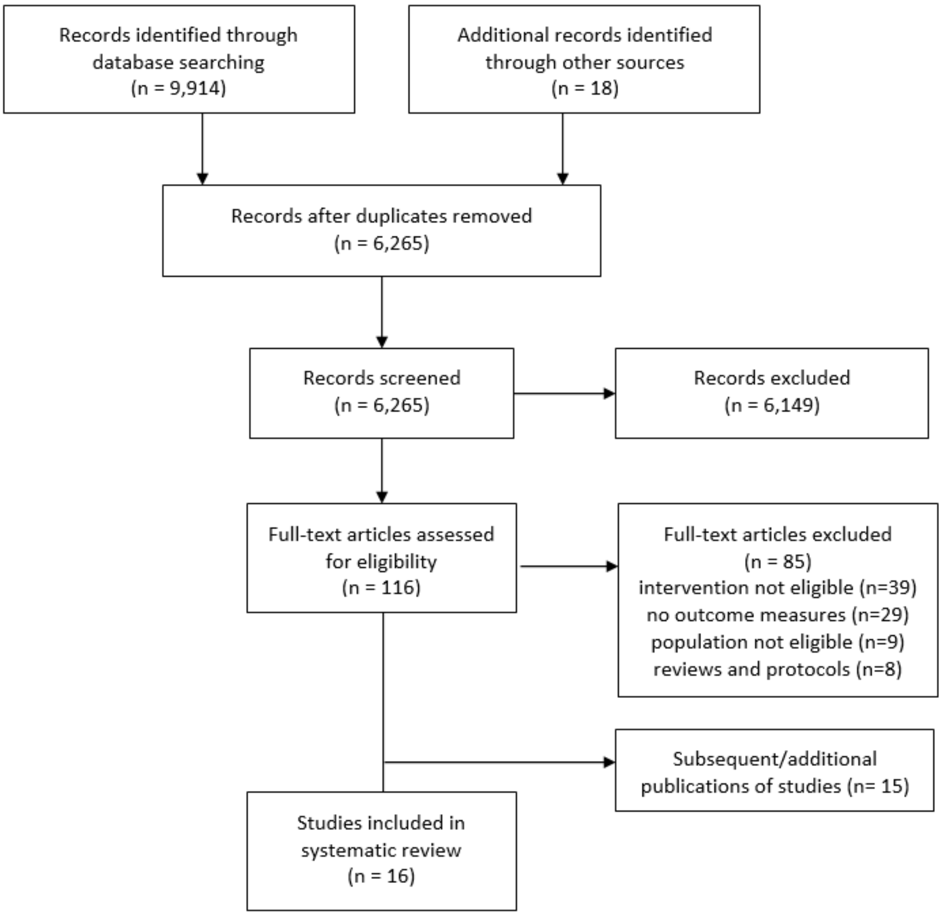

Figure 1: Article selection process for this review.

From Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097.

Table 1: Details of included studies (up to 2017)

Study	**Quality**	**Country**	**Method**	**Intervention**	**Population**	**Study period (attrition)**	**QOL outcomes**	**Other outcomes**	**Subsequent reports**
Clark et al. (2013) **(44)**	31	USA	Randomised controlled trial	Multi-disciplinary group intervention	Advanced cancer outpatients n=129 Mean age: 59.3	27 weeks (14.7%)	FACT-G. Intervention group had higher QOL at week 4 (p=0.02), significance lost by week 27 (p=0.88)	FACT-SWB, POMS, caregiver QOL No significant difference found	Gender differences in response at week 4 (70) After 1 year, participants over 65 (n=16) had longer lasting benefit than participants under 65 (n=38) (71)
Classen et al. (2001) **(45)**	30	USA	Randomised prospective study	Supportive-expressive group therapy	Advanced breast cancer outpatients n=125 Mean age: 53.4	1 year (18.4%)	N/A	POMS, IES Improvement in impact of events scale (p=0.03) Secondary analysis removed death-proximal participants (n=10): statistical difference in mood disturbance (p=0.02) & greater significance in IES (p=0.01)	Intervention reduced pain experience (p=0.001) (57); improved emotional self-efficacy, (p=0.55) and emotional suppression (p=0.01) (58). No survival difference after 14 years, 86% mortality (59)

Edelman et al. (1999) **(46)**	30	Australia	Randomised prospective study	Group cognitive behaviour therapy	Advanced breast cancer outpatients n=92 Mean age: 50	6 months (31.5%)	N/A	POMS, Coppersmith self-esteem inventory Improvements in mood disturbance (p=0.036) & self-esteem (p=0.048), statistical significance lost by 6 months	No survival difference after 5 years, 70.2% mortality (62)
Edmonds et al (1998) **(39)**	31	Canada	Randomised prospective study	Long-term therapeutic support group	Advanced breast cancer outpatients n=66 Mean age: 50.7	14 months (42.4%)	FLIC. No statistically significant result.	DUFSS, POMS-SF, MAC, rationality/ defensiveness, social desirability Only significant difference in MAC helplessness scale (p=0.05)	No survival difference after 5 years (p=0.35) (63)
Goodwin et al. (2001) **(47)**	32	Canada	Randomised prospective study	Supportive-expressive group therapy	Advanced breast cancer outpatients n=235 Mean age: 50.2	1 year (37.4%)	EORTC QLQ-C3O. No statistically significant result.	POMS, pain and suffering scale Improvements in mood disturbance (p=0.02) and pain experience (p=0.04) after one year. Participants with higher baseline distress benefited more from intervention	Cost-minimisation analysis using resource & outcomes, no significant result (Lemiuex, 2006). See also report on recruitment and enrolment (Goodwin 2000)

Goodwin et al. (2003) **(48)**	29	UK	Non-randomised prospective comparative study	Palliative day care	New referrals to 5 centres (mixed diagnoses - 96% cancer) n=149 Mean age: 66.2	12-15 weeks (57%)	MQOL. No statistically significant result.	POS. Better pain control at 'baseline' (p=0.065) Better symptom control at 6-8 weeks (p=0.053), lost by 12-15 weeks	Cost effectiveness study using resource use, limited evidence available, inconclusive result (Douglas et al.,2002)
Higginson et al. (2010) **(49)**	31	UK	Quasi-experimental prospective comparative study	Palliative day care	New referrals to palliative care (mixed diagnoses - 87% cancer) n=132 Mean age: 71.8	12-15 weeks (55.3%)	EQ-5D VAS. No statistically significant result.	HHI, POS, healthcare usage. Increased hope (p=0.007) at 6-8 weeks Reduced use of therapeutic healthcare services (p=0.003)	Increases to hope lost by 12-15 weeks (p=0.51), but low numbers due to attrition (Guy et al 2011)
Kilonzo et al. (2015) **(50)**	25	Ireland	Reports on implementation of PROMs (no control)	Palliative day care	Day care attendees (mixed diagnoses - 68% cancer) n=102 Mean age: 69	8 weeks (66.7%)	MQOL. 56% of participants improved over 8 weeks	ESAS, EFAT, PCPSS. Symptoms improved in 70.6% of participants Functional status improved in 53% of participants Problem severity improved in 58% of participants	N/A

Kissane et al. (2007) **(40)**	28	Australia	Randomised prospective study	Supportive-expressive group therapy	Advanced breast cancer outpatients n=163 Mean age: 51.7	2 years (47.4%)	EORTC QLQ-C30. Improvement in social functioning subscale (p=0.03)	MILP, IES, M-MAC. Reduced depression (p=0.002), intrusive thoughts (p=0.04) and helplessness (p=0.03) at 6 months	Qualitative report on the experience of SEGT (67)
Leppert et al. (2014) **(51)**	31	Poland	Prospective comparative study across three settings (day care, home care, inpatient unit)	Palliative day care	Advanced cancer patients n=150 Mean age: 67.3	7 days (14%)	EORTC QLQ-C15-PAL. All groups improved, higher in day care than other groups (p<0.0001)	ESAS, KPS. Day care group improved wellbeing (p=0.002), fatigue (p=0.011) & appetite (p=0.033) Day care group had better performance status at baseline (p<0.001)	N/A
Miller et al. (2005) **(52)**	33	USA	Randomised prospective study	Supportive-affective group therapy	Outpatients with mixed diagnoses n=69 Mean age: 61.3	1 year (26.1%)	N/A	BDI, SSAI, spiritual wellbeing, death distress. Reduced meaninglessness (p=0.09) Secondary anaylsis removed non-compliant ppts (n=7): reduced depression (p=0.04) & improved spiritual wellbeing (p=0.054)	N/A

Roulston et al. (2012) **(42)**	31	UK (NI)	Pilot study of intervention (no control)	Condition-specific multi-disciplinary group intervention	Advanced lung cancer outpatients n=5 Mean: 63.4	4 weeks (No attrition)	EQ-5D. Remained constant.	ECOG, EQ-VAS, HADS. Participants reported improved overall health, anxiety and depression.	N/A
Rummans et al. (2006) **(41)**	31	USA	Randomised controlled trial	Multi-disciplinary group intervention	Advanced cancer outpatients n=103	27 weeks (20.4%)	LASAs. Significant difference between groups at week 4 (p=0.047), lost by week 27.	POMS-SF, FACT-SWB, SDS. No significant difference in overall scales. POMS subscale differences in tension/anxiety (p=0.42) & confusion/bewilderment (p=0.014). LASAs subscale differences including social activity (p<0.0001) & social support (p=0.001)	Effectiveness at all time points for participants over 65 years (70). Relationship between caregiver age, caregiver QOL, and patient QOL (72) See also reports on role of exercise (73) social worker (74)
Spiegel et al. (1981) **(53)**	26	USA	Randomised prospective study	Long-term therapeutic support group	Advanced breast cancer outpatients n=58 Mean age: 54.4	1 year (48.3%)	N/A	POMS, HLC, maladaptive coping. Total mood disturbance significantly reduced (p<0.01), less maladaptive coping (p<0.01)	Survival difference after 10 years (p<0.0001) (68) Survival differences independent of treatment (69)

Sviden et al. (2009) **(54)**	26	Sweden	Prospective study with matched comparison group	Palliative day care	Advanced cancer outpatients n=48 Mode age: 51-70	5 weeks (27.1%)	EORTC-QLQ-30. No statistically significant result.	Mood adjective list. Emotional wellbeing higher in intervention group but result not statistically significant.	N/A
Tsianakas et al. (2017) **(43)**	29	UK	Randomised controlled trial	Group walking intervention	Advanced cancer outpatients n=42	24 weeks 45.2%	FACT-G. No statistically significant result, differences at baseline remained stable.	Physical activity, fatigue, stress, anxiety, depression. Only statistically significant difference in level of physical activity	N/A

Key: DUFSS: Duke UNC Functional Social Support Questionnaire. EFAT: Edmonton Functional Assessment Tool. EORTC QLQ-C15-PAL: European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Core 15 Palliative Care. EORTC QLQ-C30: European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Core 30. EQ-5D: EuroQol 5 dimensions questionnaire. EQ-VAS: EuroQol Visual Analogue Scale. ESAS: Edmonton Symptom Assessment System. FACT-G: Functional Assessment of Chronic Illness Therapy – General. FACT-SWB: Functional Assessment of Chronic Illness Therapy – Spiritual Wellbeing. FLIC: Functional Living Index for Cancer. HADS: Hospital Anxiety and Depression Scale. HHI: Herth Hope Index. HLC: Health locus of control. IES: Impact of Event Scale. KPS: Karnofsky Performance Status. LASAs: Linear Analog Scales of Assessment for QOL. MAC: Mental Adjustment to Cancer scale. MILP: Monash Interview for Liaison Psychiatry. M-MAC: Mini Mental Adjustment to Cancer scale. MQOL: McGill Quality of Life Questionnaire. PCPSS: Palliative Care Problem Severity Scale. POMS: Profile of Mood States POMS-SF: Profile of Mood States short-form. POS: Palliative Outcome Scale. QOL: Quality of life. SDS: Symptom distress scale. SSAI: Speilberger State Anxiety Inventory

3.3.2 Group therapeutic interventions

Group therapy had statistically significant effects on psychological outcomes including mood disturbance (P. J. Goodwin et al., 2001) (Spiegel, Bloom, & Yalom, 1981), helplessness (Edmonds et al., 1999) (Kissane et al., 2007), emotional impact of stressful events (Classen et al., 2001), emotional regulation (Classen et al., 2001) coping (Spiegel et al., 1981), intrusive thoughts, and depression (Kissane et al., 2007). Four studies reported survival, with three studies finding no effect (Classen et al., 2001) (Edelman, Bell, & Kidman, 1999) (Edmonds et al., 1999) and one study reporting significant survival effect ten years after the intervention (Spiegel et al., 1981). Two studies reported significant effects on perception of pain (Classen et al., 2001) (P. J. Goodwin et al., 2001). All studies were randomised, which increases the strength of this evidence.

Participant baseline distress influenced intervention effectiveness (Classen et al., 2001) (P. J. Goodwin et al., 2001) - more distressed participants benefitted more from the intervention. Edmonds (1998) controlled for baseline psychological differences, intervention compliance, and the use of self-help strategies, reporting a statistically significant result in helplessness only. However, the control group of this study received considerable support (CBT tasks, supportive telephone calls and relaxation exercises). Classen (2001) conducted secondary analysis by removing 10 participants who died within one year of outcome measurement, demonstrating a stronger effect on mood disturbance and emotional impact of stressful events. This approach was supported by unpublished data of a death-promixal rise in emotional distress in the last year of life. Miller (2005) initially identified non-significant improvements, but removal of 7 non-compliant participants for secondary analysis showed statistically significant results in depression and spiritual wellbeing, suggesting sufficient dose to be necessary.

The Duke-UNC Functional Social Support Questionnaire was used by Edmonds (Edmonds et al., 1999) and identified no significant change. However, the authors report that the questionnaire prioritised support received from the family unit and therefore appears insensitive to gains in social support occurring because of the intervention. Miller (2005) measured baseline social support, stating that it was not expected to be influenced by the intervention (without further elaboration) and controlling for this variable; drop outs from this study had higher baseline social support, suggesting that the group format was not suitable or relevant for these individuals. Edelman (1999) suggests social support should be monitored in future studies – warning that too much consideration on minimising participant burden can impede study design through the use of insufficient outcome measures, ultimately leading to less effective research and use of participant time. Poor sensitivity and floor effects of outcome measures were reported (Edmonds et al., 1999) (P. J. Goodwin et al., 2001).

3.3.3 Palliative day care

Day care was reported to have a statistically significant effect on symptoms (D. Goodwin, Higginson, Myers, Douglas, & Normand, 2003) (Leppert, Majkowicz, Forycka, Mess, & Zdun-Ryzewska, 2014) and hope (Higginson, Gao, Amesbury, & Normand, 2010). Studies with longer study designs found this was not apparent over time, possibly due to attrition and small sample size (D. Goodwin et al., 2003) (Higginson et al., 2010). The majority of participants in an observational study benefitted from 8 weeks of day care (Kilonzo, Lucey, & Twomey, 2015) but attrition makes it difficult to establish whether the intervention was beneficial for non-completers. Improved symptomology reported by Leppert (2014) could have been influenced by baseline differences in physical activity and symptom burden.

Methodological difficulties included large individual fluctuations over time (Sviden, Furst, von Koch, & Borell, 2009) and difficulty in obtaining a true baseline prior to day care attendance due to ethical concerns (D. Goodwin et al., 2003) (Sviden et al., 2009). Goodwin (2003), Leppert (2014) and Sviden (2009) suggest using different outcome measures that might be more responsive, less vulnerable to floor effects, and better tailored to the goals of psychosocial interventions, including perception of social support.

3.3.4 Group practical interventions

Group interventions may have a temporary effect on quality of life (Clark et al., 2013), however three studies (Roulston, Bickerstaff, Haynes, Rutherford, & Jones, 2012; Rummans et al., 2006; Tsianakas et al., 2017) reported that quality of life measures remained stable. Social support was not used as an outcome measure. Rummans (2006) identified improvements in social wellbeing through quality of life subscales. A pilot study with mixed methods (Roulston et al., 2012) appeared to have positive effects on mood and perceived health; all five participants cited social support as a useful component of the intervention. Tsianakas (2017) reported that questionnaires used were not sufficiently sensitive, and draws from qualitative insights to suggest that a specific social support measure be used in future work.

3.3.5 Economic evaluation

Economic evaluation was attempted by only two of the included studies – Goodwin (2001) on group therapy for women with metastatic breast cancer, and Goodwin (2003) on palliative day care – both attempted a cost-effectiveness study by hypothesising that an effective intervention would reduce participants' use of other health care resources. Lemieux (Lemieux, Topp, Chappell, Ennis, & Goodwin, 2006), reporting on Goodwin (2001), calculated incremental cost-effectiveness ratios for change in mood and pain outcomes. A significant difference between health care resource use between intervention and control group was not identified, however the difference in resource use appeared to be larger for participants with higher distress at baseline. Douglas (Douglas, Normand, Higginson, Goodwin, & Myers, 2003), reporting on Goodwin (2003), presented evidence on intervention cost and highlighted challenges of obtaining accurate cost estimates for multidimensional interventions such as day care. Participant health and social care resource use appeared to differ between the intervention group and comparison group – patients accessing palliative day care accessed fewer community services. Conclusions were limited by group size and extent of missing data.

3.3.6 Quality appraisal

The quality appraisal method used in this review (Hawker et al., 2002) was selected to allow for methodological heterogeneity, as evidence-based practice cannot rely solely on randomised controlled trials in areas of ethical sensitivity and fluctuating or deteriorating health. All studies were rated as fair for quality (more than 23 points out of a maximum of 36) or good (more than 31 points), although this frequently reflected the quality of reporting rather than the study itself. The lowest scoring domain was ethics and bias, reflecting that issues of confidentiality, consent and bias were not sufficiently articulated in the articles. There is some risk of reporting bias at study level and it is possible that publication bias may have limited the likelihood of null results being identified.

3.4 Discussion

3.4.1 Summary and discussion of findings

This review systematically examined available quantitative evidence on palliative care interventions that include facilitation of social support outside of the home. Multiple domains and a heterogeneity of outcome measures were apparent across the sixteen studies included. The majority of papers reported psychological wellbeing to be improved by the intervention, indicated by improved mood, reduced depression or fewer maladaptive cognitions; seven studies reported significant differences, four studies non-significant improvements and two reported no change. Twelve papers reported on quality of life outcomes, five of these identified improvements but this was statistically significant in only two studies. Only one study used a validated measure of social support, social wellbeing subscales were employed within generic measures in other studies. Economic evaluation was attempted by two studies. Consistent with other reviews (Singer et al., 2016), cancer diagnoses dominate the included studies.

Baseline psychological distress influenced intervention effectiveness: more distressed participants reported more benefit. This is in accordance with a meta-analysis of 61 studies on psychosocial treatment across all cancer stages, which concluded pre-intervention distress moderates intervention effects, more so than intervention format, setting or dose (Schneider et al., 2010). Baseline social support might influence participant’s experience of an intervention and its acceptability (Miller, Chibnall, Videen, & Duckro, 2005). Participant gender (Lapid et al., 2013) and age (Chock et al., 2013) may be relevant but research is limited. The relevance of caregiver quality of life was highlighted as an important influence on patient quality of life (Clark et al., 2013; Rummans et al., 2006; Shahi et al., 2014).

Survival differences were reported by one study, but not confirmed by three other studies reporting this outcome. This discordance might reflect sociocultural differences between studies and populations, for example it has become more acceptable for cancer to be discussed in public (Spiegel et al., 2007). It is also possible that the reported survival difference (Spiegel, Kraemer, Bloom, & Gottheil, 1989) is anomalous: the survival curves of the intervention and control groups did not diverge until after notable attrition had taken place, and the 12 participants remaining in the control group by this time differed markedly from regional survival norms for breast cancer (Fox, 1998). Despite ambiguity over survival, psychosocial interventions can influence other clinical outcomes (Temoshok & Wald, 2002). Sufficient dose may be necessary for effectiveness (Miller et al., 2005), supported by survival analysis of the Edmonds study (Cunningham et al., 1998) identifying differences in active engagement with the intervention to be significantly associated with survival. An adjusted meta-analysis reported that, with sufficient dose, psychosocial and behavioural interventions may prolong survival for at least some cancer patients (Xia, Tong, & Feng, 2014); interestingly, a subsequent meta-analysis across cancer populations reported a survival benefit in group interventions, but not individualised interventions (Fu et al, 2016).

There were numerous methodological limitations reported by included studies. Outcome measures frequently lacked sensitivity to change or specificity to expected domains of outcome. Many of the patient-reported outcome measures used in trials of palliative care lack adequate responsiveness in the context of life-limiting illness (Kearns, Cornally, & Molloy, 2017). Relying solely on randomised controlled trials can be unsuitable for populations with deteriorating health, warranting creativity in study design (Aoun & Nekolaichuk, 2014). A sufficient number of time points and length of study period is required to account for individual fluctuations that may obscure results. Ethical considerations must remain at the forefront of palliative care research but being overly reticent towards participant burden can damage the validity of results, meaning that the valuable contributions made by participants to research are inadvertently reduced. Attrition is to be expected in this population and empirical studies should plan statistical power accordingly (Stevens et al., 2011). Distinguishing between types of attrition and reporting on reasons for withdrawal can be revealing (Higginson et al., 2013). Selection of outcome measures and other elements of research design should be informed by the experience of other researchers (Gaertner et al., 2016).

Consistent with other reviews (Singer et al, 2016), there is a strong dominance of cancer diagnoses in the included studies and the majority of studies include only metastatic cancer patients, frequently breast cancer. This does not reflect the global palliative care need, of which the majority arises from non-malignant disease, most commonly cardiovascular disease and chronic obstructive pulmonary disease (Connor & Bermedo, 2014). Although oncology has been historically dominant in palliative care, both research and practice should seek to respond to the palliative care needs of the population by actively including non-malignant diseases and multi-morbidities (Etkind et al, 2015). Given its significance in advanced illness, future research endeavours should attend to interventions that promote the expansion of social support (Applebaum, 2014).

3.4.2 Limitations of review

This review has limitations associated with search strategy and eligibility criteria. We used eight electronic databases, supplemented with hand searching of key journals, and checking all citations and references. However, only English language articles and grey literature were searched due to resource limitations, introducing a source of bias and limiting the comprehensiveness of this review.

Intervention descriptions were occasionally insufficient to determine whether or not social support was facilitated - we did not include individualised therapeutic tasks completed in a room alongside others without explicit reference to group communication (Imriea & Troop, 2012) - it is therefore possible that relevant interventions were not included. A number of interventions were retrospectively evaluated as having enabled social support by the researchers, but were designed for a different purpose such as self-management (Roulston et al., 2012). All interventions involved multiple components, so it is possible that benefits such as symptom control would be more appropriately attributed to other components like clinical input or self-management skills. The use of mixed methods in research can help to untangle the relationship between components and outcome (Higginson et al., 2013).

The criteria for inclusion in this review were developed from scoping searches, using patient experience of psychosocial palliative care interventions. We focussed explicitly on interventions taking place outside of the home, informed by a qualitative meta-synthesis concluding that a change of scenery and getting out of the house were necessary for alleviation of both physical and psychosocial isolation (Bradley et al., 2010). This meant that well-established examples of community-based support programmes, for example the Good Neighbourhood Partnership in Ireland (McLoughlin, Rhatigan, et al., 2015) and the Neighbourhood Network in India (Sallnow, Kumar, & Numpeli, 2013), were excluded from the review. However, models of home-based palliative care (which may or may not include facilitation of social support) are better represented than other settings in the research literature (Brereton et al., 2017), and we are aware of an ongoing systematic review of community-led support interventions for adults living at home with palliative care needs (Mcloughlin, Furlong, et al., 2015). An additional consideration is the increasing availability of different formats, for example social networking interventions (Owen, Bantum, Pagano, & Stanton, 2017). Given the high prevalence of limited mobility in this population, it would be appropriate for future reviews to compare social support facilitation across different settings and formats.

3.4.3 Conclusion

Responding to the needs of people with life-limiting illness requires consideration of social wellbeing, including their perception of support from others. Psychosocial palliative care services and interventions have been developed that facilitate social support, with some evidence for effectiveness. It is possible that psychological and physical benefits operate via mechanisms of social support. However, social support does not appear to have been used appropriately as an outcome of palliative care interventions.

Further research is required to elucidate what forms of social support are most effective to which patients at which time points. It may be illuminating to test different intervention formats and durations; or explore individual differences in baseline distress or perceived social support. With increasing financial pressures, it is crucial that economic evaluation takes place alongside testing intervention effectiveness.

This systematic review summarises the quantitative evidence of benefits of social support interventions to people with life-limiting illness. Existing evidence suggests that patients presenting with high distress are most likely to benefit from interventions facilitating social support.

3.5 Addendum

3.5.1 Introduction

Systematic review for this project was initially carried out up to January 2017. This was updated with a non-systematic search to October 2020. The purpose of this update is to compile recent evidence for effectiveness, as measured using validated patient outcomes, of interventions offering social support to people with life-limiting illness, as well as to discuss the development of outcome research in this area.

3.5.2 Method

Following systematic searches up to January 2017, automatic weekly searches using the same search string were carried out across the databases represented in Web of Science, in titles across Scopus, and in titles and abstracts of seven key journals using Scopus. Results of possible pertinence were collected and reviewed up to October 2020. To allow for delays in indexing, Web of Science was also hand searched by the researcher for publications from the years 2020 and 2019. In addition, reference checking of recent reviews and citation checking of identified/relevant studies was carried out.

Inclusion and exclusion criteria were identical to that used previously; however quality appraisal is not carried out here. Findings are presented narratively with focus on outcomes and discussion of methods.

3.5.3 Results

Initially searches identified roughly 130 titles of interest, and this was narrowed down to 28 papers after screening abstracts using the eligibility criteria.

Papers were excluded that did not use at least one validated outcome measure to evaluate the effectiveness of an intervention offering social support to adults with life-limiting illness. Interventions were excluded that were self-help, telephone based or reflecting individual appointments with a professional.

The review required interventions taking place outside of the home - this excluded household level interventions, as well as patient navigator programs in which a volunteer is trained to mentor and coach a patient in a 1 to 1 format. Similar to befriending or compassionate neighbour schemes, these interventions can sometimes offer opportunity to get out of the house, but it is not a guaranteed component. Two papers did not describe intervention is sufficient detail, but information available suggested the intervention was individualised, Furthermore, two meeting abstracts and one paper in French were not screened due to resource limitations. Seven (n=7) papers are included in the review update (see table 2).

Table 2: Details of included studies (2017-2020)

Study	**Country**	**Method**	**Intervention**	**Population**	**Study period (attrition)**	**QOL outcomes**	**Other outcomes**
Amir et al. (2017)	Iran	Pretest-posttest controlled quasi-experimental study	Acceptance & commitment group therapy, group logotherapy, control without intervention	MS patients (not wheelchair-bound) n=33	3-4 weeks (none)	N/A	Perceived stress scale (PSS-14) ACT had greater reduction in perceived stress than logotherapy. Both group therapies had significant effect compared to control.
Feldstain et al. (2017)	Canada	Secondary analysis of clinical data	Palliative rehabilitation program: Group physiotherapy twice per week, plus clinical, nursing and social worker appts as needed or requested	Advanced cancer outpatients n=264	8 weeks (31.8%)	N/A	Distress Thermometer; Problems Checklist t-test indicates significant reduction in distress for completers.
Johns et al. (2020)	US (Indiana)	Single-arm observational study	MODEL care: mindfulness-based support to approach EOL conversations. Dyads attend 6 weekly, 2 hour sessions	Advanced cancer outpatients & their family caregivers n=26	c. 10 weeks (15.38%)	McGill Quality of Life Inventory	Openness to Discuss Cancer; Mini-Mental Adjustment to Cancer; Brief COPE; Patient Health Questionnaire PHQ-8; Generalized Anxiety Scale GAD-7; Pittsburgh Sleep Quality Index; Fatigue Symptom inventory. Observed improvements in patient depression, anxiety,

							sleep disturbance, avoidance, & QOL. And in caregiver QOL, communication, avoidance, anxiety & sleep. Effects at T2 grew more pronounced at T3.
Mitchell et al. (2020)	UK: 3 hospices in England, Scotland & Northern Ireland	Before-and-after descriptive cohort study	Palliative care day services: multidisciplinary input for the day, groups of 6-12 for 8-12 weeks	Palliative care outpatients (63% cancer) n=56	12 weeks (32.14%)	EQ-5D-5L and extended McGill Quality of Life No change at 4 weeks	ICECAP-SCM Uses staff & volunteer compositions to estimate cost. Increasing attendance would reduce cost.
Nottelman et al. (2019)	Denmark	Analysis within a randomised controlled trial	Palliative rehabilitation: optional component of 12-week group self-management and social support program	Patients with inoperable cancer (83% incurable - inc lung, colorectal, prostate, breast). n=132	12 weeks (26.5%)	Adapted problem scale from EORTC QLQ-C30	N/A
Pappa et al. (2017)	US (Washington)	Pre-test post-test quasi-experimental study	Chronic disease self-management program: Six 2.5hr weekly classes. Three conditions – groups with patient attendance, caregiver attendance, control without intervention.	Parkinson's disease patients n=52	9 weeks (11.5%)	Parkinson Disease Questionnaire (PDQ-30) Improved health status in those who also reported improved appraisal support	Interpersonal Support Evaluation List; Chronic Disease Self-Efficacy; Community Participation Indicators No significant change for participants. Social support correlated with self-management and community participation.

Ramos et al. (2018)	US (North Carolina)	Single arm pre-test post-test study	Life program: cognitive behavioural and mindfulness skills, discussion of psychological and existential stressors	Veterans receiving palliative care (65% cancer) n=26	6 or 8 weeks (session number reduced due to ppt burden) (11.5%)	N/A	Depression Anxiety & Stress DASS-21; Acceptance & Action Questionnaire-II; Self-Compassion Scale Short Form; Toronto Mindfulness scale. Reports clinically significant improvements in severity of depression, anxiety and stress. Improvement in self-compassion, mindfulness and psychological flexibility

3.5.3.1 Group therapeutic interventions

Group therapeutic interventions were acceptance and commitment therapy (ACT), logotherapy, life program, and a mindfulness-based intervention designed to encourage conversations about the end-of-life. All of these models include meaning-based components, derived from Buddhist philosophies of acceptance (ACT and mindfulness), or from existential philosophies of meaning in life (life program and logotherapy).

Amir et al (2017) observes a greater reduction in perceived stress for participants receiving ACT than logotherapy. However, both group therapies had significant outcomes compared to control. Logotherapy had fewer sessions over a longer timeframe, thus the ‘dose’ was different as well as the intervention – although this is not commented on in the paper itself. Ramos et al (2018) reports clinically significant improvements in depression, anxiety, and stress arising from a single arm trial of life program with veterans in palliative care. Attrition was low over the intervention period, but over half of the participants eligible and contacted declined to participate. Possibly this is related to transport in the semi-rural context, rather than acceptability of the intervention itself: nine participants who had initially consented pulled out citing transport limitations and the intervention was restructured according to feedback during the trial to reduce the number of sessions from eight to six. Those who did not start the intervention had higher comorbidity at baseline. Johns et al (2020) reports psychosocial improvements for both patients and caregivers arising from MODEL care: a mindfulness-based group intervention. Outcomes grew more pronounced with time – possibly ongoing improvement communication between patient and caregiver continued to alleviate or protect against depression, anxiety, and sleep disturbance. The trial also recorded engagement with advanced care planning across three behaviours, reporting that 90% of participants made progress with some aspect of advanced care planning over the study period.

3.5.3.2 Palliative day care

One study explored palliative day care, exploring three centres in three nations of the UK. Mitchell et al (2020) uses quality of life scores and cost components of staff and volunteer composition to estimate cost per day. No change in quality of life was recorded after 4 weeks. Attrition was almost a third over 12 weeks. Reporting on cost per attendance per day, authors note the high variability in cost between centres and the substantial contribution of volunteers. A detailed description of the intervention is not included. Increasing attendance would reduce cost per person, but it is beyond the scope of this paper to comment on whether this might have a detrimental impact on patient care or even a positive impact on atmosphere.

3.5.3.3 Group practical interventions

Group practical interventions were two different models of palliative rehabilitation, and a disease-specific self-management programme. Feldstain et al (2017) reports that distress was significantly reduced during a palliative rehabilitation program that included group physiotherapy twice per week, plus additional appointments as needed or requested with a clinician, nurse, or social worker. Attrition was near a third over 8 weeks. The authors report that emotional concerns were as prevalent in the sample as physical concerns. It is suggested that social support within the group enables emotional expression and support by relieving the stigma of ‘losing the cancer battle’. Nottelman et al (2019) report on a different palliative rehabilitation program, in which a 12-week group support was available, in addition to one-to-one appointments and self-help materials. 45% of participants chose the group format, and these participants reported more emotional problems at baseline than those choosing an individualised format. Caregivers were invited, but only about half of group attendees brought their caregiver, if one was present.

Pappa et al (2017) developed a mixed program of self-management and social support for Parkinson’s disease and tested three conditions: program with patient attendance, program with patient and caregiver attendance, or control group without a program. This study used social support as a primary outcome measure (Interpersonal Support Evaluation List) and a disease-specific health outcome (Parkinson’s Disease Questionnaire). There was not a significant change in social support for those participating in the intervention – however, those who reported improved appraisal support also reported improved health. Social support in this sample was correlated with self-management and community participation. Interestingly this study chose to use those who consented but could not participate (eg due to travel) as a control group. Intervention groups were higher in depression and comorbidity at baseline. Qualitative findings in this mixed methods investigation highlight the benefits of shared peer experience and connection to a community.

3.5.4 Discussion

This addendum identified seven new papers regarding the effectiveness of social support interventions for people with life-limiting illness. In several cases these were not standardised of manualised, so not all participants in the intervention group engaged in groupwork. Positive psychosocial outcomes were reported for acceptance and commitment therapy, logotherapy, group physiotherapy, mindfulness-based group therapy, and a life program allowing group discussion of psychological and existential stressors. A common component across these interventions is the opportunity to meet and share with people in a similar situation.

Although discussed in three categories (group therapeutic, day care, group practical), there is continued overlap in the interventions described here. It could be argued that many programs include both practical and therapeutic components, eg those in this review often involving patient education and peer sharing within the same session. It is necessary to research palliative day care but adequate description of each intervention is necessary – many centres include group physiotherapy and therapeutic conversations or activities, so dividing day care from other interventions is not clear cut.

Since 2016, the research literature shows an increasing interest in the needs of different cultural groups and research contributions from a greater number of countries. Researchers are engaging with single-arm trials and observational work, which may reduce some of the recruitment challenges identified by the previous review. Recruitment of new attendees at day care centres can be particularly sluggish because researchers are unable to influence referrals (Mitchell et al 2020).

However, methodological issues remain, particularly the lack of follow-up following intervention. Previously, the systematic review identified short-term benefit but a lack of long-term change observed following intervention. In this update, Amir, Feldstain and Ramos did not include any follow-up, Mitchell reports on quality of life changes during the intervention, but not at the end or subsequently, and Pappa had a 3 week follow-up after a 6 week intervention. Johns notes that outcomes grow more pronounced at the final timepoint, 3-4 weeks after the last session. There might be a temptation to reduce attrition and participant burden through shorter trial designs, but participants should be followed up beyond the intervention to properly explore its effectiveness. Little is known about those who decline group participation – thus a self-selecting ‘control’ group is probably not valid for comparison but may be useful for observation. Finally, researchers may wish to consider differences in dose as well as differences in access to clinical input when comparing interventions.

3.5.5 Conclusion

An increasing interest in psychosocial change has demonstrated improvements including perceived stress, depression, anxiety, and coping behaviours. There is limited evidence that addressing social domains (communication, appraisal) within an intervention is associated with mental health and physical health benefits (depression, health status) (Johns et al, 2020; Pappa et al, 2017).

Access to a community of fellow patients could be a hidden component of many group interventions. These interventions appear more acceptable to some participants than others, possibly related to the extent of emotional difficulties experienced (Feldstain et al, 2017; Nottelman et al, 2019).

The initial systematic review contributed two main points to research design: that certain methodological challenges appear to be enduring aspects of the research context, and that perceived social support was not adequately explored as an outcome measure. The addendum showed continued interest in a broader range of interventions offering social support to people with life-limiting illness. However, it remains challenging to design trials that are appropriately rigorous yet sufficiently flexible for a palliative population.

Chapter 4 : Methods

Responding to the needs of people with life-limiting illness requires consideration of their social wellbeing, including their perception of support from others. A breadth of social palliative care services and interventions have been developed that include a component of social support. The literature review in chapter concluded that some of the reported benefits of palliative day care and group interventions could operate via mechanisms of social support. But the systematic review found sparse research measuring perceived social support as an outcome of these interventions. If outcome measures used in evaluation do not include the things that matter most to the people involved in and using the service, palliative care could ultimately fail to adequately address those aspects of care that are most valuable to people, curtailing the beneficial impact of palliative services at the individual and population level (McCaffrey, 2016).

This thesis reports on a mixed methods exploration of social support in palliative care. This chapter describes the rationale of the research methodology and methods. It begins with an overview of research design, to introduce the methods and how these meet the objectives of the research. This is followed by a brief summary of recommendations for research in complex interventions in palliative care, identifying challenges and indicating the need for research to have coherence and pragmatism in its approach to the complexity of this field of practice. Realist evaluation, underpinned by scientific realism, is introduced as being sensitive to both context and rigour, thus potentially of merit for researching real-world interventions (Emmel et al, 2018). Having delved into the philosophical foundations and approach to complexity underpinning the methodology, this chapter closes by describing in detail the methods employed by the project. The last section describes the procedure and justification for each of the methods used for data collection by this project – these were:

- an online survey of hospices
- patient reported outcome measures
- qualitative observations,
- interviews with service-providers.

4.1 Overview of Research Design

The preceding chapters indicate that, although social support appears to be important to patients and providers in palliative care, there is sparse understanding of how to intervene effectively to provide social support, and how to identify and demonstrate this effectiveness. Beyond the very well-established conclusion that social wellbeing is indeed necessary for good quality of life, there is very little known about the mechanisms and outcomes of social support within a palliative context. Aligned with Pawson, I observe that “the more innovative the programme and the less well visited the target population, the less we tend to know”. (p.34, Pawson 2013). As such, this research project was intended to be exploratory and explanatory in nature, aiming to further understanding of social support interventions in palliative care.

Objectives of the research project were to describe the practice and clarify the meaning of social support in palliative care, contributing to the development of appropriate methods for defining effectiveness and cost-effectiveness, while postulating explanatory mechanisms by which social support obtained in hospice day services might lead to beneficial outcomes. This work will explore the real world setting of hospice day services and consider the feasibility of using patient reported outcome measures to underpin future economic evaluation. A research project such as this requires some investigation of the field of practice broadly and the specific interventions in context, as well as consideration of mechanisms and the feasibility of measuring patient reported outcomes.

4.1.1 Designing a mixed methods study

Realist evaluation is an avowedly multimethod framework for scientific research, that recognises different types of data as contributing different types of answers, and so avoids a hierarchy of evidence fixated on randomised controlled trials. Demonstrating outcomes can require quantitative evidence; qualitative investigation can be useful to reveal mechanisms; salient aspects of context can be indicated through comparative study. Underlying theories of how a programme works can be found in the narratives of the programme designers, in this case the people managing and delivering the hospice service. Evaluating each intervention in isolation is less useful because its success can be influenced by many dimensions of complexity. Each specific programme of intervention is unique in some way, as is the context to which it is applied, but evaluation of similar interventions in different contexts can develop cumulative knowledge. By asking ‘what works for whom, in what circumstances’, realist evaluation contributes an underlying programme theory as explanation of how the intervention can produce change in some situations (Pawson, 2013).

Realist evaluation is explained more thoroughly later in this chapter. This framework is adapted from an overview of the realist research process (p.153, Pawson, 2013). It explains how the objectives of this research project are met by the different components of the mixed methods investigation, and how these are presented in the thesis.

1. Formulate lines of enquiry and research questions (chapters 1 and 2)
   Introduction chapter and literature review describe abundant qualitative and epidemiological work on the relevance of this research area, but sparse effectiveness work describing, evaluating, or informing intervention.

2. Explore proposed area of research, to ascertain challenges and contributions of previous research and if necessary to redefine research question (chapter 3)
   Systematic review confirms minimal effectiveness work so far, identifies consistent research challenges and infrequent use of social domains for outcome measurement of social interventions in palliative care.

3. Explore area of practice to ascertain relevant interventions for research and guide subsequent collection of data (chapter 5)
   Survey of hospices reports on interventions used by hospices that facilitate social support in palliative care, this was necessary to understand current service provision and ascertain relevant hospice services. Results describe an active field of practice and guided the sampling of research locations for subsequent data collection.

4. Identify hypothetical explanatory accounts of how these interventions work, to develop programme theories (chapter 7)

   Qualitative investigation explores social support interventions and service-provider experiences in independent hospices across multiple locations. Analysis uses realist ontology to describe context, mechanism, outcomes; and construct these into configurations.

5. Explore the feasibility of testing configurations with empirical evidence, comparing outcomes by intervention and context (chapter 6)

   Patient reported outcome measures in an observational cohort study with four hospices recruiting thirty patients. Feasibility of measures is established, but small samples limit statistical analysis.

6. Respond to emerging programme theory and refine with previously published research (chapter 8)

   Discussion chapter revisits configurations, quantitative findings, and published research, to articulate an initial programme theory as a suggested explanation for change occurring as a result of these interventions.

7. Document the process in an explicit and transparent manner (whole thesis)

   The research process, its procedures, and findings are presented in a doctoral thesis. Methodological rationale is a focus of chapter 4, researcher reflections are housed in chapter 8, and implications are in chapter 9. Figures are used where possible to communicate complex concepts.

4.1.2 Challenges to research

Hospice day services are considered a complex intervention with multiple components, multi-disciplinary input, and a diversity in offering between hospices. Methodological difficulties in palliative populations are consistently described, warranting creativity in research design to deal with issues such as deteriorating health (Aoun & Nekolaichuk, 2014). This section briefly summarises identified challenges and existing recommendations for evaluation of complex interventions in palliative care. The recommendations most relevant to this project were considered to be those presented by MORECARE, but the MRC framework for evaluating complex interventions is also drawn upon.

Palliative care research has made substantial developments in recent decades, but many challenges remain related to research using palliative care patients, who may be emotionally and physically frail (Gotay, 1985). The ethical concerns require their own consideration due to their importance and are turned to in the next section. In terms of practical challenges to research, palliative care has multiple interacting components and outcomes are expected to vary between patients – it is therefore a complex intervention as defined by the Medical Research Council. Research design may benefit from mixed methods that can provide descriptive and experiential insight (MRC, 2019). Description of specific intervention setting, components and comparator models is often insufficient in existing research (Brereton et al, 2018; Fulton et al, 2018).

As consensus is lacking on what constitutes patient benefit, outcomes measured are highly variable (Brereton et al, 2018). Focusing on health-related quality of life as a primary outcome measure may be inappropriate in context of incurable illness. Stakeholder input during research design or feasibility work can usefully inform the selection of sensitive outcome measures for this context (Higginson et al, 2013). Randomised controlled trials to date have been limited by poor recruitment, attrition, confounding variables, and small sample sizes, which all have potential to bias findings (Higginson et al, 2013).

Randomisation may not always be the best use of research resources - observational or quasi-experimental studies can be good alternatives if issues of selection bias are appropriately considered (Medical Research Council, 2019). Appropriate matching of subjects is made more difficult by clinical complexity (Gotay, 1985). It is not possible (or ethical) to control for variables such as symptoms, pharmacological treatments, or social time outside of the intervention, which substantially limits the possibility of control within a randomised controlled trial. Recruitment continues to be a limiting factor for the success of trials (O'Riodan, 2019; Shinall, 2019) and fluctuations in health could obscure the effect of intervention.

Attrition is to be expected in this population, and the uncertainty of the disease and its progression makes it challenging to predict accrual and attrition rates. Empirical studies should plan to have sufficient statistical power to detect significance in the presence of substantial attrition rates - this requires feasibility work to identify sensitive measures and estimate effect sizes. Distinguishing between types of attrition (e.g. due to death, due to illness, at random) (Higginson et al, 2013) and participants' reasons for withdrawal can be insightful.

The context of the intervention might be crucial to its success (MRC, 2019). Interventions offering social support across patient and non-patient populations have struggled to establish an evidence base of effectiveness or transferability. What appears to be consistent across effective interventions is that targeting social isolation and loneliness benefits from interventions that are able to respond to local contextual factors: The local context shapes the needs of service-users, such that interventions to target social isolation and loneliness appear more effective if they able to respond to contextual features (Gardiner, Geldenhuys & Gott, 2018).

Research could benefit from embracing this complexity, rather than reducing and controlling for it, which produces a high degree of artificiality. As knowledge is always partial, evaluation is always partial; but there can be a focus of evaluation on one (or maybe more) of the aspects of the complexity. Increased attention to social support as a process variable in palliative care is recommended, ideally occurring within mixed methods study, as this can reveal aspects of intervention that are therapeutic (or problematic) for people involved, but not yet recognised by researchers (Higginson et al, 2013). Any psychological or physical improvement as a result of these interventions cannot be completely ascribed to greater social support without also demonstrating a relationship between changes in perceived social support and other improvements (Temoshok & Wald, 2002).

It is known that there is variability in the practice and extent of intervention to offer social support for people with palliative care needs – what is not known is the extent to which this variability impacts on the success of the intervention (however it is defined), and crucially, which factors of the context and intervention make a difference to achieving positive outcomes. How can we ask ‘does it work?’ without understanding what ‘it’ is (the social support) or how to recognise something that ‘works’ (what the goal is). This dilemma is resolved by turning to a realist definition of an intervention – underlying mechanisms can lead to the emergence of changed outcomes in some contexts, but not all. Evaluating (and understanding) an intervention operating on the complex social world requires us to forget about demonstrating ‘it works!’ and instead ask ‘what works, for whom, in what circumstances?’, which is the most succinct way to explain the realist approach (see page 91)

4.1.3 Ethical considerations

Pragmatic researchers should be aware that there are substantial practical and ethical challenges in conducting research in the palliative care population, related to the size and nature of samples (Williams, 2018). Patients could be vulnerable to coercion or burden, and concerns about this vulnerability might lead to gatekeeping or strict inclusion and exclusion criteria that affect the potential generalisability of results (Gotay, 1985). There is a balance to be found between giving people the opportunity to take part in research, which many find valuable, whilst protecting participants from undue burden and being aware that those with cognitive impairment can have limited capacity to consent. Rodin (2013) argues there is an ethical imperative to allow individual to make autonomous informed decision of whether to take part in the research, for burden to be minimised, and endeavouring not to waste the valuable contribution made by the participant. These concerns were kept at the forefront of research design in this project.

It is an ethical imperative that research makes the best use of the time and contributions of palliative care patients (especially), which warrants thoughtful research design and feasibility work. Exploring the perspectives and challenges of health care professionals recruiting palliative cancer patients to a randomised trial indicates that randomisation can be a particular source of discomfort for them. This is because recruiting a patient to be allocated to a control group feels like a contradiction to their ambition to provide the best possible care

– randomisation might increase difficulties with recruitment, lead to more gatekeeping and protective behaviour, fuel attrition by disappointment, and thus produce less generalisable findings than hoped for (Holm et al., 2017). Although not resolving issues of selection bias, non-randomised study designs might include more of those patients that would otherwise have declined to participate, or not been invited in the first place.

At each stage of research, participants consented to be involved in a research project and given the opportunity to ask questions to the researcher. For the online survey, this was an information and consent webpage presented before the questions. For the patient reported outcome measures, this was an information sheet and a consent form (appendix D and E). For the qualitative interviews, this was a slightly different information sheet and consent form (appendix H and I). These contained the researcher's contact details as well as contact details for the university's research ethics and governance team. For the observations, the researcher was introduced to everyone in the room in advance of the researcher being present, and at the beginning of each day or activity. The researcher also produced informational handouts about the project as whole, which were provided when visiting hospices to introduce the research project and make the researcher's contact details more widely available for any questions.

The researcher's role and reactivity may affect data collection and interpretation, especially in challenging topics associated with isolation and dying (Borgstrom & Ellis, 2017) The position of the researcher as an experiencing and reactive being is explored further in the discussion chapter. Here it is noted that the researcher worked with a supervisory team and hospice decision-makers to develop this project, seeking their expertise as far as possible; and maintained a research journal throughout data collection so as to identify their own responses to the experience. Subjectivity and reflexivity should be systematically and transparently managed, but the processes of managing these potentially tricky aspects of research can be methodologically productive when theorising about people (Madden, 2010).

This research received approval from the University of Liverpool ethics committee [February 2017, Appendix B]. Where required, the project also received approval from hospice boards and/or research committees.

4.2 Introduction to Realist Evaluation

Realist evaluation is the practical application of realism, as a form of scientific explanation, to real-world interventions and methodological challenges. This section visits the principles of scientific realism as underpinning the epistemological and ontological position of this thesis; it then explains how realist evaluation supports the exploratory and explanatory intentions of the research.

4.2.1 Philosophical foundations of realism

Within the natural sciences, experiments are designed to trigger a hypothesised mechanism, in specific conditions, so that an expected outcome is observed (or not) and the null hypothesis is rejected (or not). The scientific method seeks to go beyond description towards understanding – it is the theory-driven pursuit of generative mechanisms through observation of physical properties (Emmel et al, 2018). The natural sciences offer a sequential and logical approach to ascertain causation that is reliant on a closed experimental system. However, the real world is a far cry from the experimental laboratories in which the laws of physics were tested and tweaked over generations of inquiry. In the social sciences, it is not possible to genuinely achieve a well-controlled system for experimentation - “society is made by, but never under the control of, human intentions” (p.5).

Society is permanently changing, and the objects of study changing with it - patients, stakeholders, interventions, and institutions are not fixed entities – they are consequential within complex and shifting systems (Archer, 1995). Interventions do not produce change, they alter the course of change that is already and always occurring. Society is in a constant state of self-transformation, but social change is not completely haphazard – there are relatively enduring aspects of society, which give rise to patterns that are the object of realist inquiry (Tilley, 2018). Realist research seeks to identify the generative mechanisms driving observable patterns or ‘demi-regularities’ (Archer, 1995).

Both the natural sciences and social sciences use theory to make sense of observable regularities. Scientific understanding is the product of cumulative explanation, not objective observation (Popper, 1992). Continuous and cumulative efforts to explain these patterns allows for development of theory that is sufficiently abstract to be applicable across different spheres of society (‘middle-range theory’ - Merton, 1967). Seemingly diverse interventions and behaviours across different social structures can have a common thread, producing patterns across society – developing middle-range theory represents an unpicking of this thread (Pawson, 2013). Realist evaluation searches for, tests, and refines its explanations of a specific intervention, known as programme theory, in a specific context or setting, and then takes these hypotheses together with published literature to develop middle-range theory. This process of abstraction guides continued inquiry, informs generalisability, and contributes theoretical depth.

4.2.2 Understanding reality

Realism asserts a stratified social reality in which reality exists, independent of our ability to observe it – things exist whether or not they are measurable. The social world is real, it is enabled or constrained by the physical world but not reducible to it (Williams, 2018). Social objects are not necessarily material, observable, or clearly definable. The objects of the social world interact, and one might cause another, in a chain of somewhat predictable events, just as in the physical world. However causal chains in the social world are not operating under the necessity conditions of natural laws of science, they are messy constructs forming a dynamic system characterised by possibility, not probability.

In a stratified reality, each level has powers to cause effects at other levels, and influences are expected to be bidirectional (Bhaskar, 1997). This power at one level of reality exerts change at a higher or lower level - mechanisms operate at different levels and different timescales to the outcomes they generate (Westhorp, 2018). The definition of a social object as either mechanism or outcome depends more on perspective and research requirements than an absolute. These concepts can be explained with an example:

Consider that we might see tears in a person’s eyes and infer that they are experiencing an emotion – we have identified a causal influence on what we observe (Emmel, et al, 2018). It would be a mistake to believe that emotions do not exist because we cannot see them, to assume all tears reflect the same emotion, or to conversely to believe that if a person’s eyes are not producing tears that they are not experiencing that emotion. Outcomes are observable results of generative mechanisms. In this example, emotions are the mechanism which generate the tears. Some people cry frequently, some people never do -

between different people, the observable outcomes may be different, (e.g. aggressive behaviour, reclusiveness), but there might be something in common driving the outcome. Furthermore, responses to negative emotion usually depend on where the person is at the time – in an office meeting, or in their own home? Having a run of bad luck, or feeling optimistic about their lives? Context is clearly important in determining whether a certain mechanism produces a certain outcome, and 'the context' is the result of numerous temporal, spatial and personal factors.

Classically in realist evaluation, mechanisms of an intervention or programme are constructed as 'individual reasoning' by participants/stakeholders in response to 'collective resources' offered by the intervention (Tilley & Pawson, 1997). However, causation in the complex system of society cannot be entirely explained through the decision-making of individuals, and the focus of realist inquiry appropriately goes beyond the individual (Westhorp, 218) to include (e.g.) organisational behaviour, infrastructure and policy when appropriate to the research question. Therefore 'reasoning and resources' is useful as a methodological starting point but is not a complete definition of mechanisms – instead, we look for mechanisms by asking which parts are necessary for the emergent properties of the system.

*A*ll characteristics of all stakeholders and the institutional, cultural, and historical surroundings of an intervention are considered relevant to understanding the intervention itself. This contrasts with reductionist, purely positivist investigation might treat contextual factors as confounding variables to be controlled out of calculations. Realism takes a non-positivist philosophical position while attempting to rescue "the science of the social" (Pawson, 2013). It is considered to represent a firm methodological footing to integrate empirical evidence with theoretical development.

4.2.3 Embracing (and bracketing) complexity

Complexity is a feature of society and interventions are not separable from this. All medical interventions involve social encounters (p. 135, Pawson, 2013) – whether the treatment in question is a pill or a support group, the interpersonal interactions and social expectations encountered by the patient change their adherence behaviour, motivation, and expectation of the treatment; and are not controllable by the research team. The ideas driving an intervention can be multiple and competing, and the same intervention could trigger change in a myriad of ways. The different contexts in which an intervention could be applied are as varied as society itself. The perception that a medical treatment is a singular, well-defined event is misleading – intervention chains are long and complex in different ways.

Ultimately, realists argue that the research challenges identified for complex interventions in psychosocial palliative care are endemic across health research. The requirements of a randomised controlled trial (RCT), and thus the expectations of evidence frameworks that prioritise RCTs and meta-analyses of RCTs, are defined and communicated, but they rely on ungrounded assumptions of control and replicability within an open, fluid, multi-layered system like the real world. This means they lack pragmatism and flexibility to respond to enduring, but crucial, research questions, like those around supporting people until the end of their lives. Realist evaluation embraces complexity, considering aspects such as the volitions of the people involved and their contexts, and the role of time and rivalry between people, ideas and organisations. Emergence refers to the outcomes of an intervention changing the intervention or its context in some way. Applying contextual thinking exponentially increases the complexity of evaluation, and the complexity of reality means that priorities are chosen based on the research question and researcher.

It is mistaken to accept objectivity even when it is claimed, because the decision-making processes driving every step of the research process are shaped by society. For example, the reasoning of the researcher and their relationship with reality decides which measurements to collect and how to collect them – the quality of their reasoning is just one determinant of the quality of that data (Emmel et al, 2018) Science, too, is a social process and asking the right questions of complex social interventions will never completely escape researcher bias and assumption – allowing inquiry to be guided by multiple subjective experiences is considered to add trustworthiness and plausibility to the conclusions drawn (Pawson, 2013). Empirical evidence remains vital for falsifying, limiting, testing, and thus developing these theories – the idea of ‘realist closure’ requires at least some measurement. Realism is pragmatic in approaching its data sources. Mixed methods are typically chosen for the value added by subjective experience and stakeholder explanations (Pawson & Tiller, 1997).

4.2.4 Developing explanations

Realism asserts the aim of research to be closing the gap between what is real and our knowledge of it. To approach this task, realist evaluation seeks to identify: salient features of the context, generative mechanisms that (may be/are) unobservable, and possible outcomes; using evidence-based deduction to construct context-mechanism-outcome configurations. Context-mechanism-outcome configurations (CMOs) are if-then propositions supposed to depict the interconnected constituents of an intervention as testable and refineable hypotheses (Pawson, 2013) There are always multiple contextual features, mechanisms and outcomes and the line between them is vague (Westhorp, 2018) – however the CMO is useful as an explanatory device because it specifies a process of generative change.

Context-mechanism-outcome configurations articulate the programme theories proposed to explain the specific intervention under inquiry. These configurations make claims about underlying factors that make a difference towards (or against) the goals of the intervention (p.6). They explain causality in the form of fallible and testable theory; and improve understanding of social programmes in a manner that is useful to practitioners and policy-makers. Often programme theories are linked to middle-range theory, sufficiently abstract to fulfil explanatory purposes across multiple settings and populations.

Context-mechanism-outcome configurations are models of a reality that we cannot fully grasp because of its complexity and changeability through time. They might be increasingly accepted through empirical closure in specific circumstances, but the mechanisms proposed remain proposals. Opposing mechanisms can be operating concurrently so that their existence is masked – mechanisms always act “in concert and in competition” (p.50, Westhorp, 2018) with other mechanisms and contextual features.

Configurations are intended for further theoretical and empirical development - realist explanation can be confirmed or refuted through empirical work in testing the models proposed by programme theory (empirical closure), over time contributing to acceptance of the hypothesis presented. However not every implication of the model and researcher assumption can be identified, measured, or experimentally studied. The biggest challenge for realists is what to measure and how to measure it - this is at the heart of empirical closure and resonates with the evaluation challenges facing psychosocial palliative care. Empirical measurement of social objects (e.g attitudes – p.34) can be attempted, but we cannot be certain whether the measures correspond to the potent aspects of the mechanism to be tested.

Explanations provided by realist evaluation aim to be a *good enough* answer to 'what works, for whom, in what circumstances?' Programme theories are preferred that have empirical content in their development and that represent parsimonious, falsifiable models. Realism recognises that we could never have complete knowledge of reality, because it is constantly changing, and so theory remains theory and thus open to cumulative development (by which realists define scientific progress). The success of a realist evaluation is judged by its rigour, relevance, and richness (Pawson, 2013). While it may be beyond the scope of this project to fully consider the relevance of its contribution, it is hoped that this thesis write-up is able to demonstrate its rigour and richness.

This chapter now moves on to consider each of the data collection methods of this project in turn. These were: an online survey, patient reported outcome measures, researcher observations, and interviews with service-providers.

4.3 Survey of Hospices

4.3.1 Survey aim

Exploring patient experience has led several authors to conclude that social interaction is the core of palliative day care (Hyde, 2011; Kernohan 2006; Lee 2002). Low (2005) comments that although these findings may have high content validity established through qualitative data collection, by offering little description of the type of service and focusing on single centres, studies are limited in their usefulness to practice because it is unclear how generalisable they are to other settings. Focusing only on the patient perspective neglects that there is a configuration of services being explored and number of different stakeholders involved (Low, 2005).

Some hospice day centres run formal interventions, numerous activity groups and an active social programme, offering informal social interaction during group activities, shared meals, and unstructured social time (Payne, Hartley & Heal, 2008). Volunteers are commonly involved, contributing an important social role as well as creative activities, complementary therapies, transport, counselling and pastoral faith-based support (Burbeck, 2014; Copp 1998). Furthermore, other group interventions, social settings and community-level initiatives are being developed within hospice settings.

Much of the informal support offered by hospices remains unquantified (Hospice UK, 2016). We know more about palliative day care than other group interventions which might differ starkly in their aims, processes, outcomes, and costs. Resolving this ambiguity is important for addressing issues of access and of cost-effectiveness.

It was necessary to better understand current service provision in order to ascertain which hospice services are perceived to offer social support by the people providing the service; understand the aims, professional roles, volunteer roles and criteria for attendance at these services; and use this to inform next stages of data collection. An online survey is a practical approach to data collection from a broad geographical area that enables respondents to complete the survey at a time convenient to them. Surveys are helpful in illuminating the bigger picture, they can enable knowledge exchange and help to focus research endeavours (Burbeck et al 2014). The survey aims to gain an overview of hospices service models that facilitate social support for adults living in the community with life-limiting illness.

4.3.2 Survey design

An online survey was developed and data collected through SurveyMonkey. The survey was initially designed by NB and redrafted with input from MLW and CFD; it was then piloted between June and August 2017 via relevant existing contacts known to the research group in order to promote survey reliability (i.e. questions reliably interpreted in similar ways by different respondents). Feedback from the pilot suggested improvements to question clarity and user interface. Adjustments were discussed and made before data collection began. The full survey is included as Appendix C.

The survey began with questions about the hospice itself; specifically regarding location, staff and volunteer roles, diagnosis mix, funding source, and transport availability. Each respondent was asked to identify any services that they considered to offer social support to people living in the community with life-limiting illness. The survey allowed between 1 and 8 different services to be identified free text boxes, and then asked further questions about these services. Respondents were then asked to identify which of these services to offer *most* opportunity for social support, and gave detail on eligibility criteria, discharge procedures, use of outcome measures, and availability of cost data for this service.

4.3.3 Inclusion & exclusion criteria

The survey aimed to gain an overview of hospice services that facilitate social support for adults living in the community with life-limiting illness. The social needs of individuals and the barriers they have to accessing adequate social support will to some extent be determined by where they live and in particular whether they reside in the community or in a healthcare setting (i.e. hospice, hospital, or care home). The outcomes and aims of services will also be determined by where they take place – i.e. whether in the patient's home or elsewhere. Previous literature describes palliative day care as relieving social isolation by providing an opportunity to get out of one's home, as such this research focuses on social support opportunities outside of the home. The social outcomes and significance of at-home services are worthy of separate study. Target respondents for this survey were hospice staff involved in the management of outpatient or day care services for adult patients, and those representing hospices *only* offer inpatient or home care were not included.

As detailed below, there were two hundred and eight (208) eligible hospices in the UK & ROI and these were invited to participate in the survey.

4.3.4 Data collection

Data collection began in August 2017 and ended in May 2018. The survey was promoted via eHospice (a global news resource in palliative care) and the mailing lists of the Association of Palliative Day Services and the All Ireland Institute of Hospice & Palliative Care. In addition, a contact from each hospice identified as eligible to participate in the survey was emailed an invitation to participate, with a link to SurveyMonkey. If contact details were available from the hospice's website, this was the lead/manager of hospice day services, or the equivalent identifiable role (e.g. lead psychosocial care, or head of outpatient support), or the director of the hospice itself. If specific contact details were not available, a generic email address was used and the email marked for the attention of management staff of day services, day care, or outpatient services. Following this, telephone contact was made with each site, aiming to identify the most relevant member of staff and introduce the survey directly to them if possible, and obtain an appropriate email address.

The Hospice UK directory was considered the most comprehensive list of hospices in the United Kingdom and so was used as a framework to identify respondents and calculate response rate. The directory (accessed 11/05/2017) listed 288 hospice addresses in the UK; of which 51 are children's hospices only, 12 inpatient only, and 10 homecare only. Some hospices operate from more than one location (commonly two, but up to eight including satellite sites) – 14 entries in the directory were for this purpose duplicates, where more than one address was listed for the same organisation. There are nine hospice organisations in the Republic of Ireland providing support for adults with life-limiting illness, but two of these provide only homecare or inpatient care and so were not eligible for this survey. Therefore, the total number of hospices eligible to participate in this survey was calculated as 208:

(288 total in UK +9 total in ROI =297 total) MINUS (51 children's + 21 homecare/inpatient +14 duplicates =89) EQUALS 208 [1]

A target response rate of 100 hospices was chosen as a manageable goal that might capture a broad section of eligible hospices. Email and telephone contact was made with each hospice in the first six months of dissemination, with reminder emails sent to non-respondents on up to two occasions between January and May 2018. No financial or other incentive was

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[1] Hospice UK have figures from 2011. There are calculated differently because their directory includes hospital palliative care (NHS) and Macmillan (national charity), and also counts multiple locations by the same provider individually. Their directory suggests 275 palliative day care locations in total. Estimates for this survey have used hospice websites and conversations with management staff during survey dissemination, as sources of current information on service provision (i.e. 2017/18). - *Help the Hospices. (2012) Hospice and palliative care directory: United Kingdom and Ireland, 2012-2013. London: Help the Hospices*

provided. Respondents consented to taking part in the study as part of a larger research project at the University of Liverpool and were asked whether they consented to being contacted in the future for further involvement.

4.3.5 Analysis

Survey responses were exported from SurveyMonkey at the end of data collection. Descriptive statistics calculated in Microsoft Excel were used for quantitative data. Partial responses were included in analysis, but missing item data was not imputed or pursued, instead questions are summarised independently to each other. Non-numerical data was grouped thematically using both manual coding and NVivo12. Services identified by respondents were grouped progressively, summarising the information to reach an overview of the different services offered to facilitate social support - as identified by these survey respondents, and interpreted by the research team.

Representativeness of the sample was considered in terms of location, funding, and diagnosis mix. There were a small number of instances in which two responses were received from the same hospice – these were reviewed and only the most complete set of survey responses was used. Results of the survey are presented in the next chapter.

Survey results in this thesis informed maximum variation sampling of hospices for observations and interviews.

4.4 Patient Reported Outcome Measures

4.4.1 Research aim

Randomised controlled trials can provide valuable evidence but are not suitable for all scenarios. Observational studies have significantly contributed to clinical and public health knowledge and constitute the majority of research papers published in clinical speciality journals (Vandenbroke et al, 2007). Vandenbroke and colleagues developed a reporting checklist to improve the standards of reporting for observational studies, including cohort, case-control and cross-sectional study designs. In cohort studies, participants are followed over time. Information is obtained at baseline, and outcomes may be assessed at multiple timepoints during follow-up. Investigators examine exposure and outcome variables and make contrasts between groups of individuals with different categories of exposure (Vandenbroke et al, 2007).

This is an observational cohort study which aimed to follow participants for 3 time points as they were about to start attending, were in the middle of attending, and were finishing, a hospice-based intervention offering social support. Alternative strategies would be the use of randomisation to decide which patients are denied or delayed in having the intervention, or the recruitment of a well-matched and suitable control group from a different sample. The research design chosen was acceptable to the hospices involved and did not disrupt patients in the hospice support that they received – to them, it represented an additional questionnaire, rather than a change to care trajectory.

This study is focussing specifically on individuals who are able to access social day services (meeting eligibility criteria and geographical catchment) and chose to do (indicating some motivation to attend – this might be a high level of unmet need or inadequate social support). It is possible that people accessing such services differ from the broader palliative population and these differences may influence their experience of the intervention. As such, this study aims to explore outcomes and variables in this specific group of participants. Results are likely to be of practical interest to those involved in design, implementation, and evaluation of hospice services.

4.4.2 Access and recruitment

The research aimed to establish a multi-site cohort study, recruiting patients as they start to attend and following them over time to analyse outcomes and contextual variables. Research sites were identified using insights from the survey, where survey participants had consented to be involved in further research related to the project. This purposeful sampling intended to invite a breadth of hospices (eg both rural and urban), to include common interventions offering social support, i.e., multi-component services, such as palliative day care, and activity groups, such as exercise or art groups; and less common models such as social coffee mornings and satellite café locations. Not all the hospices that were invited were able to take part in recruiting patients (due to e.g., service redesign or personnel changes), but many of these did take part in the qualitative investigation. An overview of the four recruiting sites is provided as a table in chapter 6.

The chief executive officer, day patient services leaders, or head of research governance (where applicable) was approached with an invite to participate in a funded PhD project, led by Natasha Bradley and supervised by Professors Mari Lloyd-Williams and Chris Dowrick. Exact process differed in each hospice. Some sites had formal research governance procedures in place, meaning that a research committee formally reviewed and recommended the project. In others the researcher met with relevant decision-makers to explain the purpose of the research directly and answer their questions. Early in-person meetings were helpful to understand potential concerns of managers or staff, and perhaps so that the team felt more engaged with the project because they had a ‘face to the name’.

A three-month recruitment window was initially agreed with each hospice, with a review at the end of this period to allow each site to decide whether to continue to recruit for a further 3 months. The intention of using a recruitment window rather than a fixed number of participants per site was to reduce issues of selection bias, as it was intended that all eligible patients starting to attend the service within the recruitment window would be invited to take part. However, it was difficult to elucidate how closely this procedure was followed.

Recruitment at each site occurred on a rolling basis, with the first site starting recruitment in August 2018 and all sites finishing recruitment by the end of April 2019. Patients were eligible to be included in this study if they were deemed eligible by the hospice to attend the day service to be studied. Additional eligibility criteria included the ability to participate in the research methods - to have adequate cognitive ability and English language skills. Each participant was invited to take part in the research after they had been assessed, invited, and decided to attend a particular hospice day service. The researcher was not involved in this assessment process.

Participant information sheet is given in Appendix D. Participants had the opportunity to ask any questions from either hospice staff or the researcher prior to giving written consent, see Appendix E for consent form. Brief demographic and clinical information were obtained at the same time as baseline outcome variables (Appendix F). Due to sparse available literature in this area, ethical approval was initially obtained for 100 participants for a feasibility study. Recruitment is difficult in palliative populations and the sample size was determined by the success of recruitment across the sites.

4.4.3 Data collection

Data collection took place at baseline, 6 weeks, 12 weeks – this might become longer if participants miss weeks of attendance. Participants were adults with life-limiting illness, currently living in the community (i.e. not inpatients or residing in a long-term care institution) and accessing hospice day services. Participants were recruited from 4 hospices, when they were about to start or had recently started attending day services at that hospice. An understanding of each service was achieved by the researcher during a concurrent qualitative component to this research project. Emphasis during research design was on flexibility to allow patients to participate and reduce missing data. In order to plan for the fluctuating health and thus attendance of many hospice patients, data collection was scheduled for the beginning, middle, and end of the hospice intervention, rather strict dates.

The researcher visited each research location for a minimum of three days for qualitative data collection and to begin patient recruitment with the service-providers. Patients were eligible to be included in the study if they were about to start attending the hospice group intervention, having been deemed eligible by assessment criteria of the hospice itself, and were able to participate in the research methods, i.e. not cognitively impaired, ability to read and write English. Hospice service-providers identified eligible patients and invited them to participate. Either an identified staff member or the researcher took consent and answered any questions. Most participants completed written question booklets themselves, within the hospice. The participant question pack is presented in Appendix G.

Printed information for services, for patients, consent forms and question packs were provided to hospices by the researcher, with addressed envelopes for the return of question packs. This was done by post if the researcher was not due to visit the site, with emails at either end to confirm. Patient reported outcome measures used were: MOS-SS questionnaire for perceived social support, UCLA 3-item loneliness scale, BEDS for depression in advanced illness, and EQ-5D-5L for health-related quality of life.

4.4.4 Choice of outcome measures

Sensitivity to change of outcome measures, or ability to detect benefit from an intervention, is a reported challenge in this population. Furthermore, measurement of distinct but potentially interacting concepts such as social support and loneliness is not straightforward, especially when wishing to minimise participant burden. Regardless, progress in outcome measurement is needed to further the evaluation of psychosocial interventions in general, and in palliative care specifically.

4.4.4.1 Social support: MOS-SS

Measures of social support can be long and sometimes do not distinguish between functional and structural social support (ie perceived social support and social integration) or include any of the support received from outside of the family or healthcare encounter (Gasiorowski and Rudowicz, 2017). The Medical Outcomes Study (MOS) was a large two-year study of chronically ill patients, for which a relatively brief multidimensional self-administered social support scale was developed (Sherbourne & Stewart, 1991). Nineteen questions reflect perception of availability of different types of social support – emotional, informational, tangible, affectionate, and positive social interaction – with an additional question to construct an overall social support index. This five factor model of functional social support has been shown to have validity in cancer patients (Priede et al, 2018), and is distinct from measures of structural social integration and from measures of negative loneliness feelings (Valtorta et al, 2016).

An alternative would be the Duke-University Functional Social Support Questionnaire (DUFSS), which has fourteen question and five question versions available and has been used in a palliative care setting to explore supportive relationships (Saracino et al, 2014). However, researchers using this measure for the evaluation of a palliative care intervention reported that questions appeared to prioritise support occurring within the family unit (Edmonds et al, 1999). An eight-item modified version of the MOS-SS scale has been recently used in a trial of volunteer support in the last year of life (Walshe, 2016). Results suggested favourable changes in social support, but these were not statistically significant. Its possible that the nineteen- question version will be useful and not too burdensome for the present study.

4.4.4.2 Loneliness: UCLA scale

The concept of a lonely person carries negative connotations that can make it difficult for individuals to recognise and admit to feelings of loneliness in themselves. A suggested consequence of this is that measuring loneliness with direct questions such as ‘do you feel lonely?’ leads to underreporting, whereas loneliness measures that have multiple ‘indirect’ questions can have better reliability (De Jong Giervald, Tilburg & Dykstra, 2016).

The UCLA loneliness scale (Russell, Peplau & Ferguson, 1978) is commonly used and has been revised and adapted for several contexts and countries. Its earlier format included twenty questions with a mixture of direct and indirect questions, reflecting positive and negative social experiences. This was deemed too lengthy and complex to be included, as participant burden was a concern.

A simplified and shorter version contains three indirect questions related to feelings of lacking companionship, being left out, or feeling isolated, with validity demonstrated in population based surveys (Hughes, Waite, Hawkley, Cacioppo, 2008).

An alternative would be the De Jong Gierveld scale (De Jong Gierveld & Van Tilburg, 1999), which consists of 11 items, and draws on Weiss’s early theoretical distinction between social and emotional loneliness in its early development (Weiss, 1973). A shorter version was developed with 6 questions (de Jong Gierveld & Van Tilburg, 2006). However, the questions, in reflecting this distinction, in some cases appear to be similar to perception of social support (‘there are people I can rely on when I have problems’) and also to depression (‘I experience a sense of emptiness’). Of course these constructs are all connected, but it was felt that the UCLA questions focused on loneliness as a subjective experience in a more direct way, without using the word ‘lonely’.

4.4.4.3 Depression: Brief Edinburgh Depression Scale (BEDS)

Brief Edinburgh depression scale was designed with the recognition that physical symptoms of depression and chronic illness are difficult to untangle, thus it focuses on cognitive and emotional symptoms only (Lloyd-Williams, 2008). Depression measures such as the Hospital Anxiety and Depression Scale (HADS) ask questions that could have both a physical and emotional cause (e.g. dizziness) and can be difficult to complete by declining patients. Early work evaluating the use of the Beck Depression Inventory in advanced cancer concluded that using just non-somatic symptoms could differentiate patients with depression (Plumb & Holland, 1977).

The Edinburgh Postnatal Depression Scale is a ten-question measure, developed to be straightforward to complete by people without psychiatric training, and without the somatic symptoms of depression (Cox et al, 1987). Its sensitivity and specificity were demonstrated in palliative care inpatients (Lloyd-Williams, Friedman & Rudd, 2000). Further study with advanced cancer patients found that six of the ten questions showed discriminant validity, indicating a brief and sensitive method for screening that is shown to be suitable in this population (Lloyd-Williams, Shiels & Dowrick, 2007).

An alternative could be the PHQ-9, which has nine questions derived from diagnostic criteria, reflecting somatic, emotional, and cognitive depressive symptoms (Kroenke, Spitzer & Williams, 2001).The measure has been shown to fit a one-factor model in primary and psychiatric care, but in palliative care samples the three somatic items are statistically distinguishable from the six cognitive-affective items and data better fits a two-factor model (Chilcot et al, 2013). Although sensitive for use in practice, the PHQ-9 with somatic symptom criteria has been shown to be highly influenced by disease load in advanced illness patients and so was deemed less suitable for this study (Lie et al, 2015).

4.4.4.4 Quality of life: EQ-5D-5L

Commonly used measures of health-related quality of life are EQ-5D-3L, SF60, HU13. These might not be sufficiently sensitive to the impact of palliative care patients but are familiar to patients (McCaffrey, 2016). The five domains of the EuroQoL’s EQ-5D-3L were considered to be relevant and recognisable, but the -3L measure has been shown to have poor responsiveness to clinical change in many studies, not just in palliative care contexts (Tordrup, Mossman & Kanavos, 2014). Consequently a newer, five level version was developed and tested by the EuroQol group (Herman et al, 2011). Saclone and colleagues (2013) compared EQ-5D-3L with the newer 5L version – with five possible answers for each domain, rather than three – in a large sample of chronic kidney illness patients, indicating the scale was more informative and showed fewer ceiling effects. Responsiveness to clinical improvement was confirmed by Nolan and colleagues (2016) in COPD patients, before and after rehabilitation, and in diabetes patients (Pan et al, 2015).

An alternative measure considered was the EORTC QLQ-C30 (Fayers et al, 2002). This is extensively used in research, but is much longer, with thirty questions. The focus of this thesis is social support, and so less focus on health-related quality of life was preferred. Furthermore, the Eq-5D measure is fundamental to the use of Quality-Adjusted-Life-Years (QALY) as a unit in health economics. The use of the QALY for resource allocation in palliative care is under debate, but highly relevant to the UK context in which the National Institute for Health and Clinical Excellence (NICE) uses QALY estimates to support its decision-making. (Wichmann et al, 2017). At present it remains unclear if 5L is as responsive to clinical deterioration (Golicki et al, 2015) and what effect its use would have on cost-effectiveness estimates (Hernandez, 2017).

4.4.4.5 A&E attendance and overnight stays in hospital

Costing methodologies have received less attention than outcome measurement, but a substantial proportion of costs to the state near the end of life are via unplanned hospitalisations. Attendance at the emergency department and overnight stays in hospital are distressing for patient and family, sometimes unavoidable, and a significant resource component to consider. Formal measures are available to get a more complete view of a person's health service use, and these can be useful to also capture the experience of the caregiver (Nickel, Barth & Kolominkey-Rabas, 2018). However, these receipt inventories can be cognitively taxing, increasingly so the more healthcare commitments a person has. For the purpose of this investigation, two simple direct questions were used to elicit the most relevant health service use, with the knowledge that it may not be completely accurate as it is not verified against patient records. A brief proxy measure of healthcare resource use was obtained by asking if any visits to A&E or hospital inpatient stays had occurred in the previous 6 weeks.

A more in-depth approach to resource use could be obtained by use of a Client Service Receipt Inventory, but this was deemed too burdensome to be used in addition to the outcome measures (Round, 2016). It would have been preferable to have an indication of day care attendance and involvement for each participant (intervention dose and compliance).

However, obtaining accurate information would have constituted further burden on the hospice staff. Furthermore, health conditions may be confounding in interpreting compliance - for example, the participant may have wished to attend, but been unable due to healthcare appointments or fluctuating health and energy.

Hospices anticipated this fluctuation, and thus the patient would be given twelve weeks of attendance, not just a straight twelve weeks date to date. It is possible that the availability of services would have some benefit (e.g. the ‘peace of mind’ that someone is available to talk to soon), even if the participant did not attend every week. This project did not track the attendance of each participant but did consider in detail how the procedures of each included hospice related to its the access and availability.

4.4.5 Analysis

Sensitivity to change of outcome measures, or ability to detect benefit from an intervention, is a reported challenge in this population. If one does have a well-matched control group, it may be illuminating to compare rate of change in, for example, QOL between the intervention and control group. This strategy was used in the ELSA trial (Walshe, 2016), reporting that participants who received a befriending intervention had slower decline in physical quality of life than those in the control group, and that this difference was significantly significant. The sample size achieved here was small, and analysis therefore focusses on describing the sample, observing change over time for participants with two or more timepoints, and comparing groups of participants. This approach is aligned to realist logic, which breaks down the analysis of outcomes into variables relating to context and process.

4.5 Qualitative Observations

Qualitative research is characterised by an intention to see through the eyes of the people being studied, emphasising the significance of context, subjectivity and meaning. It is a flexible approach that is able to tolerate complexity and uncertainty is necessary in attempting to understand the social world. Inductive reasoning is intended, for the experiences of the participants to be prominent over the expectations of the researcher. The goal is to use methods that are appropriate for uncertainty, richness, and vitality - so that research might “account for the social world without assassinating the life contained within it” (p. 21, Back and Puwar, 2013). In this case, the focus of the researcher is deepening understanding of the social world of hospice day services.

4.5.1 Aim

A survey is useful for many purposes, and necessary as a scoping exercise of this field of practice, but it to be unlikely to provide the depth of description required to understand different models and their outcomes. Qualitative observation is probably needed (Higginson, 2000) but rarely attempted in palliative care (Walshe, Ewing & Griffiths, 2011). Concluding a survey of palliative day care, Copp and colleagues emphasise the limitations of their descriptive data and advocate for in-depth studies that explore and compare the issues experienced by individual services, and their relationship of different models of support to patient care (Copp et al, 1998).

Clarke and Neale (1994) used a variety of data collection methods but noted that fieldnotes and journal entries made from observations of hospice services added particular value by adding “richness to the data which would not be otherwise present”. It is through “listening for the background and the half muted” that it is possible to study ordinary yet remarkable things (Back, 2007) - such as, perhaps, the accrual of social support resources through interpersonal interaction.

Following the online survey of service provision, a diverse sample of hospices were approached for detailed investigation of their day services and/or support groups. Researcher observations were carried out of hospice day services. Comparing and contrasting different services within and between hospices helped to deepen the description and understanding of the researcher. The process was influential in connecting the interviews to real interactions. People’s lives are not sedentary, and so accompanying people to explore their routine settings reveals sensory aspects of their reality that might be missed in a static and remote interview. Interviews care commonly used, allowing ‘someone to say what they do’, whereas observations allow the research ‘to see directly what someone does’ – they contribute different types of information and can help to broaden the types of people included in the project (Walshe et al., 2011). For this study, researcher observations of the day services helped to ground the interviews in the real-world setting that was to be discussed.

Observations were conducted as focused ethnographic observations, defined below. Although not the focus of this thesis, observations and fieldnotes revealed divergences in professional objectives between interview participants and tangible differences to patient experience between seemingly similar hospice locations. By visiting the hospice locations for more than a day, the researcher also saw features of the local area – this was practical, in terms of how easy it was to get to the hospice on public transport (for example), but also gave glimpses into the visibility of the hospice in the community.

4.5.2 Focused ethnography

Ethnography is sometimes considered synonymous with participant observation. Observational roles can range from detached observer, perhaps collecting quantifiable data on intervention fidelity or interaction content within a positivist and 'objective' position; towards more participatory roles that increase familiarity and use the 'self' as a research tool for a subjective understanding of the setting. Social processes and events are "complex because they necessarily exceed our capacity to know them" (p. 6, Law, 2004). We can never be party to all the possible spheres with which it is possible to view the world, so it is necessary to either restrict our viewpoint, or to move away from presumption of coherence to make progress in understanding the world as it is.

Knoblauch (2005) delineated what he terms 'focused ethnography' from more traditional, anthropology-derived ethnography that might be wide-ranging. Cultural and social aspects of contemporary society are increasingly differentiated and fragmented - Knoblauch argues that as fields to be researched are becoming more short-term and diverse, it is appropriate for the approaches used in this research to become more flexible and short-term – focused on particular issues or interactions.

Focused ethnography is characterised by shorter lengths of time in the field, often in settings that are part-time, rather than operating permanently. The construct of focus is not necessarily a group, organisation, or place, but rather situations, interactions, and activities – during focused ethnography, the researcher seeks to observe the basic segments of social life: situated everyday social interactions (Knoblauch, 2005).

Classical anthropological ethnography would study "the other", i.e., a culture or group different to that of the researcher; considering any pre-existing knowledge to be distorted by hearsay, prejudices, earlier reports etc. Ethnography within one's own society must take a different orientation towards strangeness, due to the researcher's implicit and explicit knowledge of the society itself and the area they are studying. Knoblauch (2005) argues that familiarity with the society is 'member's knowledge' that produces a backdrop of common understanding, allowing the identification of differences and specific features of the group being studied and thus supporting the brevity of focused ethnography. Pre-existing knowledge could be necessary for the ethnography to *be* focussed - in order to focus on aspects of a field, it is necessary to have knowledge of the field.

The construct of focus is not necessarily a group, organisation, or place, but rather situations, interactions, and activities – during focused ethnography, the researcher seeks to observe the basic segments of social life: situated everyday social interactions (Knoblauch, 2005). Ethnographies connect the focus of their study to other aspects of daily life and through this process contribute to an understanding that is grounded in modern society rather than disconnected from it (Madden, 2010).. Attempting to disengage from common societal understanding may therefore be counter-productive – rather, the influence of pre-existing knowledge on observations is acknowledged and reflexively considered by the researcher privately throughout fieldnotes and explicitly in the researcher reflexivity section.

4.5.3 Researcher role during observations

The researcher observed some or all of the hospice day services on offer at six hospices (three rural, three urban) for between 2 and 4 days. For three other hospices, the researcher had tours of the building prior to the qualitative interview with the service-provider (next section). The researcher spent time in the local hospice surroundings as well as, the space of the day service itself, prior to the arrival of patients. This was sometimes an opportunity to take photos of the space to support memory, as disruption by the researcher during the service itself was kept to a minimal. If photos weren't possible, a quick drawing of the room itself was made. Interviews were made more conversational and analytical because the researcher had developed a (partial) shared knowledge of the day hospice through observation, which allowed the interviewee to make references to specific aspects of the service.

The researcher made extensive fieldnotes describing the day service. Initially, notes and short phrases were noted down and these were extended more fully immediately after the observation, to include description and summary of: services offered, location, history or ethos comments, immediate surroundings, public transport, arrival, sensory aspects of being there, group size and mix, specific activities, staff and volunteer roles, research activity/attitudes, recent or ongoing changes to service, similarities and different to other hospices. The resulting fieldnotes reflected on the tangible, emotive, and sensory aspects of: getting there, being there, leaving; observed instances or remarks considered to represent social support (instrumental, informational, emotional, companionships); other salient interpersonal moments; possible consequences or outcomes not recorded; and notable resource items or considerations.

Fieldnotes were jotted down as words or phrases – cues to be padded out in the evenings, and sometimes added to subsequently. Keeping attention on the social aspects of the setting, rather than on detailed note-taking, was considered beneficial for two reasons – staying open to emotive and sensory cues, and communicating my openness to the other people in the room, who might have been perturbed by a more ‘closed-off’ researcher scribbling furiously. At other times, for example, in the hospice café, the presence of a notebook actually felt useful in reducing my conspicuousness.

The researcher was introduced to the hospice and the people within by a manager or service lead, the researcher also produced written information introducing the project to staff. Establishing access to research environments and demonstrating legitimacy may require academic credentials and professional demeanour, but this brings the possibility of being seen as a credible outsider, who’s presence influences behaviour and situation dynamics (Walshe et al, 2011). It is difficult to fully participate in some worlds - I was only ever ‘alongside’ patients and volunteers - but I sought to emphasise my ‘student status’ so that my presence could be inquisitive but non-judgemental.

Movement, potential movement, blocked movement, and immobility can be a way of understanding society. This perspective is relevant to this population, due to fluctuating or declining physical function. The researcher saw how the pace of different hospice day services differed. Stillness, waiting, and slowness may be just as important to many situations as sensations of movement and excitement, such that understanding pace of services was seen as worthwhile engagement in the setting (Merriman, 2014).

Knowledge is co-produced, and researchers must attend to the role they play. I was conscious of how my age, ethnicity, size, accent, clothes, hair, and body language might contribute to how I was perceived, in addition to my role as a visiting researcher from a (usually) far off university. Through keeping a research diary, I recorded my own experiences during observations and interviews - affective/emotional, sensory (smells and sounds as well as visuals), and aspects related to mobility within the environment. Another helpful cue after observations was – 'What were you surprised by? What does this surprise tell you about what your expectations?' Illness and death have been described as the main themes of the patient social talk (Langley-Evans & Payne, 2016) but notably the majority of this death talk was conducted in a light-hearted jovial manner. I did see lots of this, but it was by no means the main themes in many cases, and this could be due to my presence in the room, if patients were reactive to (e.g.) wanting to include me in conversations or to portray the hospice in a 'lively' light.

4.6 Qualitative interviews with service providers

4.6.1 Aim

Creative approaches can be useful particularly to sensitive topics, but the most common qualitative method, the humble interview, remains an important tool and is capable of multiple adaptations to tailor it to the specific research question. (Mason and Dale, 2011). The participant engages in analysis of their experiences, just as the researcher analyses their data, which means that interviews are best carried out 'in situ' as knowledge is situated/contextual and so cannot be separated from the situation in which it is produced (Mason & Dale, 2011).

Qualitative interviews are an opportunity to explore the wisdom of service-providers. The people involved in designing, managing, and delivering an intervention have an understanding of why they are doing what they are doing – there is an implicit programme theory that might be different, or richer, than the explanation articulated in official documents giving the stated aims of a service. Service-providers have experience-informed ideas about what works and what doesn’t, for which patients; they are important stakeholders with wisdom to benefit this research (Tilley & Pawson, 1997). Realist interviewing is about comparing the researcher’s emerging ideas with the reality experienced by the service-provider.

4.6.2 Interview procedure

These interviews aimed to elicit interviewee thoughts regarding the context of the intervention, its mechanisms, and outcomes. Interview style was informed by skills of active listening, open questions, and clarification. The researcher considered the interviewee the expert and therefore their interviewing style allowed space for the conversation to flow, for new or unexpected topics to come up, using questions as opportunities to clarify their understanding of what was being discussed. An interview guide was used as a reminder for topics, and to offer a break for the participant, the guide was not used as a strict list of questions. Observations of services, or tours of the hospice, allowed for site-specific questions and reflections to be shared. Early ideas from psychological literature and survey were brought into these conversations for feedback from the service-provider.

Interview participants were service-providers representing a broad selection of hospice day services offering social support. Participants were invited to take part in the research and given written information (Appendix H) and the opportunity to ask questions before giving written consent (Appendix I). Interviews took place in a private room and were audio-recorded before being transcribed. As described in the previous section, observations of hospice day services (or a walking tour of the building) took place before the interview, which is considered to have allowed for deeper and more analytical conversations.

4.6.3 Analysis

Written transcripts from interviews were analysed using NVIvo 12, making references to observation fieldnotes as helpful. Initially, transcripts were coded for mechanisms related to resources, reasoning, interpersonal interactions, and processes occurring beyond the hospice walls. Salient features of context, and outcomes for different stakeholders were also brought together. Differences between sites were helpful in identifying what sites had in common. Analysis of interviews constructed early context-mechanism-outcome configurations aligned with a realist definition of social change. In the discussion chapter, I draw these configurations together with insights from other strands of the study and from published literature. This process supports the development of an initial programme theory, which is proposed to describe the context, mechanisms, and outcomes of these interventions and thus presents an explanation of change.

4.7 Summary

Realism asserts that variables themselves do not have causal powers, and as such their practical significance is shown by building explanations. Each stage of this project informed subsequent stages to develop an explanatory programme theory:

- Literature review highlights the relevance and risks of social support in life-limiting illness and the significance of social intervention in palliative care.
- Systematic review reports little use of social domains as outcome measures and underscored the difficulty of attempting recruitment and randomisation.
- Survey results inform maximum variation sampling of hospices for interviews and observations and to be invited to recruit patients.
- Observing patient reported outcome measures suggests these services might influence perceived social support, loneliness, and depression for some patients.
- Analysis of interviews goes on to detail the social context of patients and mechanisms of services, suggesting how social support could lead to mood improvements and behaviour change in particular contexts.
- Discussion of findings with literature pulls together these configurations into an initial programme theory and suggests directions for future research.

The initial programme theory describes the context, mechanisms, and outcomes of these interventions and thus presents an explanation of change. However, realist evaluation is never finished – all knowledge and thus all evaluation is partial (Pawson, 2013). The next step of a realist evaluation would be further validation and development of this theory, including service-receivers (patients) and other stakeholders (such as family). Ideally service-providers interviewed would be asked to give their feedback and thoughts on the initial programme theory. Secondary analysis of outcome evidence is not possible with the sample size obtained, but lessons learnt from this feasibility work could be useful to design future quantitative study. Further methodological development could lead to methods of economic evaluation that are more pragmatic to the realities of complex interventions in palliative care.

Chapter 5 : Survey

5.1 Introduction

Hospices recognise unmet social need in the patients they support, and as such provide day services that meet social objectives such as increased social interaction, decreased isolation, personal growth, a sense of control over the illness experience, and reassurance about the future (Payne, 2006). Systematic reviews have concluded that access to social support in palliative day care is highly valued by patients (Bradley, 2010) and referring health professionals (Bradley, 2011), although there is sometimes reluctance to refer for purely social reasons (Bradley, 2011).

There was early uncertainty attempting to define palliative day care as either ‘medical’ or ‘social’, but it is probably both (Higginson 2000) and both sides may be important to patients and carers (Low 2005). Indeed, the importance of social opportunities in palliative day care has been clear since its establishment – the first report of palliative day care (Wilkes et al, 1978) describes a ‘rallying point’ for patients and families to come together and cope with loss. This was further articulated by Faulker and colleagues (1993), writing that day centres provide social interaction, a stimulating environment, friendship for patients, and confidence-building opportunities for personal growth.

There are clear issues facing the hospice sector, including access and sustainability (Calanzani, Higginson & Gomes, 2013; Allsop; Sleeman. Multicomponent interventions such as palliative day care have a high cost per patient and may become increasingly untenable. Innovation in service design is ongoing and some hospice day centres offer a broad menu of psychosocial opportunities that are poorly described in present literature. Better intelligence is needed to understand how hospices offer social support to people with life-limiting illness.

The survey aims to gain an overview of hospice service models that facilitate social support for adults living in the community with life-limiting illness. Description of survey design, dissemination and eligibility criteria are provided in the previous chapter, section 3.3.1. This chapter presents survey results with a brief discussion.

5.2 Results

5.2.1 Respondents

Management staff at two hundred-and-eight hospices were invited to participate in the survey via email and telephone contact with the hospice. Survey responses were received from one-hundred-and-three hospices (n=103, response rate 49.5%) between August 2017 and May 2018. Responses were received from England (82), Scotland (7), Wales (7), Northern Ireland (5) and the Republic of Ireland (2) (Table 3, Figure 2). Most respondents (83.5%) were in management or senior leadership positions; nursing was the most common discipline represented, followed by allied health professionals, clinicians, and social workers.

Table 3: Survey respondent location

England	82
Scotland	7
Wales	7
Northern Ireland	5
Ireland	2
Total	103

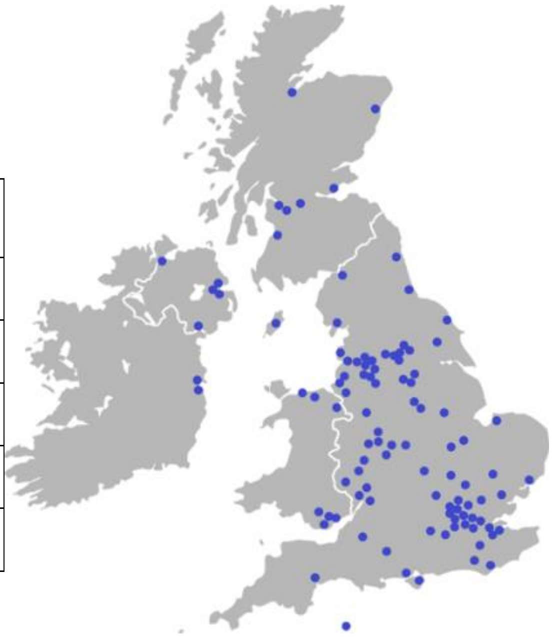


Figure 2: Survey respondent location as shown on a map of the UK & ROI

5.2.2 Hospice characteristics

Respondents answered general questions about the hospice before specific questions regarding services they considered to offer social support. Unless otherwise stated, n=103. Most hospices in this sample had a mixture of statutory and charitable income, receiving some funding from the NHS or local authorities (mean average = 31.3%, Table 4). Four respondents indicated that their hospice received no funding from statutory sources, and four respondents were fully funded by the NHS or local authorities.

Transport was offered by almost all the hospices in this sample (Table 5). This was usually provided by volunteers (77.7%) or paid staff (13.5%). Five hospices offered transport provided by a different organisation (4.8%) and four offered none (3.9%). Forty-five of the hospices in this sample (43.7%) offered services to people who do not themselves have a life-limiting illness (Table 6). Twenty-seven of the hospices in this sample (26.2%) were linked to a compassionate community project, about half were not, and twenty-four respondents were unsure (Table 7).

Most hospices in this sample (75.7%) did not ask for payment towards any services (Table 8). Where requested, payment was most commonly an optional donation per session (11.7%) or a set charge for lunch/catering (11.7%). Occasionally, there was an optional donation towards lunch (4.9%), an optional donation towards transport (3.9%), or a set charge for some activities/services (3.9%). Respondents indicated that hospice services to be offered in locations outside the hospice building (Table 9). Most frequently this is in people’s homes (74.2%); but also in community centres, libraries and other non-religious buildings (23.7%), outdoors in gardens or parks (16.5%) and in religious buildings such as church halls (13.4%).

The survey presented respondents with a list of roles, asking is this role was present at the hospice and whether it was carried out by paid staff, volunteers, or both (Table 10). Nurses, administrators and catering staff were the most common paid roles. Common voluntary roles were complementary therapy, befriending and hairdressing. Doctors, pharmacists, and social workers were the least likely to be volunteers. When counting both paid staff and volunteers, over eighty percent of responses indicated the presence of nurses, administrators, cleaners, complementary therapists, catering staff, religious leaders, doctors, psychotherapists, and physiotherapists.

In an optional question (n=79), respondents estimated the proportion of individuals that the hospice supports with certain common diagnoses (Table 11). Cancer was by far the most common (mean average = 65.5%), followed by mobility issues/frailty (14.2%), neurological disease (10.7%) and respiratory disease (9.6%). There was variation in the extent to which cancer dominated the diagnosis mix, as shown in Figure 3. The most extensive variation between respondents was in the category of mobility issues and frailty.

Table 4: Percentage of funding provided by statutory sources

Mean	31.3%
Median	28
Mode	30
Max value	100
Min value	0
Standard deviation	21.2

Table 5: Percentage of hospices offering transport

Answer given	Frequency	% of total
Yes – (provided by volunteers)	80	77.7%
Yes – (provided by paid staff)	14	13.5%
Yes – (provided by a different organisation)	5	4.8%
No	4	3.9%

Table 6: Does the hospice offer services to people without a life-limiting illness?

Answer given	Frequency	% of total
Yes	45	43.7%
No	58	56.3%
Not sure	0	0

Table 7: Is the hospice linked to any 'compassionate communities' project?

Answer given	Frequency	% of total
Yes	27	26.2%
No	52	50.5%
Not sure	24	23.3%

Table 8: Payment requested for hospice services

Answer given	Frequency	% of total
None	78	75.7%
Optional donation per session	12	11.7%
Charge for lunch/catering	12	11.7%
Optional donation for lunch/catering	5	4.9%
Optional donation for transport	4	3.9%
Charge for some activities/service	4	3.9%
Set charge per session	3	2.9%
Charge for transport	2	1.9%

Table 9:

Locations of services offered outside of the hospice building

Answer given	Frequency	% of total
No services offered elsewhere	21	21.6%
In people’s homes	72	74.2%
Community centre, library or other non-religious building	23	23.7%
Outdoors – e.g. in a community garden or park	16	16.5%
Religious building such as a church hall	13	13.4%
Healthcare settings (hospitals, care homes, GP practices)	9	8.7%
Other hospice locations (satellite sites, separate centres)	6	5.8%
Additional community teams	5	4.9%
Schools/universities	2	1.9%
Other (hospice retail shops, other hospices, hotels)	3	2.9%

Table 10: What roles are carried out at the hospice?

Role	Total % with this role	% w/ staff in role	% w/ vols in role	% without role
Nurse	93.2	93.2	3.9	6.8
Administrator	93.2	92.2	54.4	6.8
Cleaner	93.2	87.4	7.8	6.8
Complementary therapist	90.3	75.7	61.2	9.7
Catering staff	89.3	89.3	34.0	10.7
Chaplain/other religious leader	88.3	69.9	48.5	11.7
Doctor	85.4	85.4	1.0	14.6
Psychotherapist	79.6	76.7	34.0	20.4
Physiotherapist	78.6	78.6	6.8	21.4
Social worker	69.9	69.9	1.0	30.1
Occupational therapist	67.0	65.0	2.9	33.0
Hairdresser	65.0	19.4	53.4	35.0
Creative activity leader	64.1	50.5	26.2	35.9
Befriending	62.1	13.6	61.2	37.9
Pharmacist	58.3	58.3	0.0	41.7
Mindfulness	53.4	36.9	28.2	46.6
Other activity leader	41.7	29.1	23.3	58.3

Figure 3: Box plot presenting diagnosis mix as reported by respondents

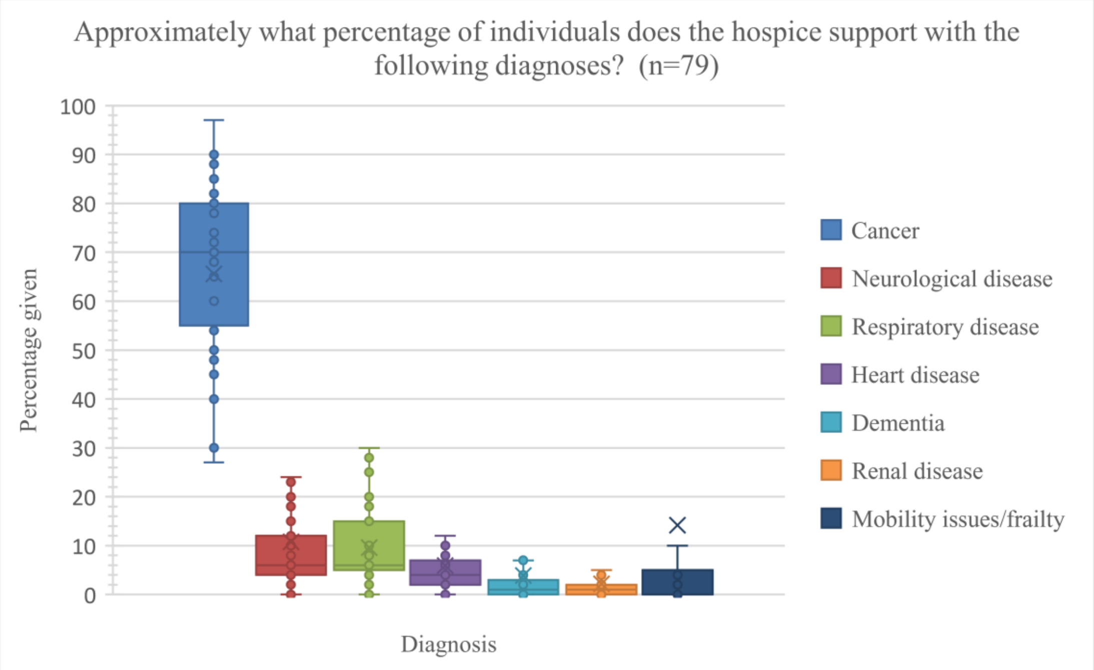


Table 11: Diagnosis mix of individuals supported by the hospice (n=79)

Diagnosis	Mean	Median	Mode	Max value	Min value	Standard deviation
Cancer	65.6	70	80	97	3	20.1
Neurological disease (e.g. MS, MND)	10.7	6	5	80	0	12.4
Respiratory diseases (e.g. COPD)	9.6	6	5	40	0	8.9
Heart disease	5.9	4	5	40	0	6.9
Dementia	3.9	1	0	50	0	8.4
Renal disease	2.2	1	0	30	0	4.1
Mobility issues/frailty	14.2	0	0	100	0	28.6
HIV/AIDS	0.2	0	0	2	0	0.5

5.2.3 What services offer social support?

Respondents were asked to identify services provided by their hospice that offer people living in the community with life-limiting illness the opportunity to spend time with other people. This could be any hospice or community-based service – the survey suggested examples of day care, respite, community centres, empowerment centres, support groups or group therapy, creative/craft groups, diversionary activities, or community engagement activities.

One hundred respondents identified 446 services in total. Eighty-seven of these (19.5%) were for carers or bereaved only and were not categorised further. 359 outpatient services for patients were categorised by the research team into broad headings - multicomponent interventions, activity groups, formal support groups, and informal social activities – as shown in Figure 4. Further detail of these results is shown in Table 12.

In total, 175 (39.2%) of identified services operated as ‘drop in’. Social activities (including cafes and coffee clubs, social programmes, friendship groups, family fun days and special events or excursions) were very commonly ‘drop in’, in 70.4% of cases. A significant proportion of activity groups and support groups (43% and 40.9% respectively) operated as ‘drop in’. Multicomponent interventions were offered on a drop in basis in 20.6% of the services identified by this survey. Thirty (30%) of the respondents to this question (n=100) did not identify any services to operate on a ‘drop in’ basis.

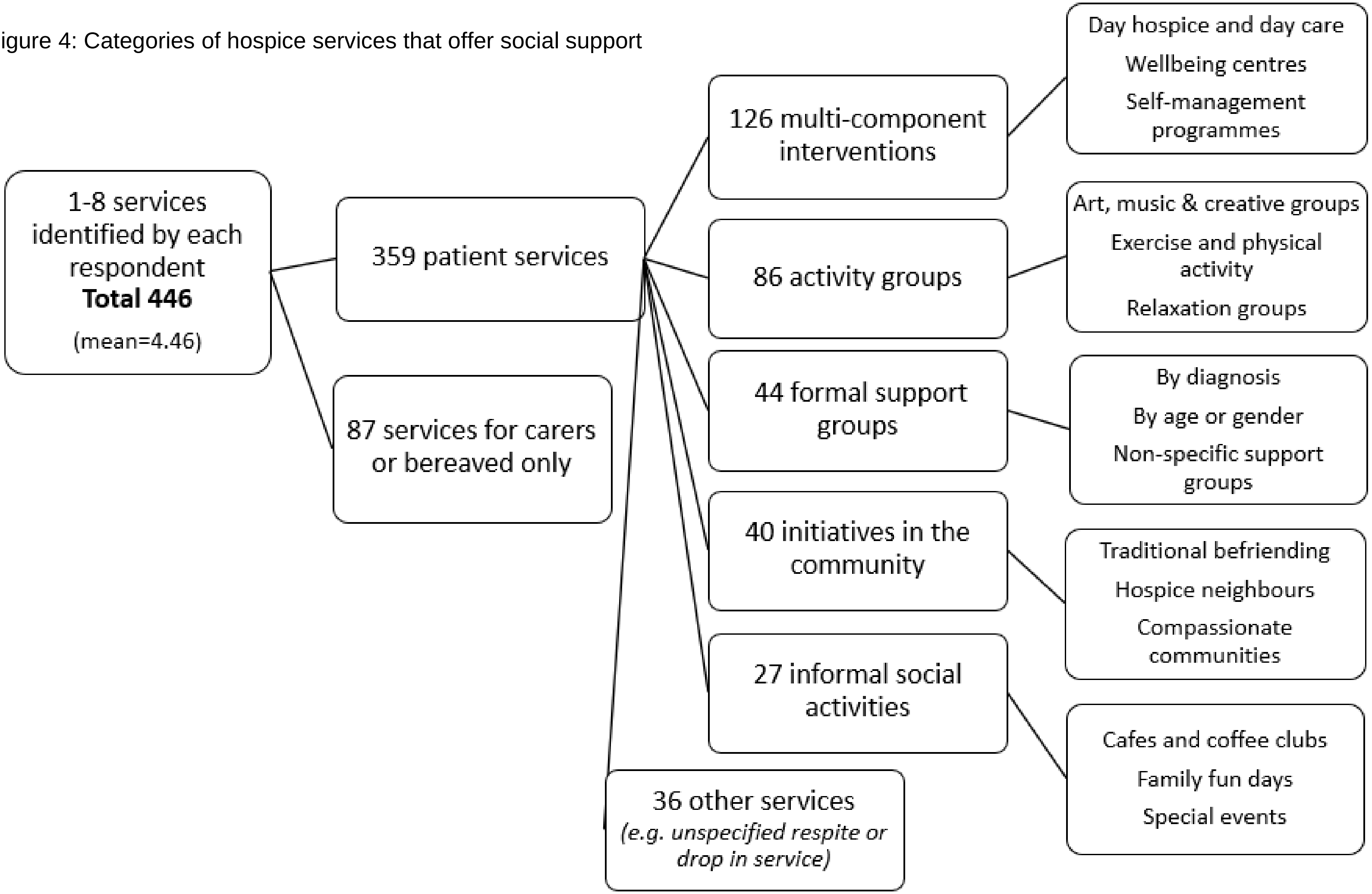
In total, 54 (11.7%) of services identified by respondents were organised by volunteers, carers or patients; eleven of these were for carers or bereaved only. Social activities were most commonly organised by volunteers, carers, or patients (29.6%) but this figure was lower for other categories – 15.9% of support groups, 7% of activity groups, and just 4% of the multicomponent interventions described.

Cost data was rare, respondents indicated that they had this information available for just 7% of identified services.

Table 12: Services identified by survey, with breakdown by categories of 'drop in' services and those organised by volunteers, carers, or patients (n=100)

Multi-component interventions Total: 126 ‘Drop in’: 20.6% Led by non-staff: 4%	Day hospice, day care, day therapy 82 Wellbeing centres 17 Self-management programmes 27 (often condition-specific eg Fatigue and Breathlessness but also more generic eg Living Well)
Activity groups Total: 86 ‘Drop in’: 43% Led by non-staff: 7%	Art and or craft groups 27 Exercise and rehabilitation 13 Music, singing, choir 11 Relaxation, meditation, mindfulness 9 Tai Chi/Qi Gung/Yoga 6 Complementary therapy groups 5 Gardening/horticulture 3 Knitting 3 Walking 3 Writing 2 Pamper sessions 2 Cooking 1 “Click a friend” 1
Formal support groups Total: 44 ‘Drop in’: 40.9% Led by non-staff: 15.9%	Support groups by diagnosis 20 - respiratory disease, dementia, MND, heart failure, cancer Support or counselling groups (not-specified) 18 Support groups for young adults/teens 2 Support groups for men 3 Support groups for younger women 1
Social activities Total: 27 ‘Drop in’: 70.4% Led by non-staff: 29.6%	Café’s and coffee clubs 15 Social programmes/friendship groups 6 Family fun days 3 Special events/excursions *inc young peoples days out* 3
Carers/bereaved only Total: 87 ‘Drop in’: 60.9% Led by non-staff: 12.6%	Carers/families 46 Bereaved 41
Befriending, etc. Total: 40 ‘Drop in’: 15%	Befriending/companion service 19 Compassionate communities/neighbours 8 At home hospice services 13
Other Total: 36 ‘Drop in’: 44.4%	Unspecified respite 12 Unspecified drop in 9 Unspecified outreach 2 Transition service 2 Information/referral support inc advice line 8 User involvement/fundraising group 2 Care homes 1

Figure 4: Categories of hospice services that offer social support



5.2.4 Which is the ‘most social’ service?

Respondents were asked to choose which of their identified services offered the most opportunity for social support, in their opinion (Table 13). They were then asked further organisational questions about that service. The most frequently selected category was that of multicomponent interventions, chosen by 62.5% of respondents (n=88). However social activities, if present, were more likely to be selected as ‘most social’ – chosen by 14 respondents and therefore 51.9% of the category. It may be notable that this percentage is not higher - some participants favoured the social support offered within multicomponent interventions, even when their hospice offered other social settings.

Most of these services were offered during weekdays (Table 14). Thirteen (14%) services were offered outside of the working day, with eleven respondents offering their ‘most social’ service at the weekend. The services that operated seven days a week (4.3%) were befriending, compassionate communities, and a social programme.

Respondents provided the stated aim for their most social service in a free text box. Often these aims were multi-faceted, reflecting the multicomponent nature of many of these services. As such the answers given were separated into individual distinguishable aims and grouped thematically as shown in Table 15. Roughly one third of the stated aims refer explicitly to social support or an unambiguously social objective. Common social aims were the facilitation of peer support and the opportunity to meet others in a similar situation; in a supportive, safe and welcoming environment; enjoying time out of the house for socialising or relaxing. It was common for stated aims to not include any social aspects, particularly (but not always) for services that provided clinical input.

More than half of the ‘most social’ services reported no outcome measurement, 15% reported the introduction of all or part of the OACC suite of measures. One hospice reporting using DeJong Gierveld loneliness scale.

Table 13: categories of service chosen to offer the most opportunity for social support (n=88)

	Frequency	% of responses	% of category
Multicomponent	55	62.5	43.7
Activity group	5	5.7	5.8
Support group	2	2.3	4.5
Social activity	14	15.9	51.9
Befriending etc.	7	8.0	17.5
Carers/bereaved	5	5.7	5.7

Table 14: When does this 'most social' service take place? (n=93)

	Frequency	%
Monday to Friday, every day (daytimes)	22	23.66
Weekdays only - one or two days/week	27	29.03
Weekdays only - three or four days/week	31	33.33
Mix daytimes, evenings and weekends - 1-3 days/week	4	4.30
Mix daytimes, evenings and weekends - 4-6 days/week	4	4.30
Mix daytimes, evenings and weekends - 7 days/week	4	4.30
Weekend only	1	1.08

Table 15: stated aims of services offering social support (n=92)

Social support	**Holistic care**
Peer support / meeting others in similar situation – 9 A supportive environment (inc. safe & welcoming) – 8 Day out/time to relax/for patient enjoyment – 7 Opportunities for social interaction/socialising – 7 Providing social support – 7 Reducing social isolation – 7 Stimulating activities – 4 Emotional support – 3 Opportunity to be heard/for mutual trust – 2	Specialist palliative care/clinical input – 17 Symptom management 10 Access to therapy/counselling 6 Spiritual support – 4 Advance care planning – 3 Individualised care – 3 Access to complementary therapies – 2 Introduction to hospice – 2 Support throughout the journey - 2 Support post-discharge – 1 Signposting - 1
Rehabilitation	**Other aims**
Rehabilitation – 4 Enhancing patient quality of life – 4 Managing at home – 4 Building confidence and independence – 3 Meeting patient goals – 2	Community building – 5 Carer respite – 4 Reduce unnecessary hospital admissions – 1

A question on group size suggests between ten and twenty people typically attend these services per session (Figure 5). A small number of respondents (4.3%) indicated that the 'most social' service at their hospice is typically attended by over forty people. Respondents were also given a free text box to input the maximum number that can attend – answers ranged from 1 to 80, mean value 20, median 16, and mode 15. Maximum group size is usually between ten and twenty people (Figure 6). Non-numerical answers indicated that capacity is determined by the physical space available, the dependency of the specific patients, and the activity of the day. Some respondents over-book the service because it is so expected to have non-attenders; some under-book to allow for increased patient complexity.

When asked how people find out about the service (Table 16), almost half of respondents described formal referral pathways. Patients most commonly hear about services through health or social care professionals, who can make a formal referral into the hospice. However, self-referral or drop-in models of access were not uncommon. Respondents reported a range of promotional strategies including advertising through local newspapers, GP surgeries, charity shops, tea rooms and supermarkets. The hospice website, email newsletters and the role of social media were also frequently mentioned.

Table 16: Referral routes to access services (n=91)

	Frequency	Percentage
Formal referral necessary, usually by external health or social care professional	45	49.45%
Formal referral but can self-refer	25	27.47%
Self-referral or drop in model	12	13.19%
Internal referral	9	9.89%

Figure 5: Bar chart of typical group sizes at the most social service, as indicated by respondents

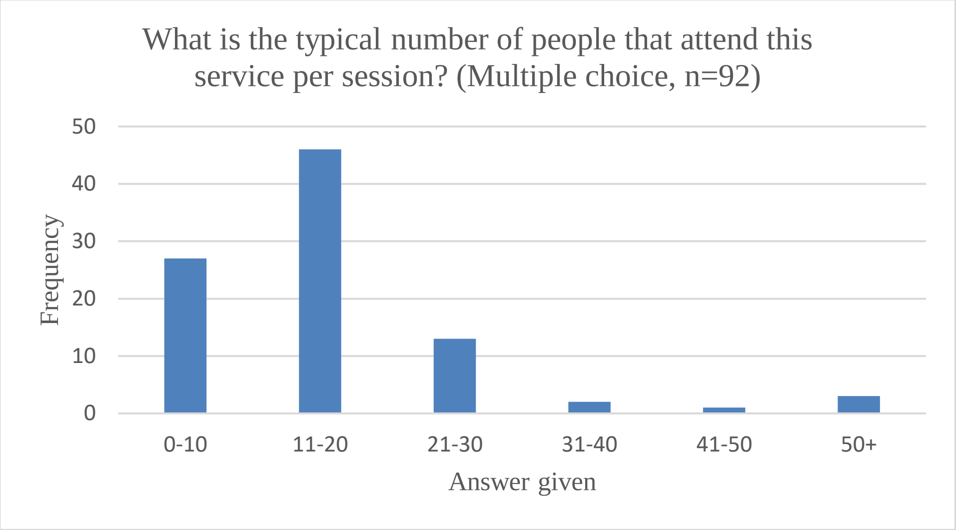
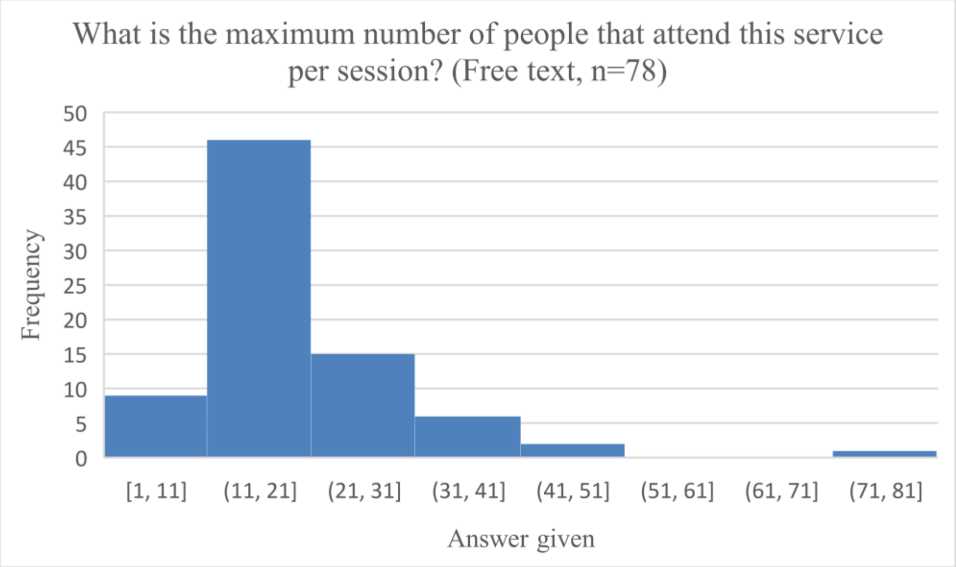


Figure 6: Histogram of maximum group size at the most social service, as indicated by respondents



5.3 Discussion

5.3.1 Summary of findings

This online survey received responses from 103 hospices in the UK and ROI. Results describe the sample to be broadly representative in geographical split, funding source and the proportion of non-cancer patients. The present survey showed diversity of approaches used by hospices in practice to facilitate social support for patients, and that many hospices recognise a number of different services, including those with a medical focus, to be offering social support. Most hospices in the sample offered transport and catering, usually for free, with roughly half offering at least some services to people who did not themselves have a life-limiting diagnosis. Roughly 25% requested a donation for a specific component or charged for lunch.

The most common were multi-component interventions and patient activity groups (especially exercise, music, art, or relaxation). This was followed by formal support groups and informal social activities such as coffee clubs. Where a social aim was stated, peer support and related ideas were common, although time out of the house for relaxing in a safe environment was also present. This aligned with conclusions from S. Bradley et al (2010), that getting out of the house was necessary for alleviation of both physical and psychosocial isolation in palliative care patients.

However, most often the stated aims of services did not reflect social aspects, with clinical aims prominent, particularly relating to symptom management. This suggests that survey respondents *do* consider the social support obtained within clinical services to be important, even when those services do not formally have a social aim. Different forms of exercise, including dance and yoga, were offered in hospices across the country, and aims indicative of a rehabilitation palliative care approach were also present, suggesting social support to acknowledged as having a role in rehabilitative approaches in practice, at least in these services. Social rehabilitation might be an aspect of many hospice services, even those less obviously ‘active’.

5.3.2 Discussion of findings

A telephone survey of palliative day care services (Copp, 1998), with a 60% response ratefound that responding day care centres all provided social and psychological support for patients, together with a range of other services. The presence of medical and formal psychosocial services appeared to be unrelated to the source of funding of the individual centres. Copp’s survey reported that 97% of palliative day care services treated mostly cancer patients. In the present survey, cancer remained dominant, but less so; mean average across sites was 65.6% and deviation was high, with responses ranging from 3% to 97% cancer, but only four respondents reported their diagnosis mix to be 90%+ cancer.

A postal survey of palliative day care centres in the Thames region received responses from forty of the forty-three services eligible (Higginson et al, 2000). Day services had social, psychological, physical, and (to a lesser extent) existential objectives. Social interaction was a reason for referral in all centres, other common reasons were carer respite, psychological support, and the assessment, monitoring or control of symptoms. Companionship and support were the most commonly reported benefits to patients. Rehabilitation was not considered an explicit aim of palliative day care at the time, unlike today. Ninety percent of patients had cancer, and on average over a quarter of patients attended the day centre for over a year. Twenty (50%) centres offered services specifically for younger people, which was much more common than in the present sample.

The findings of the Higginson survey may not be representative of the country, because the part of the UK included is better provided with palliative care services than the rest of the country, and indeed many other countries (Higginson et al, 2000). A similar profile of staff roles was described by Higginson as the present survey: most centres had doctors, nurses, chaplains, managers, aromatherapists, and hairdressers, although the contribution of cleaning and catering staff is not stated. Results of this survey indicate occupational therapists, social workers, and therapists are becoming more common. Most variation in this sample was found in whether mindfulness practitioners and inhouse pharmacists were present.

Higginson and colleagues investigated whether service characteristics and philosophies can distinguish between medical and social models. When centres were asked to describe whether the model was mainly social or mainly medical, their response was not found to be associated with reported levels of staffing, management, funding, or activities. Therefore, evidence for a dichotomy between medical and social services was not found. This regional survey suggests that physical, emotional and social support is commonly provided, which aligns with other survey work demonstrating all centres to offer social and psychological support to patients, and most (but not all) providing nursing and medical care (Copp, 1998).

The multidisciplinary team working described by this survey indicates a mix of clinical and supportive input, with over 80% having nurses, administrators, cleaners, complementary therapists, catering staff, religious leaders, doctors, psychotherapists, and physiotherapists. Multidisciplinary teams benefit from being able to offer ‘multimodal’ therapeutic options, team-working, and multiple perspectives on a patient, however effective communication, leadership and mutual respect within the team is important for optimum care (Fernando & Hughes, 2019). The composition of a ‘traditional’ palliative care team is not clear in this survey, or generally - the range of professional and voluntary members continues to evolve over time, with different hospices also having different interpretations of teamwork models and role overlap (Fernando & Hughes, 2019).

Paul and Sallnow (2013) contacted 220 hospices in the UK with an anonymous online survey, with 66% response rate, of which 60% were currently active in public health approaches to palliative care, specifically relating to community engagement, awareness raising, compassionate communities, or ‘Dying Matters’ events, with some respondents reporting that a diversity of approaches was more likely to be successful than just one approach. Due to the anonymous nature of the survey, issues of generalisability could not be considered. The present survey indicated that a quarter of respondents offered services in community centres, libraries, or other religious and non-religious buildings, including outdoors in community gardens or parks for 16.5% of respondents. At the time, six had multiple hospice locations, including satellite sites, and two were working in schools or universities. Working with schools, local businesses, faith organisations, and local events might increase the reach of hospice messaging; but approaches to working in partnership with the local community are under-researched (Paul and Sallnow, 2013).

Outcome measures tended not to be collected in the most social services identified by this survey. Some are open to the public and highly flexible – they are truly ‘drop in’ and thus collecting patient outcomes an additional set of paperwork in a relatively nonclinical setting. However, this poses challenges for the rigorous demonstration of outcomes and comparison of different service models. Similarly, cost data was not widely known by respondents (but could be known by a different team member, had the survey arrived on a different day). Patient reported outcomes are increasingly used in traditional day care, but the acceptability of outcome measurement is less established in newer settings. Lack of routine data collection presents a barrier to research in hospices which contributes to the practical challenges of palliative care research (Payne, Preston, Turner & Rolls, 2013: a working paper of the commission into the future of hospice care)

Burbeck (2014) achieved a 67% response rate in their online survey of volunteer activity in UK adult hospices and specialist palliative care services, which highlighted the social nature of the palliative care volunteer role (Burbeck, 2014). This survey reports, in agreement, that volunteers are involved in social roles such as befriending in more than half of the hospices surveyed (61.2%) and providing transport for most (77.7%). However, this survey also shows volunteers to be giving professional or therapeutic expertise in some cases: volunteers were complementary therapists, administrators, hairdressers, chaplains or other religious leaders, psychological therapists, mindfulness or meditation practitioners, and leaders of creative or other activity groups. These roles can involve a high degree of interpersonal interaction, but also have additional management or supervision requirements, which might relate to the high proportion of respondents with both paid staff and volunteers in a particular role.

A recent descriptive study of costs in three palliative day care services in the UK found that the contributions of volunteers (as complementary therapists, drivers, catering staff or hairdressing) was equivalent to roughly a third (28%-38%) of running costs per day per patient, as measured using an adapted client service receipt inventory (Mitchell et al, 2020). This is a stark finding and might be generalisable to hospices with a similar structure to the services studied; however, depending on method used, proportion of costs offset by volunteer could be even higher for the hospices that have more volunteers fulfilling more roles. The hospice sector relies on volunteers, and thus community engagement might be considered of essential relevance to workforce planning, by increasing visibility of the volunteering opportuniting (Mitchell, et al, 2020).

In Belgium, challenges to palliative day care arise from a narrow public perception of palliative care, insufficient occupancy and/or referrals, and insecure funding models (Vandaele, 2017). Very similar challenges are reported by the present survey, with respondents describing in free-text boxes how fluctuations in the funding amount available and expectations attached present obstacles for long-term planning. This survey adds that negotiating transport is a challenge – those currently providing transport do not have resources to do this for all services or for all patients. Many have recently redesigned or are about to redesign their model of services, considering social support to be an important and perhaps under-recognised part of the work they do. This is related to the findings of S. Bradley (2011), who explored reasons for referral to specialist palliative day care. There seem to be some difference in participant willingness to refer patients for purely social benefits as opposed to physical reasons. Some acknowledge that social benefits were important, but they would not make a referral based on purely social need, requiring physical reason for making the referral.

In a related study, patient and stakeholder perceptions were reported to be emphatic on the social benefits of attending palliative day care - patients appreciated a sense of belonging, companionship, opportunity to meet people in a similar situation, to draw strength from observing them cope (Bradley, 2010). However, note that the views of the patients who did not enjoy day care and withdrew from the intervention are not present, and participating patients may feel concerned to give critical feedback in case in negatively impacts the hospice in some way (Kernohan, 2006).

Ethnographic investigation has described meaningful social interactions occurring within even medicalised settings, as patients participate in companionable conversations on illness and death (Langley-Evans & Payne, 1997). Going further, Fisher and colleagues (2008) describe that the sense of community between patients, volunteers, and caring staff is really the glue that holds palliative day care together. Since people ‘vote with their feet’, in that unsuccessful groups get smaller (Frith, 2008), social experience will always have some influence on intervention acceptability and effectiveness, even in the presence of clear clinical objectives. Therefore, social support is unlikely to be inconsequential for any group intervention, even when other outcomes are prioritised by those delivering the intervention. Social objectives should not be subordinate to healthcare objectives (Payne, 2006, Goodwin, 2003). And yet, in practice, the objectives of (funding) health and social care agencies leads to the collection of healthcare outcomes and the success of groupwork is not measured in terms of therapeutic or social aims (Payne et al, 2008).

5.3.3 Strengths and limitations of survey

The survey had 103 responses, with response rate estimated at 49.5%, using the total number of hospices minus those known to only offer inpatient, children, or at home services. Representativeness of the sample to the sector as a whole is considered according to: location by country, level of statutory funding, proportion of cancer to non-cancer diagnoses served. The sample appeared to be representative in terms of geographic location and patient diagnosis mix.

Differences in organisational structure and the terminology used in describing services mean that it was a challenge to identify the most appropriate member of staff to reach with the survey. Surveys are vulnerable to respondent issues in that we assume respondents are reliable and that the answers they provide are valid. In this survey, we depend on each respondent's understanding of social support and whether social support is facilitated within a certain setting is their opinion, rather than objective empirical observation. That is to say, the data is self-reported and not validated.

Detailed questions regarding number of places per week and outcome measurement were asked only of the service identified as 'most social' by respondents. This was to reduce participant burden by limiting the number of questions of a somewhat lengthy survey, however as respondents differed in their interpretation of 'most social' there was less opportunity for like-for-like comparisons between hospices. Respondents had more hospice services available than were anticipated during survey design – 20% identified eight different services offering social support, the maximum number possible – therefore we cannot conclude that we have captured every relevant service.

This survey had an acceptable response rate and the sample appears representative as judged by funding, geography, and diagnostic split. However, non-response bias is still possible if not likely. Social support is not necessarily accepted by all to be in the remit of hospice work, as demonstrated by conflict over the ‘medical’ or ‘social’ definition of some services. Individuals who do not routinely consider social support part of their priorities are less likely to invest time in this survey. Hospice service-providers are busy and may receive a high volume of emails. Generalizability of the findings is limited by non-response bias because respondents are more likely than non-respondents to have this interest in social support. Hospice Uk has made moves to encourage a research culture is embedded across their membership. Although a significant number of hospices are now research active, including many running their own research projects ‘in house’ (Hospice UK Conference, 2018), it is difficult to establish how many hospices are open to research and, in this case, would encourage or discourage participations in online research surveys. Furthermore, it was not straightforward to establish the exact number of hospices eligible for this study with the data available.

As a descriptive exercise, the survey was successful in generating an overview of hospice service models that might facilitate social support for patients. The picture painted is one of diversifying services without national consensus on social aims. However, this is a top-level description - understanding the potential outcomes and significance of social support in palliative care requires a deeper approach. Survey findings were used to guide purposeful sampling of hospices for qualitative data collection. This meant that hospices participating in researcher observations and service-provider interviews represented abroad variety of hospice social services as possible, including those commonly reported (e.g. day care), and unique or rare examples (e.g. the one social service that measured a social outcome, and a separate café building operated by a hospice as a social signposting space but widely used by the community and generating profit).

5.4 Conclusion

This survey demonstrates hospices to be interested and active in facilitating social support. A substantial majority of respondents identified multiple services offered by their hospice with a social aim. This work agrees with Goodwin (2003) and Payne (2006) that social domains should not be inappropriately subsumed to health-related domains of quality of life in palliative care. In recent years, some hospices have gone through service development or innovation, expanding what they offer to meet different levels of patient need and provide choice. This survey captures a moment in time in which the hospice sector is diversifying its provision and engaging in critical reflection of its offering, in response to a recognition of unmet need, growing demand, and increasingly limited resources. Alongside (and possibly propelling) the diversification of hospice day services is a shifting financial landscape, with future funding and staffing levels in uncertainty. There is also some debate over how hospices should position themselves within the demographic context.

Group activities offered by hospices are wide-ranging, often more than one service offered, and more than one activity/discipline available within a service. The suggested sparsity of outcome measurement and cost data occurring in 'most social' services has implications for research and economic evaluation. The range of aims and activities may be underpinned by differences in hospice ethos – philosophies that shape the setting and thus the type of social support gained - it might be impossible to really tell how social a service is without sitting in it (Payne, 2006).

It is possible that diverse approaches used in practice may improve issues regarding access to and awareness of hospice care by better tailoring services to patient need. However, the many aspects of variability between hospices indicates many potential sticking points for a researcher attempting to define the boundaries of an economic evaluation. More work is needed to document outcomes and understand service models.

Chapter 6 : Patient Reported Outcome Measures

6.1 Introduction

Inadequate social support is considered a known risk factor for distress in individuals with life-limiting illness. Hospice day services offer psychosocial support to people with life-limiting illness, with the intention to improve quality of life by addressing unmet need. There is limited quantitative evidence on the effectiveness of these services and measurement of the social support expected to arise within these interventions has been lacking to date.

Observational cohort studies can be useful 'in real life' as an alternative to study designs that require the allocation or identification of a control group, which may be challenging for ethical or practical reasons. In particular, denying or delaying an intervention to reduce distress in end of life may be unacceptable to many practitioners, and the recruitment of palliative care patients is known to be enduringly difficult, despite significant other methodological advances (Shinall, 2019), (O'Riodan, 2019). Sensitivity to change of outcome measures, or ability to detect benefit from an intervention, is a reported challenge of psychosocial intervention.

This chapter presents results of an observational cohort study with adult outpatients recruited from the day services of four hospices in England (n=30), using patient reported outcome measures in perceived social support, loneliness, depression, and quality of life. Methodology and methods are discussed in chapter 4. The measures used and reason for their selection are summarised in table 17.

The research aimed to establish a multi-site cohort study, recruiting patients as they start to attend and following them over time to analyse outcome and contextual variables to explore effectiveness of services. Four hospices recruited patients (see table 18). The extent of analysis is limited by sample size and high attrition between timepoints, however observing patients over time and comparing differing groups using descriptive statistics and statistical tests remains informative. This chapter also reflects on the approach taken and methodological challenges experienced.

Table 17: Patient reported outcome measures used

Domain	Measure used	Reference	Description	Reason for selection
Perceived social support	MOS-SS	Sherbourne & Stewart, 1991	19 questions, inc. emotional, informational, tangible, affectionate, and interactional support	Questions about perception of different types of support including outside of the family unit and so reflect goals of intervention
Loneliness	UCLA 3-item	Hughes et al., 2008	3 indirect questions on loneliness, distinct from functional support and depressive symptomology	Brief measure of perception of relevant negative social experiences reflecting loneliness, without using word 'lonely'
Depression	BEDS	Lloyd-Williams, Shiels & Dowrick, 2007	6 questions, based on cognitive and affective depressive symptoms	Brief measure suitable for advanced illness, validated for use in palliative care
Quality of life	EQ-5D-5L	Herdman et al, 2011	5 questions – mobility, self-care, usual activities, pain, anxiety/depression – plus visual analogue scale	5 domains commonly used in practice so familiar to participants, 5L might be more sensitive to change than 3L version

Table 18: Details of the four hospices involved in recruiting for this study

Site	Recruitment dates	Hospice region (England)	Hospice deprivation decile (10=least deprived)	Urban/rural by postcode	T1	T2	T3	Intervention description
1	December 2018 – March 2019	North-West	5	Urban city and town	8	6	2	Traditional day care with clinical input
2	August 2018 – March 2019	South-West	9	Rural village	6	3	*2*[2]	Traditional day care with art and nature focus
3	February 2019 – April 2019	South-East	5	Urban major conurbation	10	6	2	Rehabilitative exercise group, adjacent social & therapeutic programme, open access space
4	October 2018 – April 2019	South Coast	5	Urban city and town	6	4	1	Open access art, exercise, & wellbeing groups, clinical input or transport by appointment

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[2] *These participants were attending fortnightly, past the end of data collection*

6.1.1 Research locations

This stage of data collection includes hospices from different regions of the country, in small villages and large cities, serving different populations, with varied deprivation profiles. Research sites were identified using insights from the survey as described in the previous chapter. The chief executive officer, day patient services leaders, or head of research governance (where applicable) was approached with an invite to participate in a funded PhD project. Exact process differed in each site – in some cases a research committee formally reviewed and recommended the project, in others the researcher was able to meet with relevant decision-makers and explain the purpose of the research directly.

Hospice day services are complex interventions with multiple interacting components, and consistency in the intervention received or outcomes experienced are not expected between patients. An understanding of each service was achieved by the researcher during a concurrent qualitative investigation, which is described in the next chapter. Not all hospices invited were able to take part in recruiting patients, with reasons cited related to ongoing service redesign or changes in personnel, meaning lack of time to commit or uncertainty in patient availability. Many of these sites did take part in the qualitative investigation.

Recruitment windows are staggered because the researcher visited sites to conduct qualitative data collection and organise the start of recruitment. All sites had a minimum of one full day participant observation of services, up to 3 days when a large variety of services were available. Interviews were conducted with between 2 and 4 service providers in each recruiting site. Two other sites intended to begin recruitment in August 2018 and participated in interviews and observations – these were a rural site in the South-East (deprivation decile 6), and a rural site in the North-West (decile 7). These hospices were unsuccessful in recruiting after three months and withdrew from taking part in this section of the study; this was due to personnel changes in one site (maternity leave and retirement within a small staff team) and low patient numbers in the other (with referrals during the study period being sparse, when present they tended to be General Practitioners referring people in the last few weeks of life). Additional interviews and visits were also carried out in three other hospices: two urban locations in the North-West (deciles 4 and 8) and a rural South-West site (decile 10). Findings from analysis of qualitative data are presented in the next chapter.

Site 1 offered traditional day care, with facilitated circle discussions often reflecting clinical concerns, and one-to-one input provided within side rooms. Site 2 was similar in many respects but had a greater emphasis on spirituality and nature, and more resources for art and art therapy, including both patient groups and family therapy. ‘Traditional’ here means full day attendance on a specified day, usually with transport and care provided. Both these sites offered time-limited attendance, but a step-down programme was in formal operation at site 2. Site 3 provided a mix of structured and open access programmes, so that a patient might attend a time-limited exercise group in the morning, choose to stay for lunch, and then join an art group in the afternoon. Site 4 also used open access activities and tailored support groups, using an appointment model for clinical input. ‘Non-traditional’ day services are characterised by flexibility – patients have a greater degree of choice between different components and in when they access the service. Both sites 3 and 4 aimed to limit use of patient transport, but a small number of patients continued to receive organised transport, and the additional care required for their level of clinical need. Through the arrangement of transport these patients had a specified day to attend the service.

6.1.2 Data collection

This is an observational cohort study which followed participants for up to three time points (baseline, 6 weeks, 12 weeks, with flexibility to account for variations in attendance). Participants were adults with life-limiting illness, currently living in the community (i.e. not inpatients or residing in a long-term care institution) and accessing hospice day services. The researcher or a trained staff member took consent and answered any questions. Most participants completed written question booklets themselves, within the hospice. Two received help to read the questions (in site 3) and a small number took their question packs home (in site 4). In sites 1 and 2, data collection fitted in with patient assessments, so these were completely independently but follow up was supported by the procedures of the setting.

Details of method are provided in chapter 4. Participants were recruited from four hospices across the UK, when they were about to start or had recently started attending day services at that hospice. Patients were eligible if they were not significantly cognitively impaired and were able to engage with the research materials. Service-providers invited the patient to participate in a study based at the University of Liverpool and provided them with information. The patient had the opportunity to ask questions and to take the materials home to think about their participation or discuss it with family, before giving written consent. Data collection comprised patient reported outcome measures in perceived social support (MOS-SS), loneliness (UCLA 3-item), depression (BEDS) and QOL (EQ-5D-5L). To indicate resource use, two questions on A&E attendance and overnight stays in hospital were added. Each question also has a ‘‘decline to answer’ box, to check acceptability with patients, with intentions to reduce or establish explanation behind any item level missing data.

Between 6 and 10 patients were recruited from each site over at least three months, Baseline data collection took place on the first or second attendance of the intervention, not the hospice. Second timepoint was collected at the midway point, c. 6 weeks, and at the end of the intervention, roughly 12 weeks later. However, participants who miss a week due to illness might not lose a week of the intervention – ie, they have twelve attendances rather than twelve weeks. Data collection for all sites ended during May 2019. Two participants in site 2 were still attending the intervention, at fortnightly intervals, having started 4-6 months prior. Unfortunately, third timepoint outcome data was not collected for these participants. Data collection and attrition is described using a flowchart in figure 7.

6.1.3 Reasons for attrition

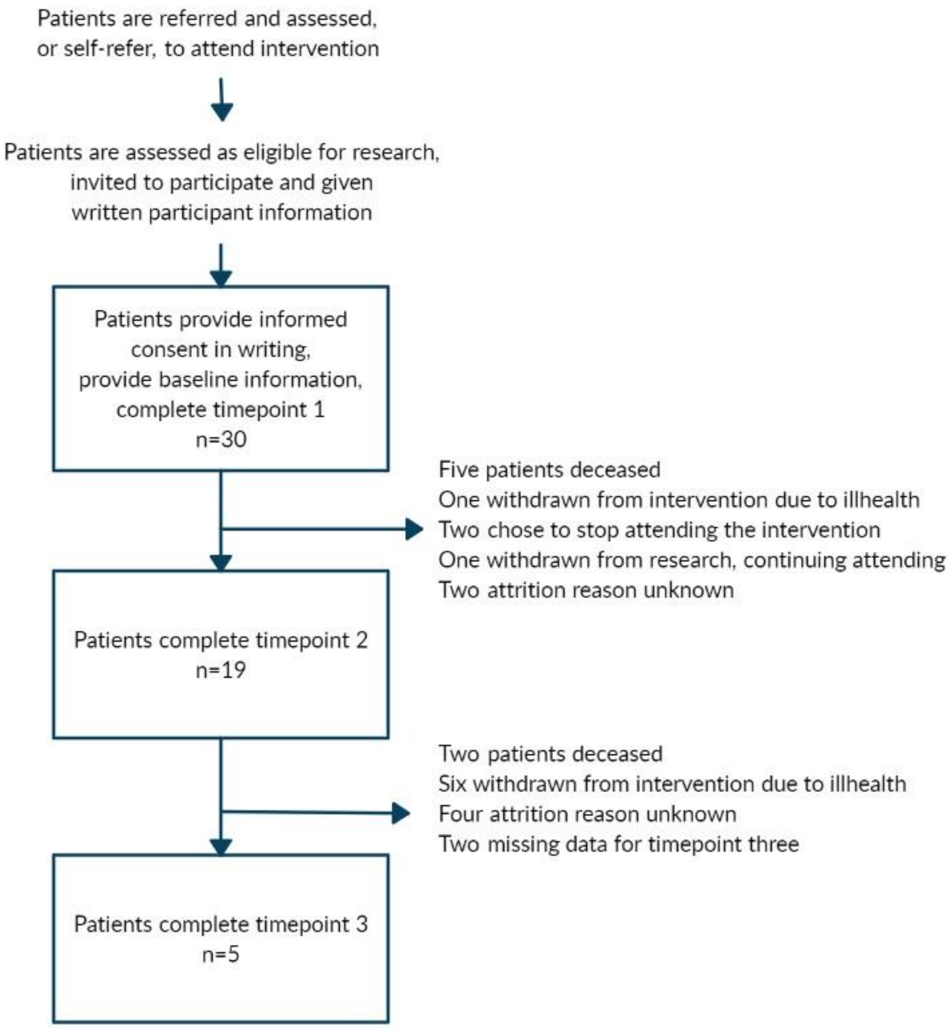
Attrition was very high across all locations by the third timepoint - whereas the majority of participants had provided outcomes at the second timepoint, few provided all three. Differences between T2 and T1 are therefore the focus when comparing change over time, but T3 data is utilised where appropriate. Differences between those who did and did not complete more than one timepoint are reported.

Two participants chose to stop attending the group, and one participant withdrew from the study because they were distressed when attending the group. Reasons for attrition and their frequency is given in table 19. Attrition categories are established from the data (informed by MORECARE recommendations, but in addition I have separated those who chose to leave from those with unknown reason).

Table 19: Reasons for attrition across three timepoints

	Number of participants	% of sample
Completed three timepoints	5	16.67%
Attrition due to death	7	23.34%
Attrition due to illness	7	23.34%
Chose to withdraw	3	10%
Attrition reason unknown	8	26.67%

Figure 7: Data collection across all four research locations



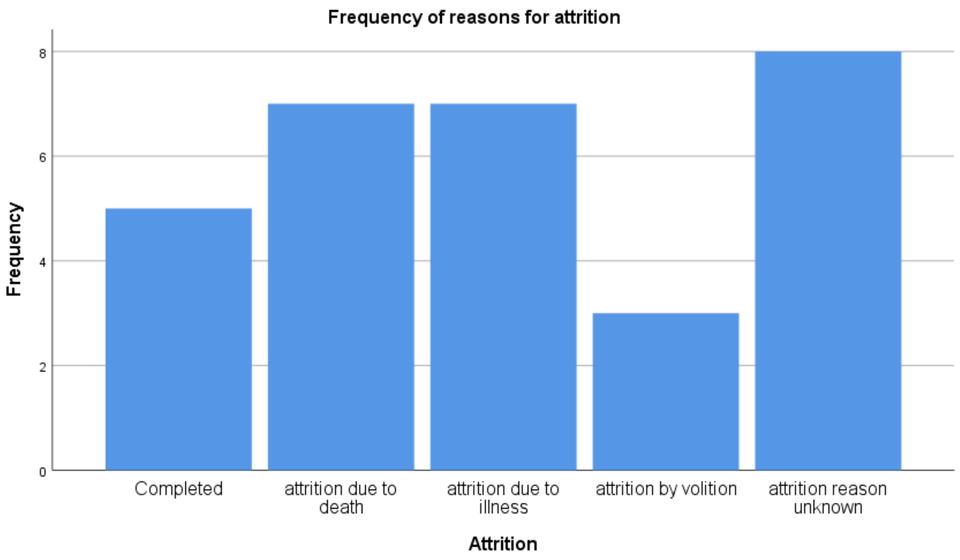


Figure 8: Frequency of reasons for attrition compared to those that completed study

6.1.4 Missing data

Attrition is to be expected in this population and providing the reasons for attrition shows that declining health or death was the cause of more than half of the non-completion in this study (figure 8). Reasons for attrition were not provided by one site - although dates of deaths indicated that two of the participants recruited died within six months, this was after data collection and not attributed here as cause of attrition. Postcode data was also missing from this site, which meant that connecting reasons for attrition with deprivation index was limited to a smaller sample.

In addition, diagnosis was missing f8r one participant, and there was item-level refusal for the visual analogue scale of the EQ-5D-5L by two participants. One question of social support questionnaire declined by one participant (who also declined VAS) – score is calculated as average of domains provided so participant scoring was not affected in this case.

Participants with an unknown attrition reason appeared to have the highest loneliness and depression at baseline – these were often in site 4, however this site did not provide postcodes for patients so we cannot indicate whether this site reflected higher deprivation than other sites.

6.2 Describing the Sample

6.2.1 Demographics and clinical features

The sample recruited is described in table 20. Across research sites, the sample was 50-50 male-female and 93% white British. The majority of this sample (73%, n=22) reported a cancer diagnosis, most commonly lung, breast, prostate, and bone. Fourteen participants (47%) reported a non-cancer diagnosis – nine participants (n=9) had both a cancer diagnosis and a non-cancer diagnosis; five participants (n=5) had a non-cancer diagnosis without cancer. Common non-cancer diagnoses in this sample were chronic obstructive pulmonary disease (COPD), heart failure, Parkinson’s disease, and arthritis. The proportion of cancer, non-cancer, and mixed diagnoses is shown in figure 8.

There was a spread of ages: 43% of sample under the age of 70, 27% were in their seventies, and 30% were over the age of 80. The youngest participant was 56 years old and the oldest participant was 91 years old. The mean age of this sample was 71 years old. Age distribution is shown with a histogram in figure 9. As shown in figure 10, participants who did not complete the intervention with an unknown attrition reason were generally older patients, whereas completers did not differ significantly from other categories.

At baseline, nine participants reported recent visits to Accident & Emergency departments (1-4 visits, mean = 1.6). Six of these participants also reported recent stays in hospital (1-16 nights, mean = 6.7). Of this group of participants, seven had withdrawn from the study by the second timepoint. The two remaining did not report any further hospitalisation during data collection. At T2, three other participants reported visits to A&E and no participants reported hospitalisation.

Table 20: Participant demographics and clinical features

	Site 1	Site 2	Site 3	Site 4	Total
N	8	6	10	6	30
Age					
Range	58-77	56-87	56-91	59-84	56-91
Mean (standard error)	69.38 (2.764)	70.5 (5.542)	68.5 (3.769)	78.17 (3.894)	71.07 (1.999)
95% confidence interval	62.84-75.91	56.25-84.75	59.97-77.03	68.16-88.18	66.98-75.15
Gender					
Male	5	0	7	3	15
Female	3	6	3	3	15
Ethnicity					
White British	8	5	9	6	28
Asian Ugandan	0	1	0	0	1
Black Caribbean	0	0	1	0	1
Diagnosis					
Cancer	2	4	7	3	16
Noncancer	2	0	1	3	6
Multimorbidity inc cancer	4	2	1	0	7
Living alone	1	1	4	2	8

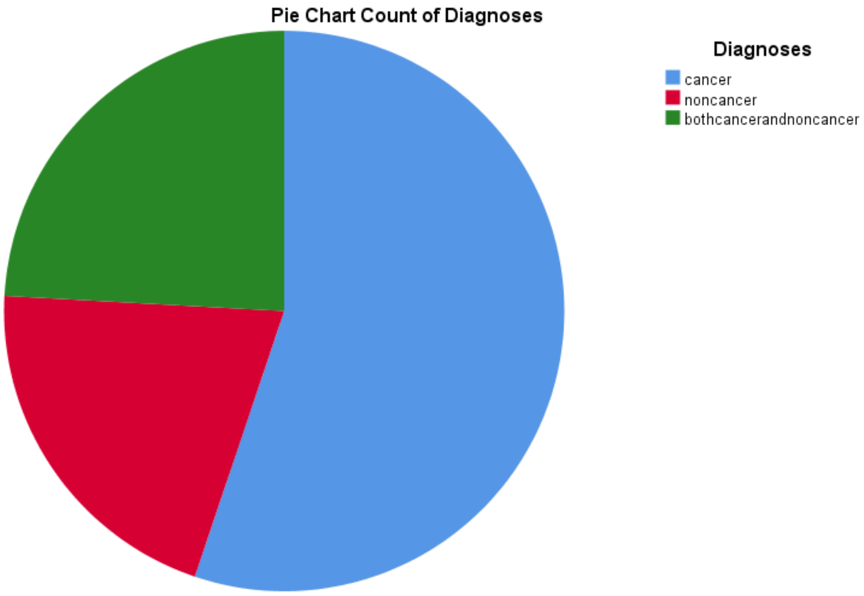


Figure 3: Pie chart showing diagnostic mix of sample

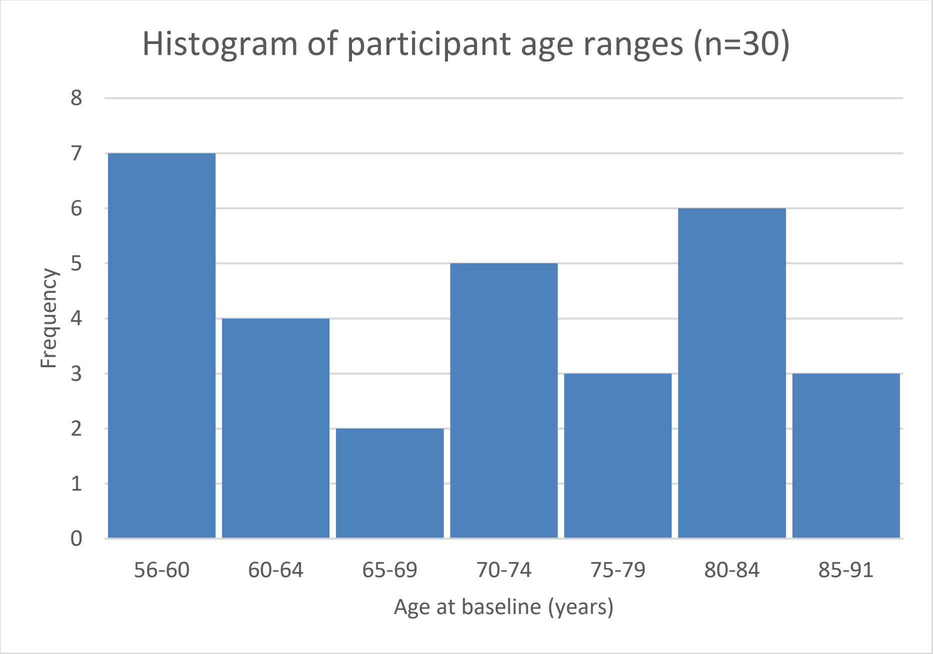


Figure 4: Histogram showing age at baseline of participants

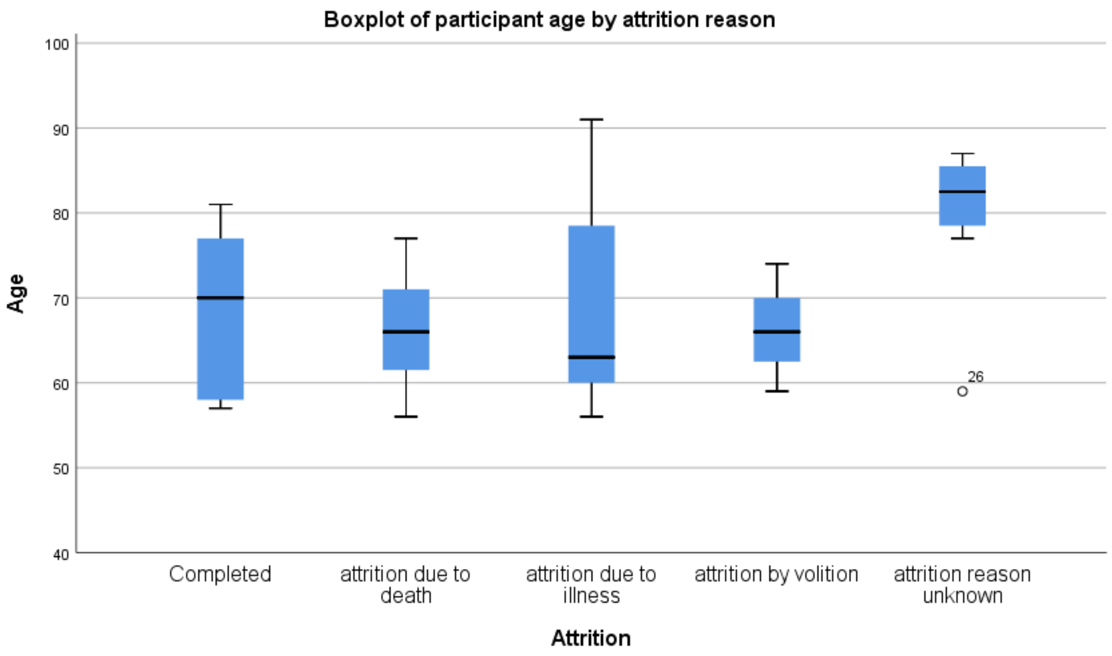


Figure 5: Boxplot showing participant age by attrition reason

6.2.2 Living arrangements

At baseline, eight participants (n=8) lived alone and twenty-two (n=22) lived with other people; most often this was one other adult. Two participants who lived alone chose to withdraw from the group or study before the second timepoint. The five participants that completed all three timepoints all lived with other people. This was not statistically significant at such small sample size (Mann Whitney U test 0.696) but might be relevant – see figure 11.

Three sites provided postcodes (n=24) and the index of multiple deprivation decile was used as a reference to interpret this data. This sample included a range from deprivation decile two (areas ranked as within the second most deprived decile in England) to ten (areas ranked as the least deprived decile). Participants were placed into two evenly sized groups, representing deprivation deciles two to six, and seven to ten. Research sites did not differ significantly in their representation of deprivation, as tested with an independent t-test using this MDI grouping (sig=0.169), but as shown in figure 13, distribution of values did differ, and referring to the median value demonstrates that site 3 (the most urban hospice included) recruited patients from more deprived postcodes.

Participants from less deprived postcodes appeared less likely to drop out of the intervention or the study. All participants who completed the three timepoints were in the ‘least deprived’ group. In the ‘most deprived’ group, five participants were too ill to continue attending, four participants died during follow up, one withdrew from the research, and one stopped attending the group. In the ‘least deprived’ group, three participants died during the study, two were still attending the intervention at the end of data collection, one participant was too ill to continue attending the group, one had to discontinue due to injury, and one stopped attending.

The number of timepoints collected by the least deprived half is depicted next to the most deprived half in the graph in figure 12. Participants in this sample were less likely to complete the study if they were from more deprived postcodes. The significance of this trend was tested with an independent samples Mann Whitney test using MDI binary group against number of timepoints (significant at the 0.1 level). Kruskal Wallis test using deciles rather than group reduced this significance (0.198).

Figure 6: Timepoints collected from patients by living arrangements

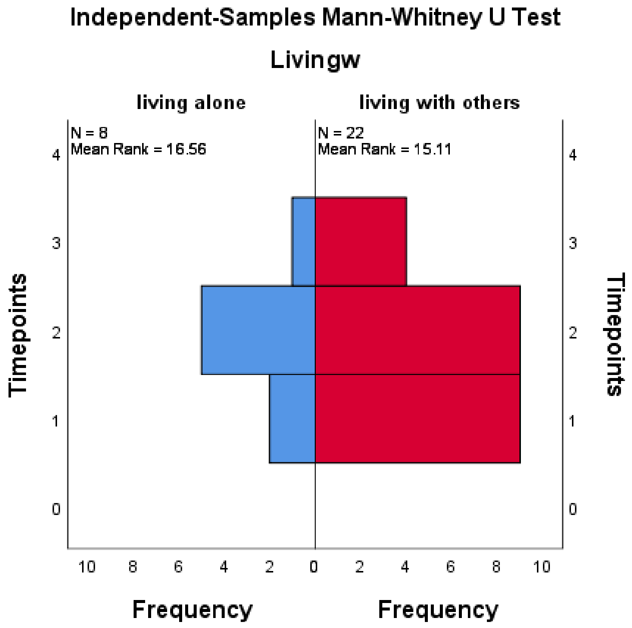


Figure 7: Timepoints collected from patients by deprivation index

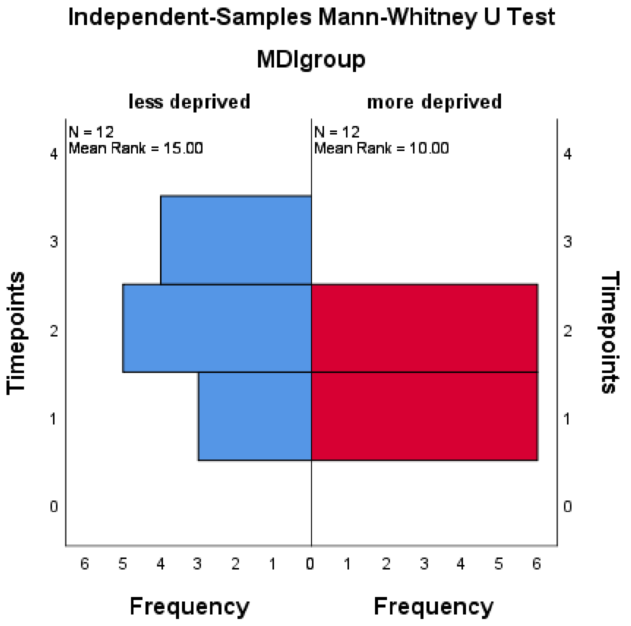
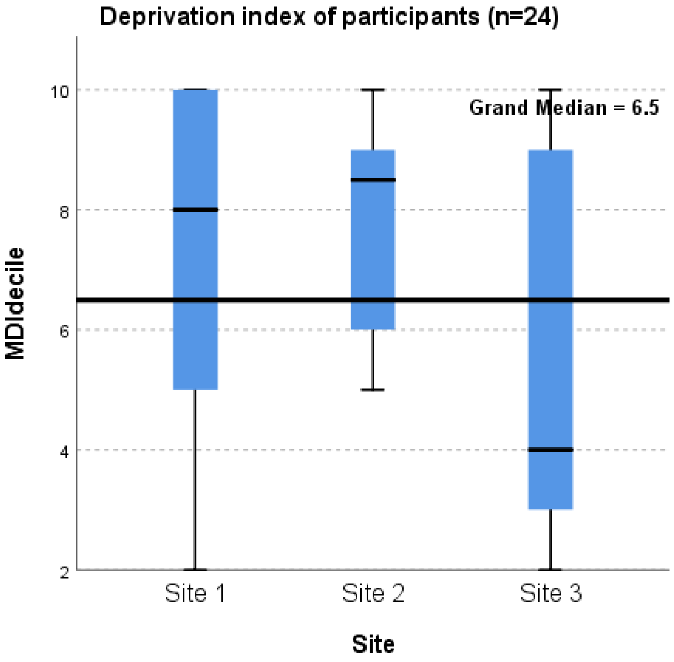


Figure 8: Deprivation index of participants by research location



6.3 Quality of Life (EQ-5D-5L)

6.3.1 Whole sample over time

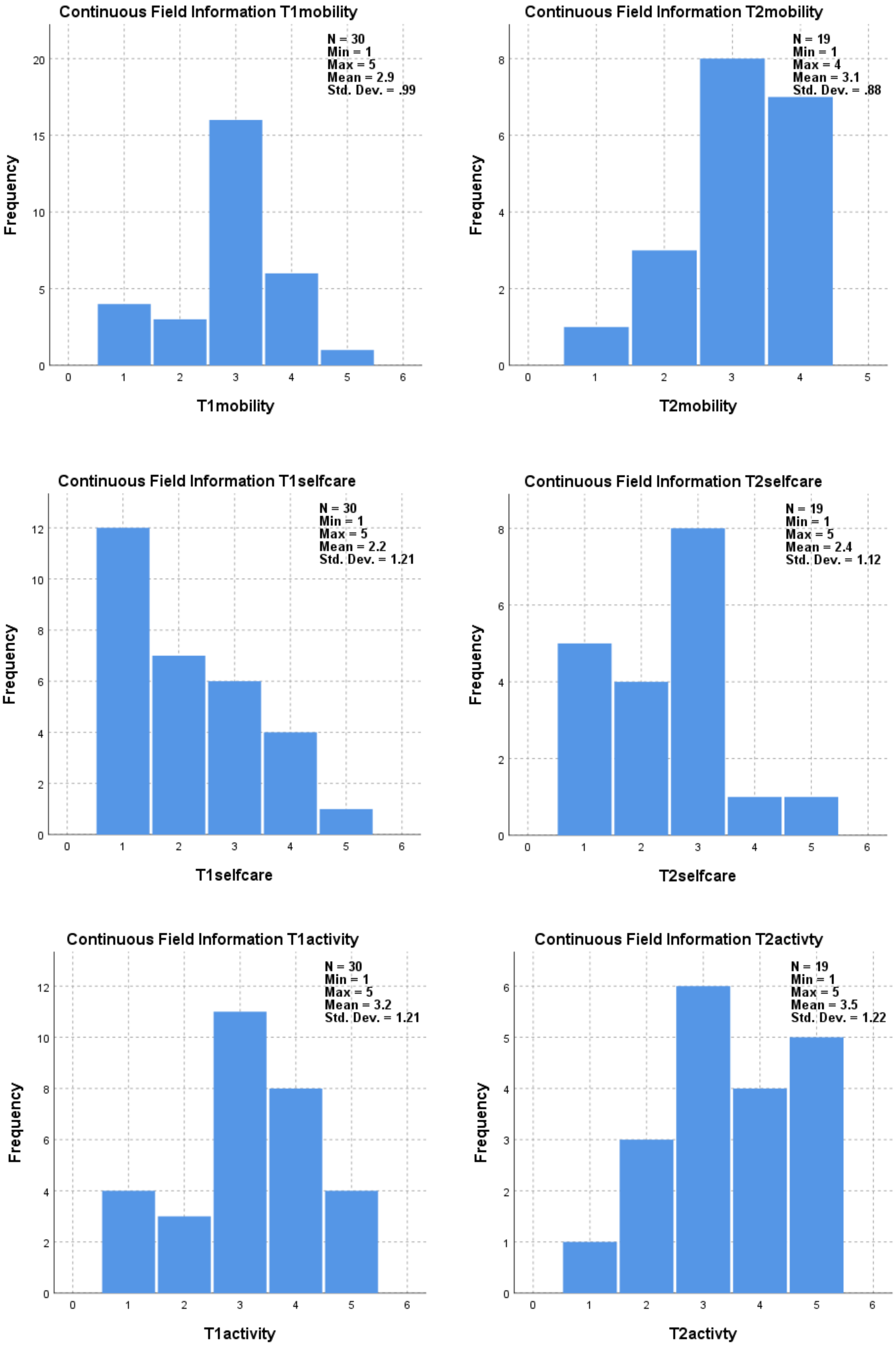
The EQ-5D-5L represents a Likert-style scale from no problems to extreme problems in each area of mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension in this measure represents one question scored 1 to 5 by the participant. This data is summarised as the frequency of problems in each dimension (see table 21). Participants also complete a visual analogue scale (0-100) to indicate their overall health on the day of the questionnaire completion. This is presented in the table with the median and mean value (with standard deviation).

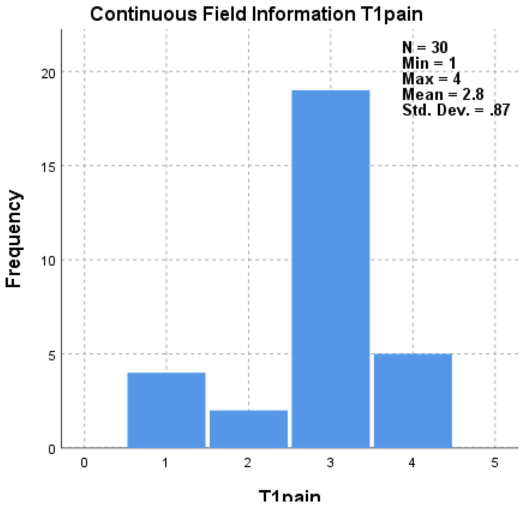
Differences between the first and second timepoint were tested with Wilcoxon signed rank test, which is suitable for paired ordinal data (n=19). This showed significant differences with problems increasing in the domain of self-care (p=0.012) between T1 and T2. Trends were for problems in the domains of mobility and daily activities to decrease between T1 and T2, and for problems with pain and anxiety and depression to decrease slightly, but these were not statistically significant. In this sample, self-rated health decreased very slightly. Correlations between timepoints were significant at the 0.1 level for all domains.

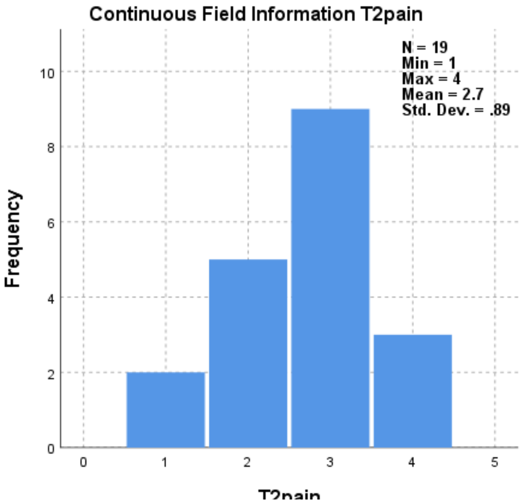
Table 21: EQ-5D-5L results for the sample with significance tested for pairs (n=19)

Dimension	T1 (n=30)	T2 (n=19)	Significance
Mobility			
1	13.3%	5.3%	0.248
2	10%	15.8%	
3	53.3%	42.1%	
4	20%	36.8%	
5	3.3%	0%	
Self-care			
1	40%	26.3%	**0.012**
2	23.3%	21.1%	
3	20%	42.1%	
4	13.3%	5.3%	
5	3.3%	5.3%	
Usual activities			
1	13.3%	5.3%	0.273
2	10%	15.8%	
3	36.7%	31.6%	
4	26.7%	21.1%	
5	13.3%	26.3%	
Pain/discomfort			
1	13.3%	10.5%	0.248
2	6.7%	26.3%	
3	63.3%	47.4%	
4	16.7%	15.8%	
5	0%	0%	
Anxiety/Depression			
1	43.3%	42.1%	0.357
2	30%	26.3%	
3	23.3%	31.6%	
4	3.3%	0%	
5	0%	0%	
Overall health (0-100)	(n=28)	(n=19)	
Median	56	60	0.420
Mean	54.18	55.63	
Standard deviation	16.678	20.421	

Figure 9: Histograms demonstrating frequency of problems in each domain of quality of life at T1 (n=30) and T2 (n=19)




Continuous Field Information T1pain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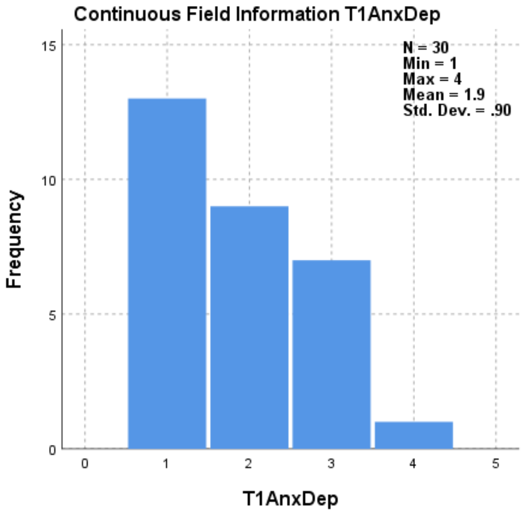
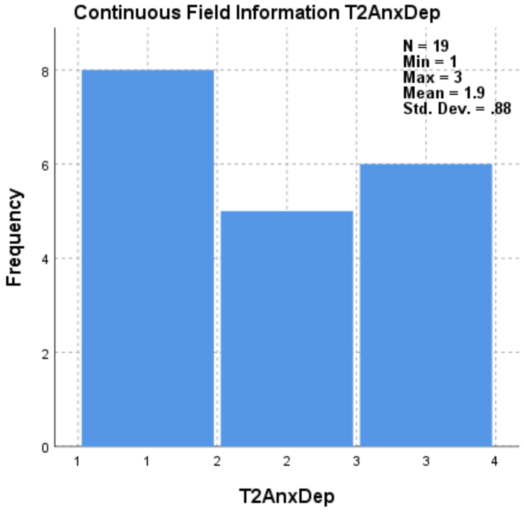

Continuous Field Information T1AnxDep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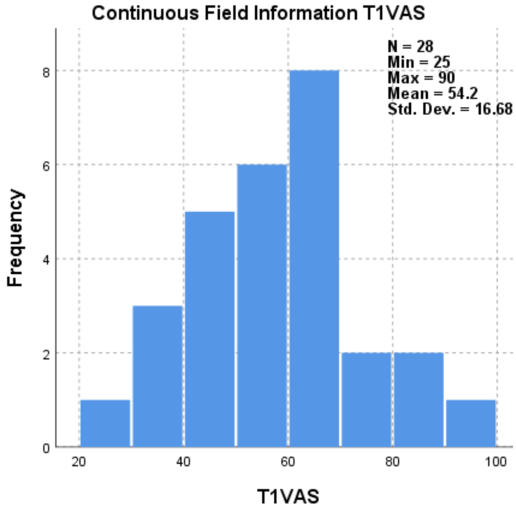
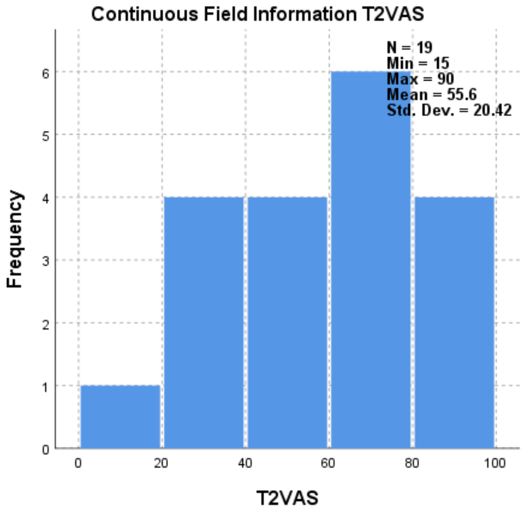
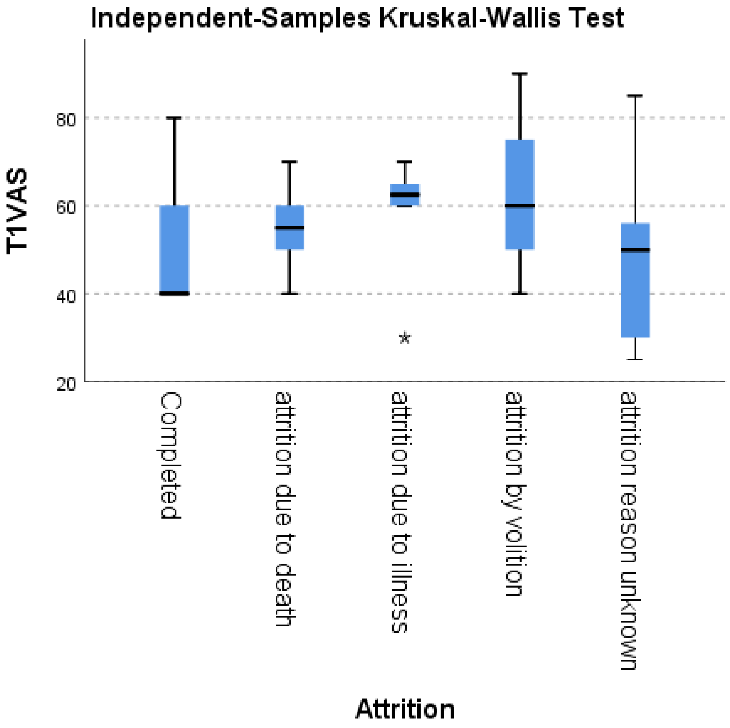

Continuous Field Information T1VAS


Continuous Field Information T2VAS

6.3.2 Comparing participants by attrition reason

Differences in quality of life at baseline were tested against reasons for attrition. This is unpaired ordinal data and so an independent samples Kruskal Wallis test was used to compare dimensions of quality of life at T1. This did not find significant differences (figure 14). Interestingly visual analogue scale suggests that completers to have a lower perception of their own health at baseline than other participants, but this was not significant (sig = 0.42) (figure 15). Dimension of anxiety and depression (sig=0.374) and self-care (sig=0.334) also show some non-significant differences. Levene's statistic showed near homogeneity of variances between participants when grouped by reasons for attrition, with most variation occurring in the dimension of self-care (sig. 0.105) between those who left the study by choice (attrition by volition) and those who left due to poor health (attrition due to illness) (post-hoc Tukey test sig. 0.168). Other comparisons were not significant.

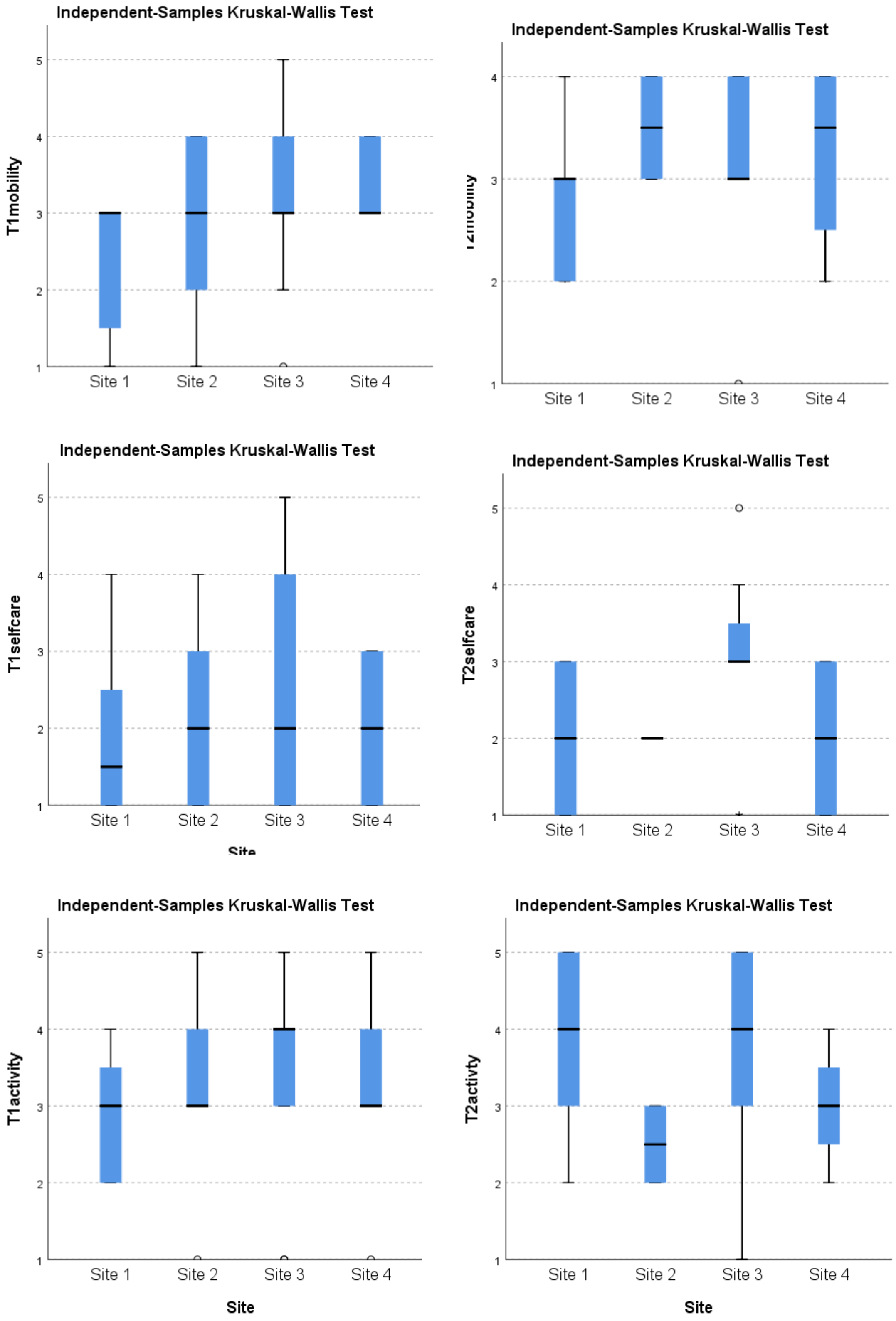
Figure 10: Boxplot of Visual Analogue Scale from EQ-5D-5L at baseline by reason for attrition

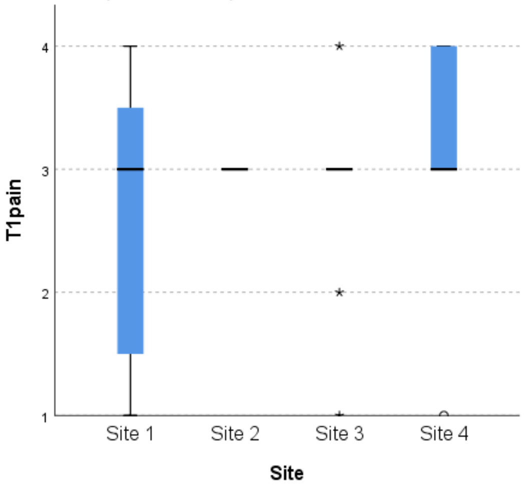


6.3.3 Comparisons between sites

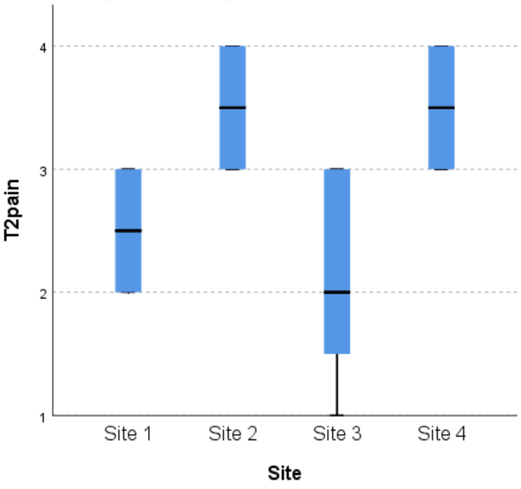
Differences in quality of life scores were tested between research sites (figure 16). Levene's statistic showed homogeneity of variance across most dimensions, however variation in pain and discomfort was statistically significant between research sites (sig=0.035). This was not centred around a particular site (post-hoc Tukey). Independent sample Kruskal-Wallis test indicated that differences between sites were not significant in the dimensions of mobility, self-care, daily activity, anxiety and depression, and visual analogue scale were not significant. Differences in problems with pain were not significant at T1 (sig=0.840) but were significant at T2 (sig=0.042), however participant numbers are small for these analyses.

Figure 11: Boxplots showing Eq-5D-5L scores between sites

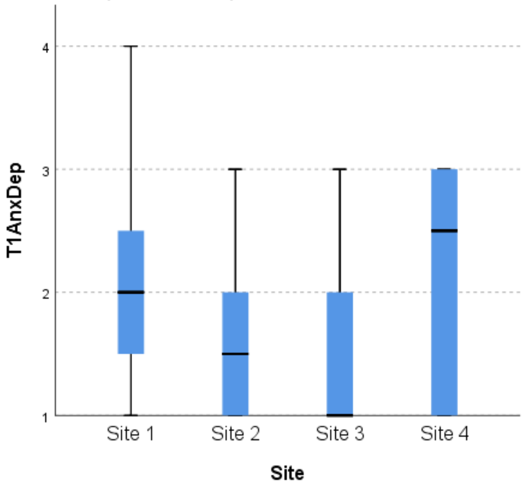




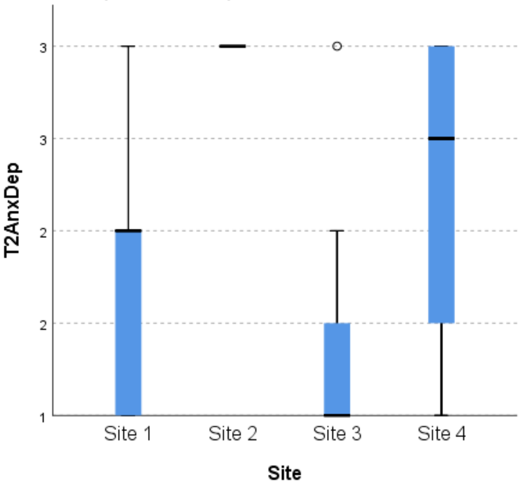
Independent-Samples Kruskal-Wallis Test



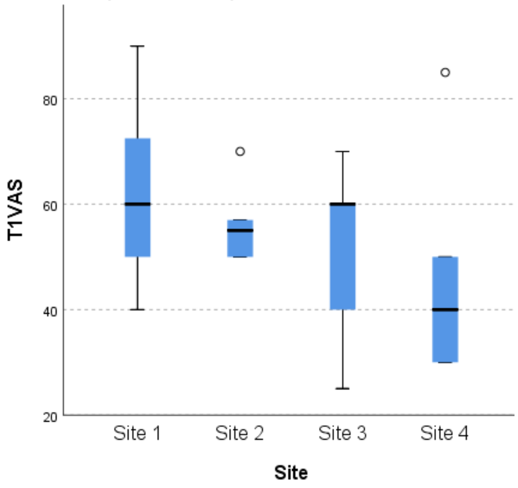
Independent-Samples Kruskal-Wallis Test



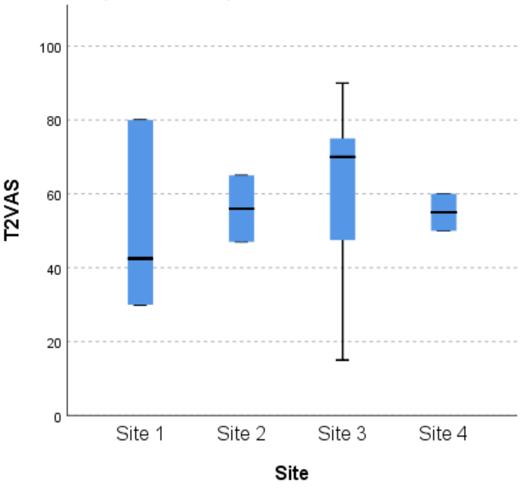
Independent-Samples Kruskal-Wallis Test



Independent-Samples Kruskal-Wallis Test



Independent-Samples Kruskal-Wallis Test



Independent-Samples Kruskal-Wallis Test

6.4 Psychosocial Outcome Measures

6.4.1 Summary of data

Participants completed measures of perceived social support, loneliness, and depression. Table 22 presents a summary of this data.

Perceived social support included nineteen questions related to emotional support, informational support, tangible support, affection, positive social interaction and one additional question on companionship (‘someone to do things with to help you get your mind off things’). Loneliness was just three questions, asking how often the participant feels they lack companionship, feel left out, or feel isolated. Depression was six questions suitable for use in advanced illness, reflecting emotional and cognitive depressive symptoms. When timepoints were completed, almost all participants completed every question, suggesting this was not too burdensome.

Positive change is indicated by increasing social support, decreasing loneliness, and decreasing depression. Table 23 shows differences between first and second timepoint. Wilcoxon signed rank text for related samples was used to test statistical significance of differences between T1 and T2 (n=19). These were not significant for depression (p=0.528) or for perceived social support (p=0.267) and were approaching significance for loneliness (p.=0.101).

Table 22: Perceived social support, loneliness, and depression, showing change between T1 and T2 (n=19),and significance calculated with Wilcoxon signed rank test

	Change T2-T1	Standard deviation	Sig.
Perceived social support	3.316	16.082	0.267
Loneliness	-0.421	1.071	0.104
Depression	-0.632	2.985	0.528

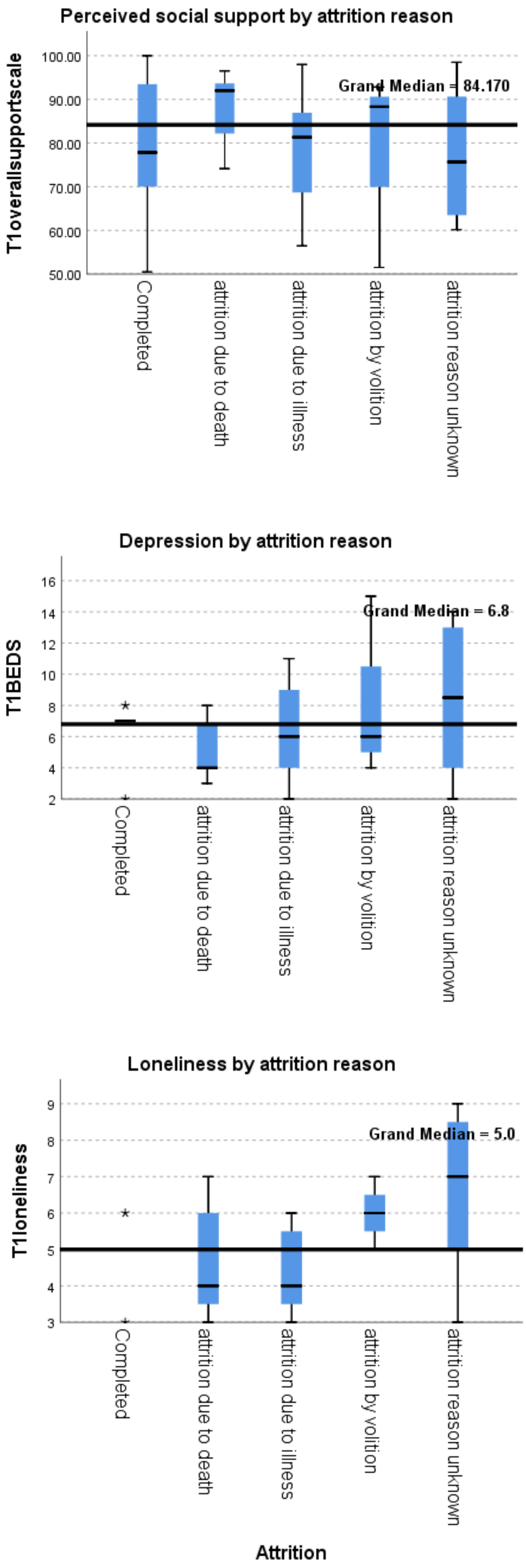
Table 23: Results of psychosocial outcome measures for whole sample

	T1 (n=30)	T2 (n=19)	T3 (n=5)
Perceived social support			
Mean	80.139	80.158	87.200
Standard error of mean	2.729	4.230	5.536
Min value	50.50	22.00	75.16
Max value	100	100	100
Standard deviation	14.945	18.437	12.380
Loneliness			
Mean	5.30	5.11	4.20
Standard error of mean	0.326	0.518	0.374
Min value	3	3	3
Max value	9	9	5
Standard deviation	1.784	2.258	0.837
Depression			
Mean	6.82	7.11	5.60
Standard error of mean	0.675	0.791	0.872
Min value	2	2	3
Max value	15	13	8
Standard deviation	3.696	3.446	1.949

6.4.2 Differences at baseline by attrition reason

This section considers differences at baseline by attrition reason and research location. Patients who died during data collection appeared to have a higher perception of social support, less loneliness and less depression at baseline than other categories. Those with an unknown attrition reason appeared to have higher loneliness. Independent samples Kruskal-Wallis test indicated the differences between patients by reasons for attrition was not significant for perceived social support (p=0.768) or depression (p=0.761) but approaching significance for loneliness (p=0.169). These results are shown in figure 17.

Figure 12: Boxplots showing psychosocial measures by reason for attrition, median line for whole sample



6.4.3 Change in perceived social support

The perceived social support scale included four domains and an additional question that added to the calculation of the overall score. Table 24 breaks down scores for domains of emotional support, tangible support, affectionate support, social interaction, and overall perception of support. Larger values indicate higher perception of support, and maximum score is 100. This is ordinal data so Wilcoxon signed rank test is more appropriate than a parametric test if the distribution is symmetrical, but this is not clear here in this small sample and so both significance figures are included in this table.

The mean change for overall social support was positive, but this is not a significant difference. The 95% confidence interval straddles zero for all domains, indicating less than 95% confidence that there was a difference over time. Change was not observed in the affectionate support subscale: the mean change is (slightly) negative. The t-value is negative and significance value is approaching 1, implying no change in perceived affectionate support. The standard deviation is lowest for this domain, indicating the least variation in change between participants. The emotional social support subscale showed the largest mean change between the two timepoints, a high t-value, and p-value <0.5. This demonstrates that change between first and second timepoint was largest in the domain of perceived emotional support (n=19). A similar pattern was seen in T3 data (n=5) – sample is small, but mean change between the first timepoint and the third timepoint was greater for emotional support (11.500) than for overall social support (8.832) (table 25).

Figure 18 shows change in emotional support subscale and the overall social support scale between T1 and T2. These are small samples and 95% confidence intervals are wide, reflecting this is not robust data, but within subject differences over time are approaching significance in a univariate model of emotional support (p=0.165) but not over social support (p=0.381). Figure 19 shows the available data for those with three timepoints – error bars if shown would pass 100, but graphs are presented to visualise the trend observed.

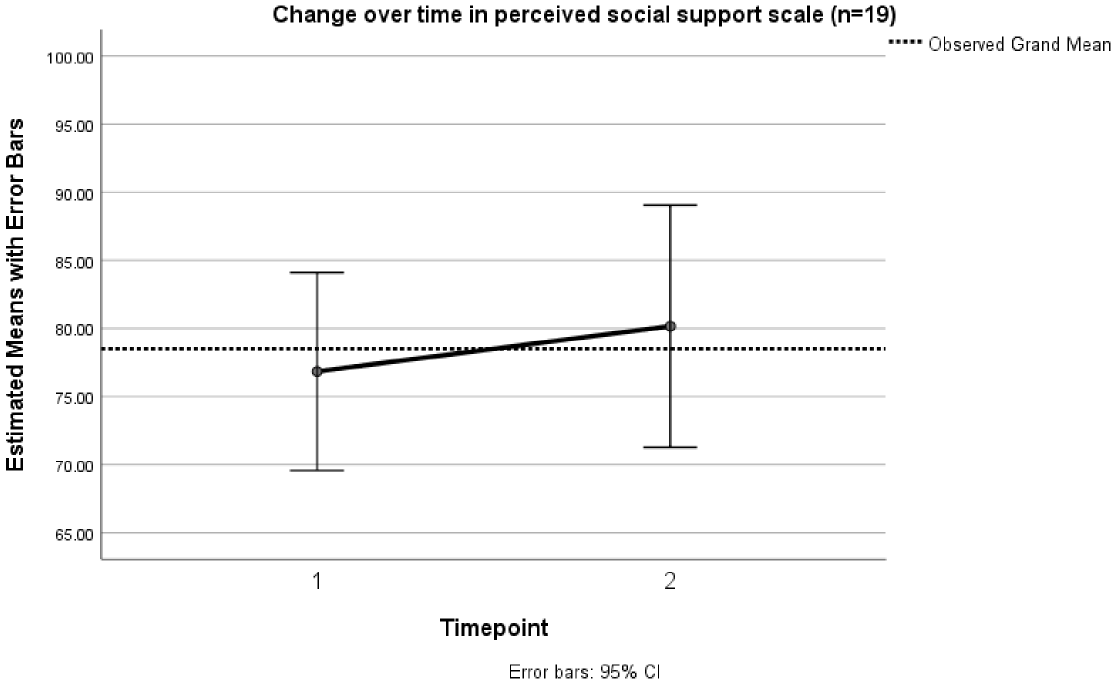
Table 24: Subscales of perceived social support (MOS-SS), showing change between T1 and T2 (n=19)

	Mean change	Standard deviation	Standard error of mean	95% confidence interval of the difference		T value	P value (2 tailed)	Wilcoxon signed rank test
Overall social support	3.316	16.082	3.689	-.435	11.067	0.899	0.381	0.267
Emotional	5.357	16.114	3.697	-.410	13.124	1.449	0.165	0.114
Tangible	5.263	24.970	5.729	-.772	17.299	0.919	0.370	0.189
Affectionate	-0.351	13.050	2.994	-.641	5.940	-.117	0.908	0.904
Interaction	4.211	18.485	4.241	-.699	13.120	0.993	0.334	0.268

Table 25: Descriptive statistics of perceived social support observed over time (all data), figures to 3 decimal places

	T1 (n=30)	T2 (n=19)	T3 (n=5)
Emotional support			
Mean	80.191	82.368	87.000
Standard error mean	3.019	4.653	8.116
Standard deviation	16.534	20.284	18.149
Tangible support			
Mean	79.667	81.579	81.000
Standard error mean	3.690	4.557	8.426
Standard deviation	20.211	19.864	18.841
Affectionate support			
Mean	86.667	85.263	90.664
Standard error mean	3.306	4.771	4.001
Standard deviation	18.110	20.796	8.946
Social interaction			
Mean	76.667	76.843	89.332
Standard error mean	3.541	4.738	4.521
Standard deviation	19.395	20.652	10.111
Overall social support			
Mean	80.138	80.158	87.200
Standard error mean	2.738	4.230	5.536
Standard deviation	14.946	18.437	12.379

Figure 13: Change between T1 and T2 in perceived social support and emotional support subscale (dotted line shows observed mean for whole sample)



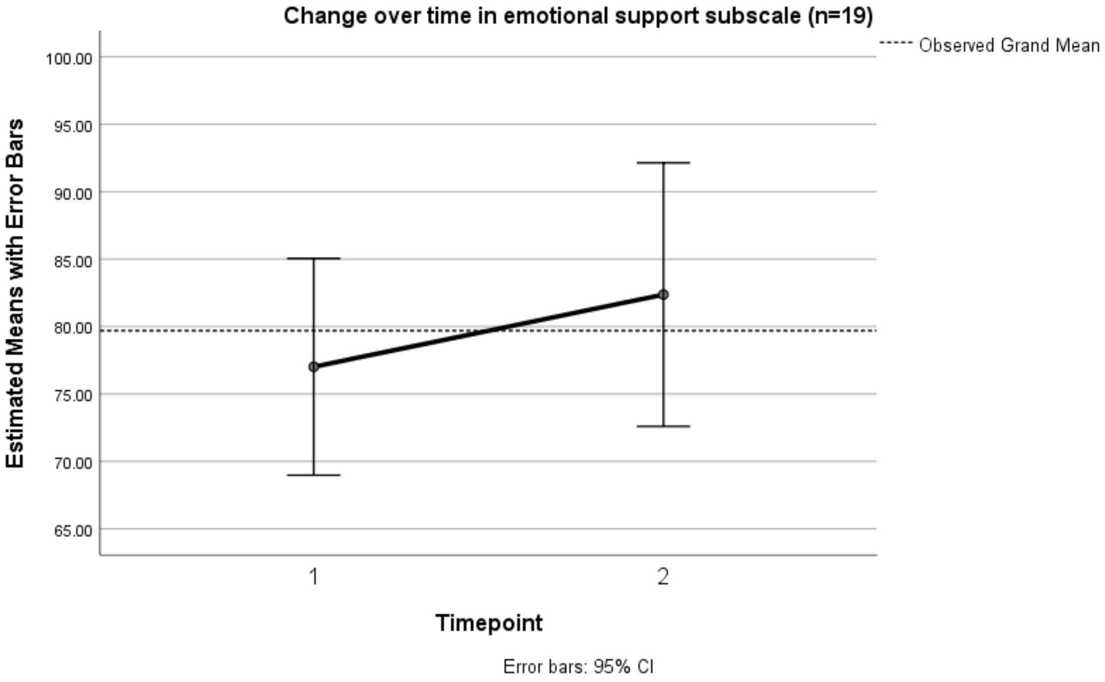
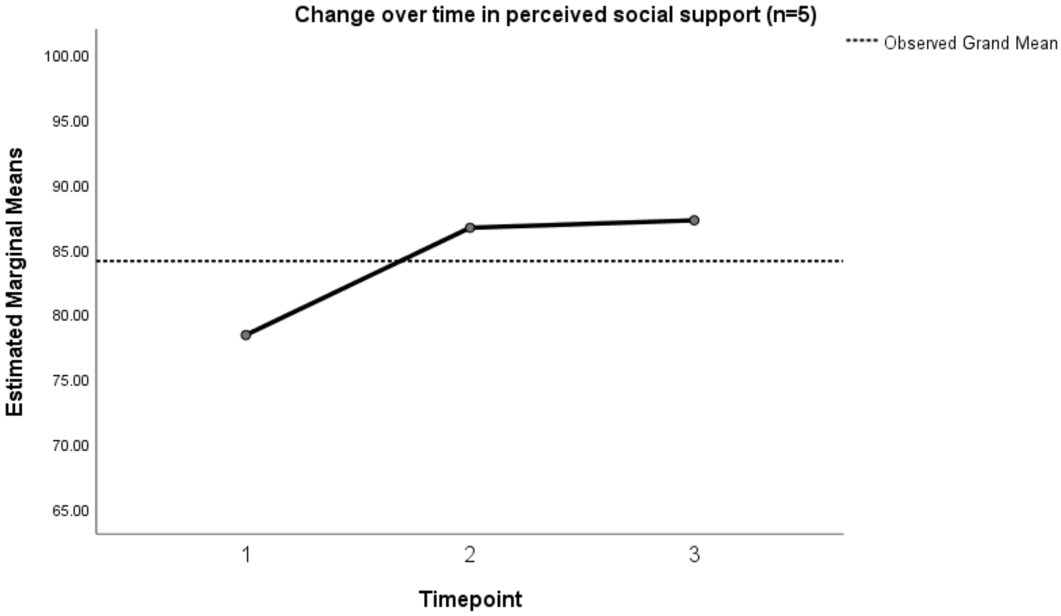
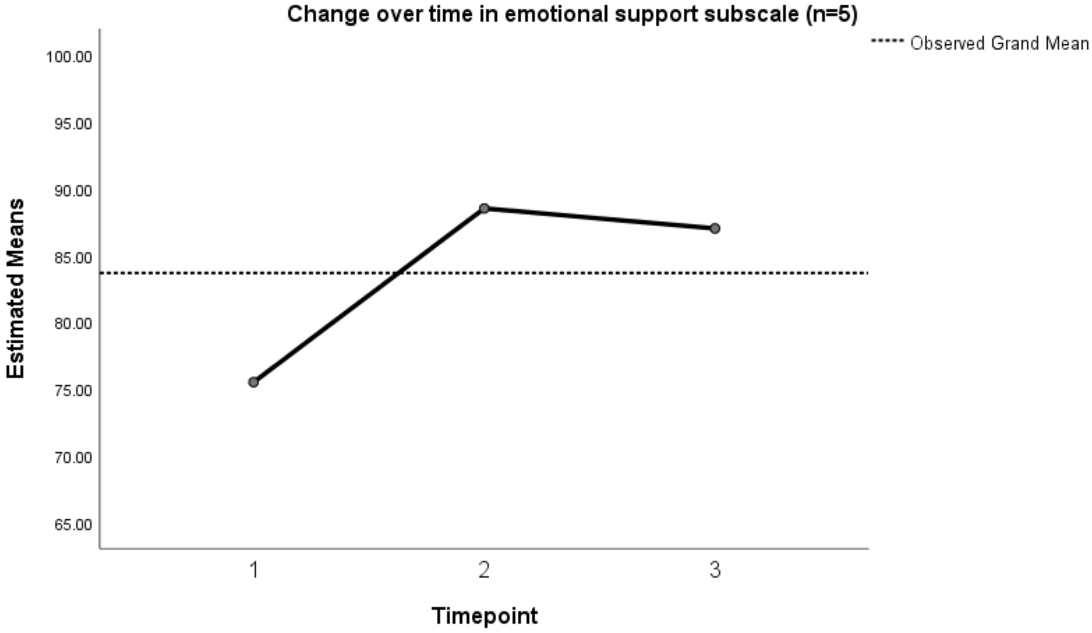


Figure 14: Change between T1 and T3 in perceived social support and emotional support subscale – improvement appears sustained for those participants with 3 timepoints (n=5)





6.4.4 Change in loneliness

The loneliness scale had three questions, each with three possible answers, giving a minimum possible score of 3 and maximum score of 9. Loneliness was observed to decline between T1 and T2 (n=19) and this was approaching statistical significance (p=0.104). Seven participants reported decreasing loneliness, nine participants maintained their loneliness scores, and three participants reported increasing loneliness. The change between T1 and T2 (n=19), and over T1 to T3 (n=5), is shown in figure 20.

Figure 15: Change over time in loneliness scale between T1 and T2 (n=19) and between T1 and T3 (n=5).

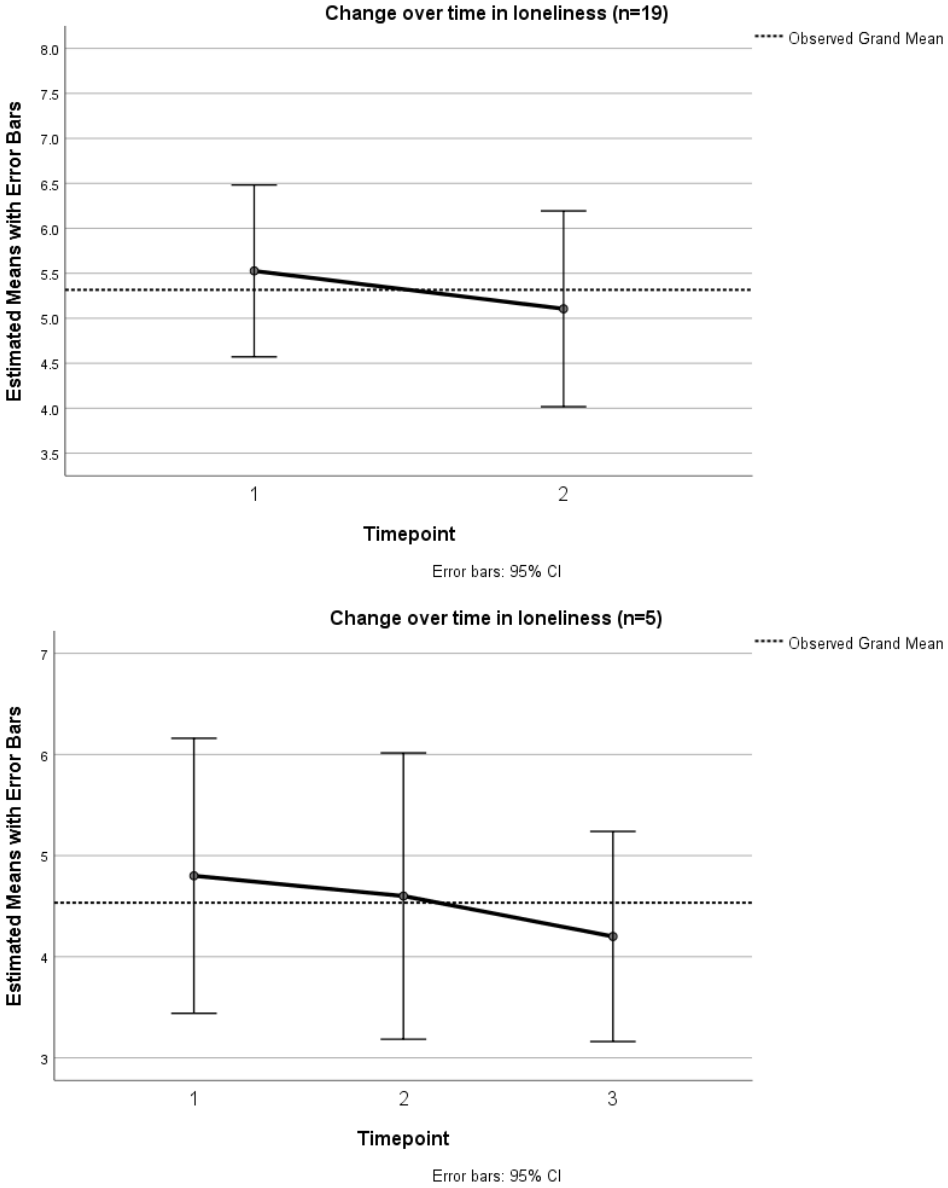
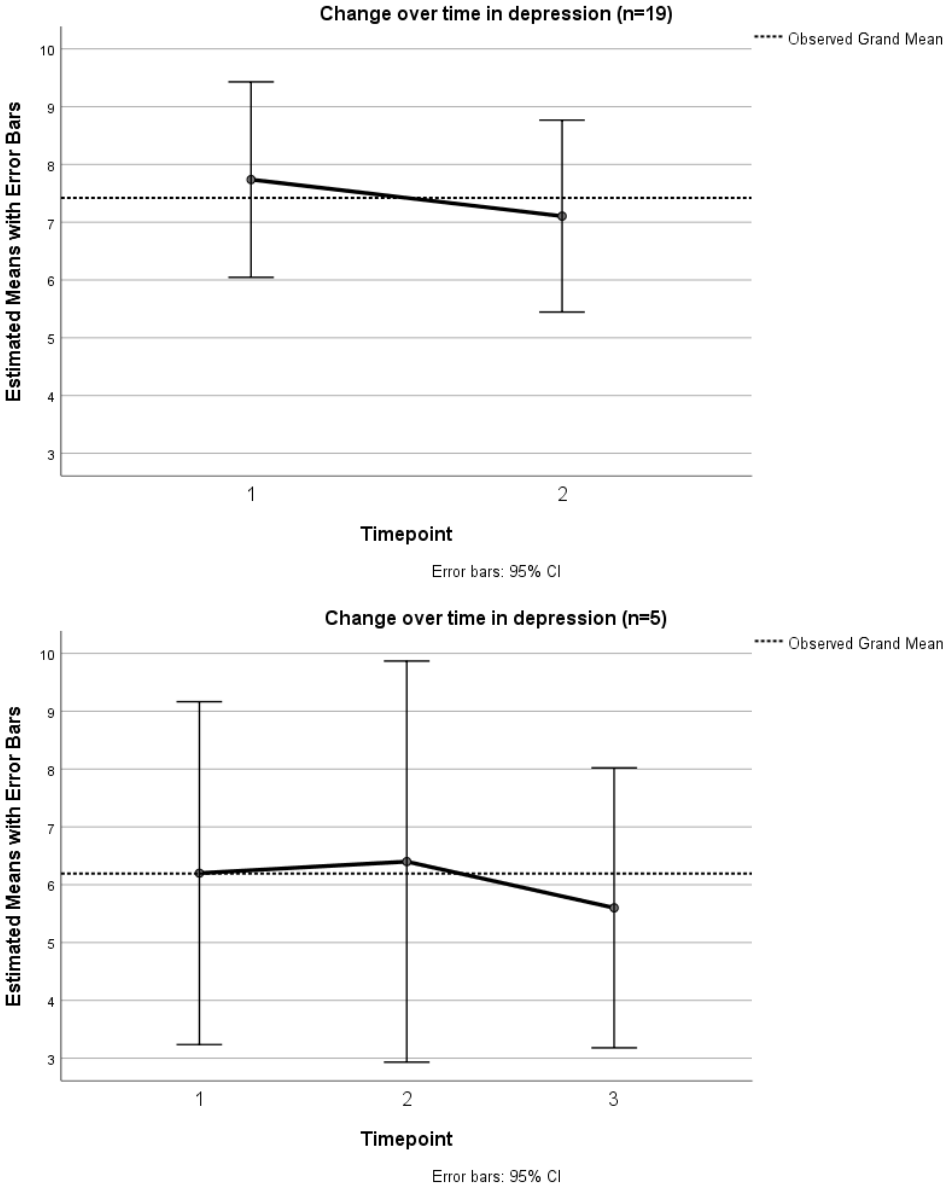


Table 266: Mean change between T1 and T2 in loneliness and depression

	Mean change	Standard deviation	Standard error of mean	95% confidence interval of the difference		T value	P value (2 tailed)	Wilcoxon signed rank test
Loneliness	-0.421	1.071	0.246	-.937	0.95	-.714	0.104	0.104
Depression	-0.632	2.985	0.685	-.070	0.807	-.922	0.369	0.528

Figure 16: Change over time in depression scale between T1 and T2 (n=19) and between T1 and T3 (n=5).



6.4.5 Change in depression

The depression scale had six questions, each with four possible answers, giving a minimum possible score of 0 and maximum score of 18, with a score of 6 considered the cut-off for a depression case. As shown in table 26, depression was observed to decline between T1 and T2, but variation was high, and the finding was not statistically significant. Eight patients reported decreasing depression, seven reported increasing depression, and four remained at the same score. The change in depression scores between T1 and T2 (n=19), and over T1 to T3 (n=5), is shown in figure 21.

At baseline, eighteen participants (60%) had a score of 6 or above, indicating a case of depression. Proportions were similar at the second timepoint, when thirteen participants (68.4%) reported a score of 6 or above. At the third timepoint, with only five participants remaining, there were two participants reporting score of 6 or higher. Cases of depression were in all sites at baseline, and scores of depression did not differ significantly between sites at T1. Scores of depression did show differences between sites at T2 (p=0.025). Figure 22 shows how the cases of depression between sites changes between T1 and T2.

Interestingly, comparing scores at baseline by attrition reason indicated that 4/5 of the participants who completed the study indicated depression at baseline, and that by the second timepoint this had reduced, in that two of these participants no longer met the cut off score of 6. Those that chose to leave the study had all left by the second timepoint. See figure 23 for a representation of this data.

Figure 17: Depression was identified in participants recruited from each site

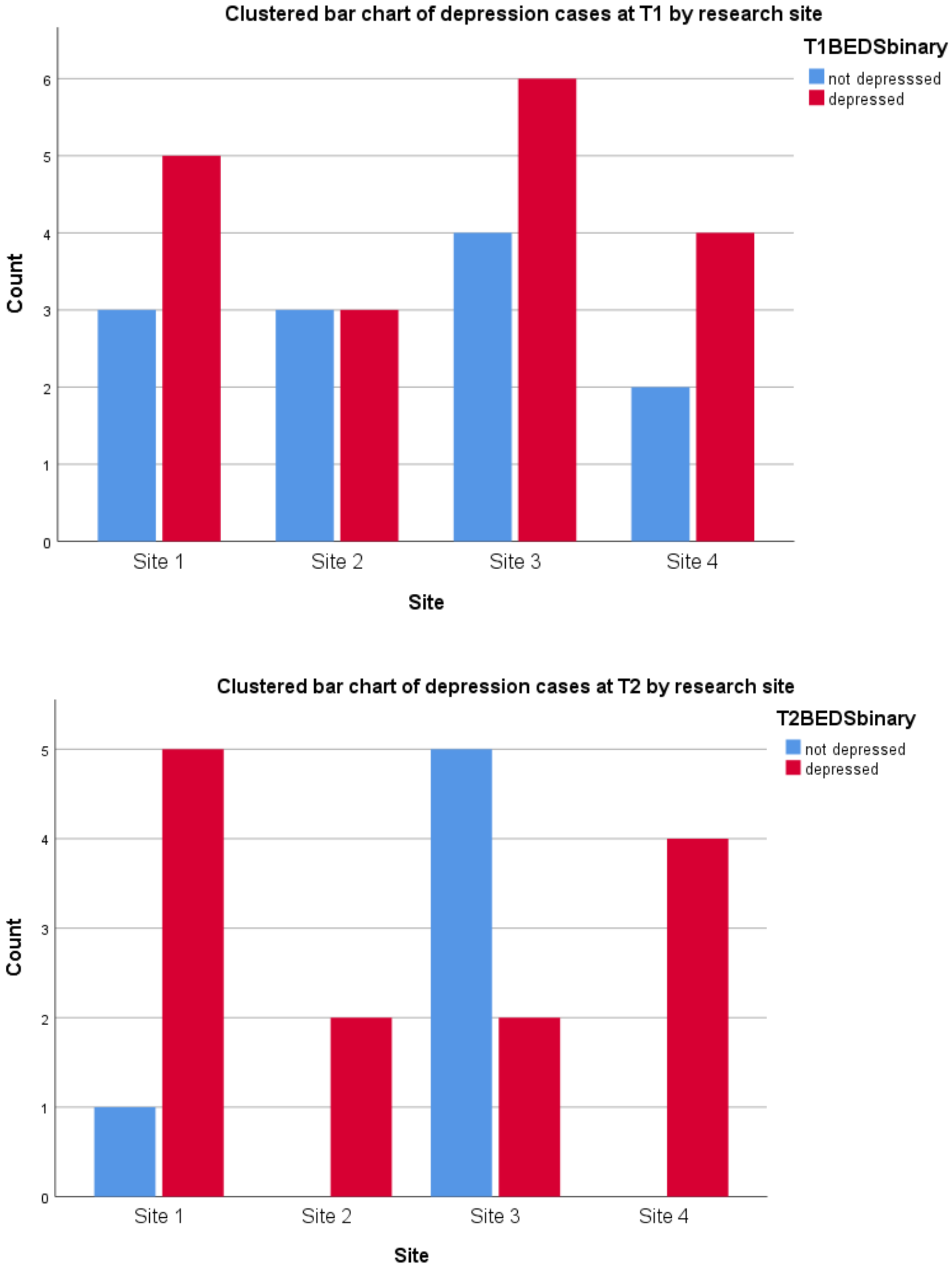
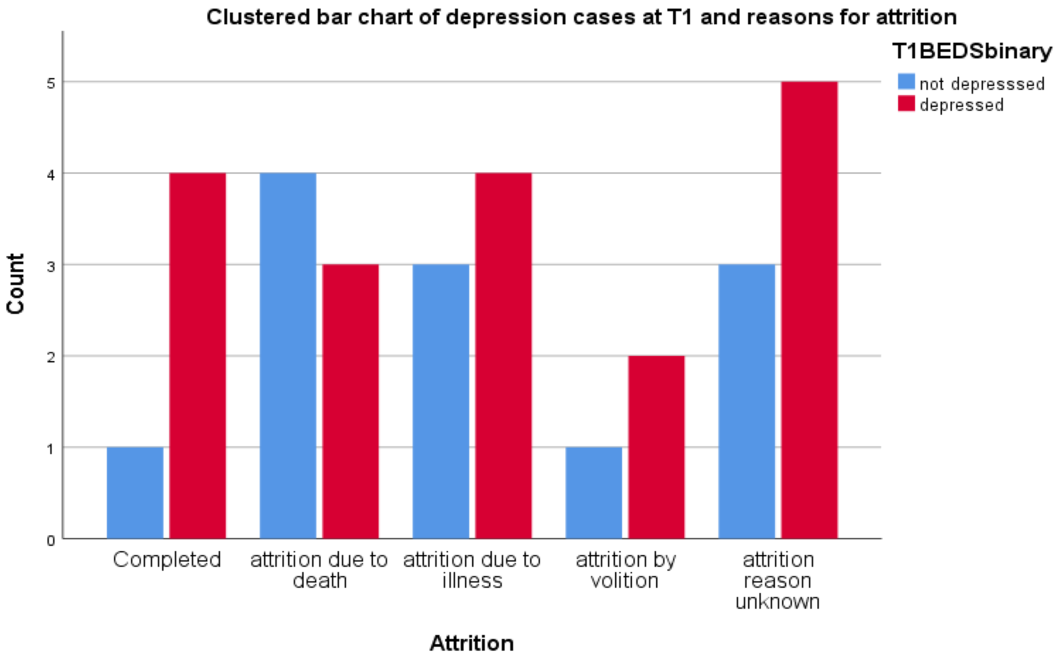
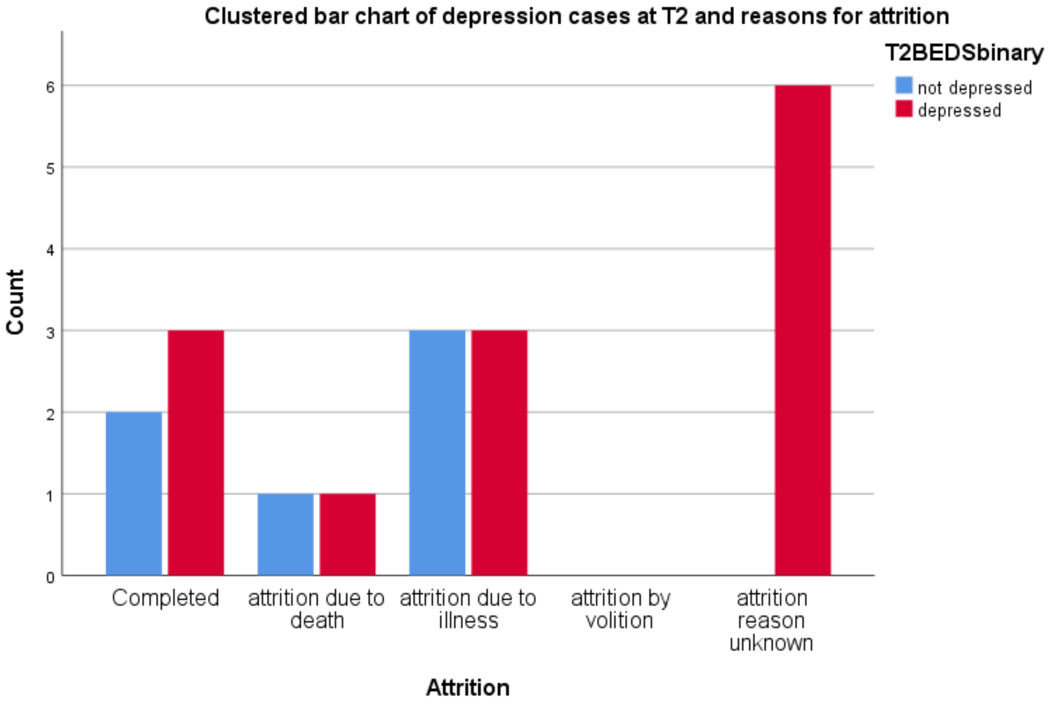


Figure 18: Those who completed the study and those with unknown attrition reason had higher incidence of depression than other patients





6.4.6 Differences between research sites

Results of psychosocial measures at baseline by research location are shown in table 27. Levene's test showed homogeneity of variance between research sites (p>0.1) for all three psychosocial measures. Kruskal-Wallis test showed differences were not significant at T1, however the differences in depression scores between sites became significant at T2 (p=0.025). Tukey post-hoc test indicates differences to be significant between sites 3 and 4. Figure 24 shows mean depression at each site shows a spread of scores in participants with more than one timepoint. The boxplots in the subsequent figure include data from all participants (figure 25).

Figure 19: Mean depression score for each site at timepoint one and two (n=19)

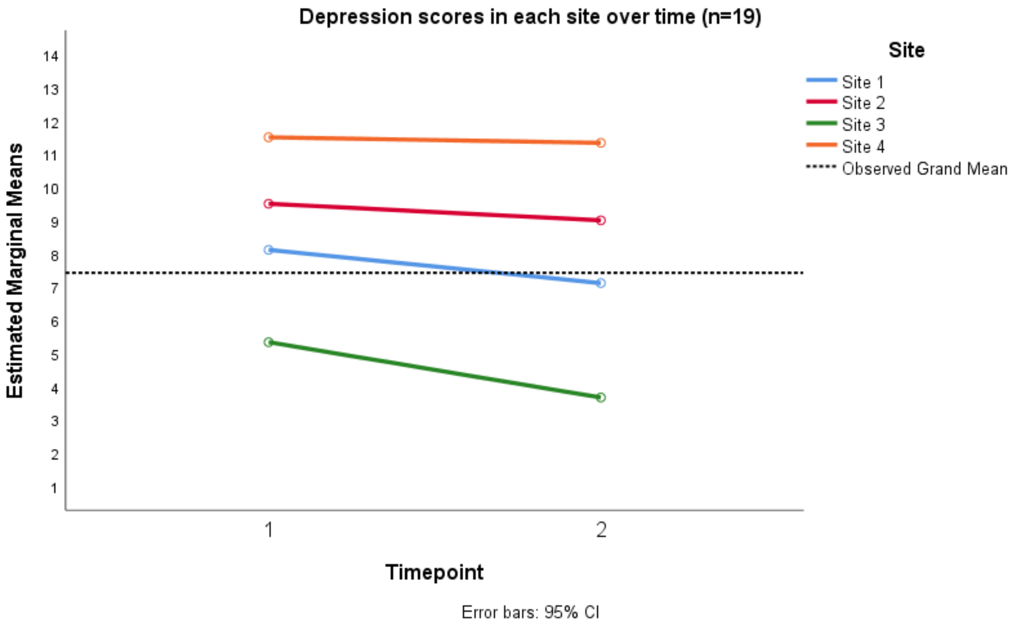
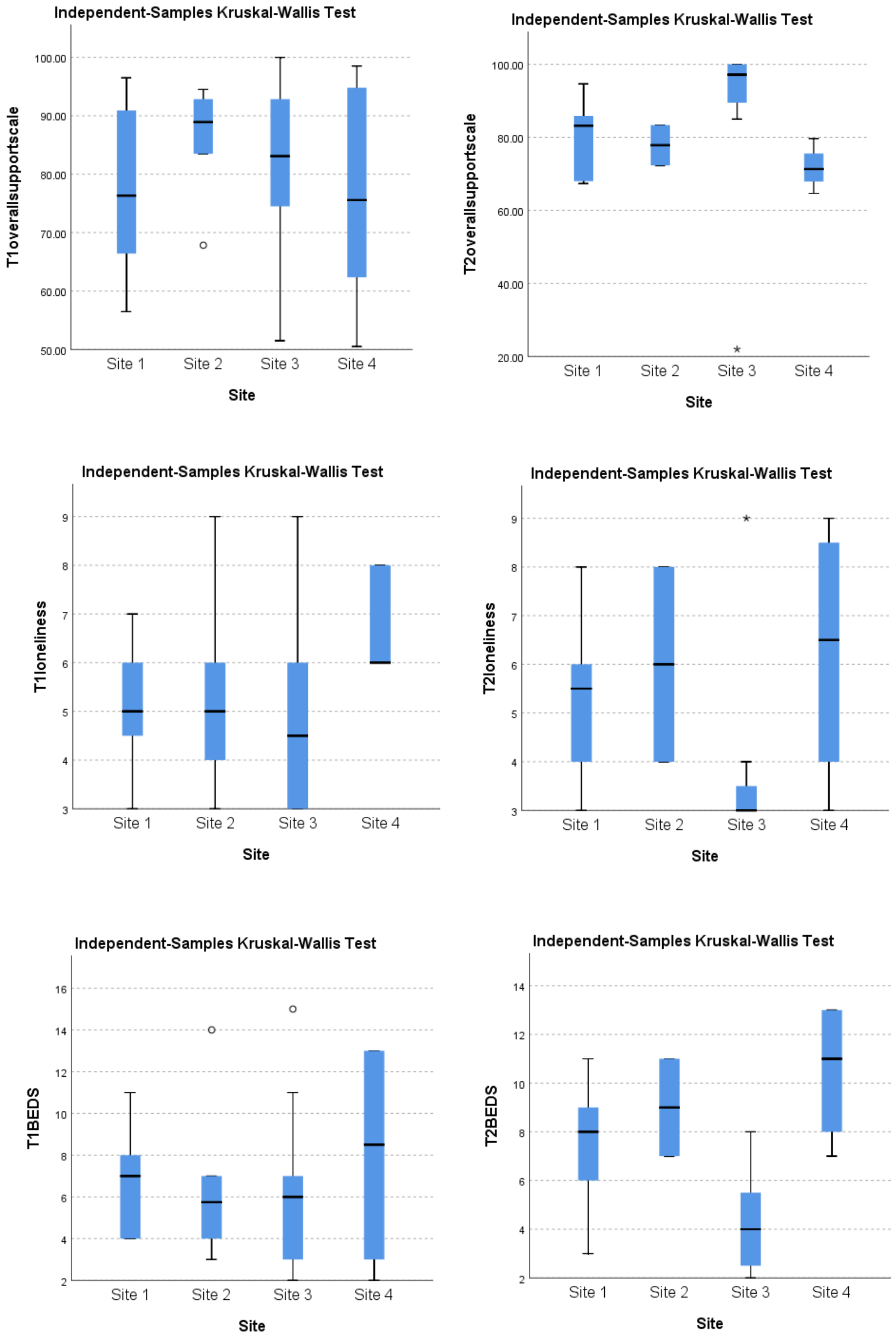


Table 27: Psychosocial measures by research location at baseline

	Site 1 (n=8)	Site 2 (n=6)	Site 3 (n=10)	Site 4 (n=6)	Total sample (n=30)
Perceived social support					
Mean	77.540	86.087	81.002	76.217	80.139
Standard error of mean	5.105	4.046	4.973	8.031	2.729
Min value	56.48	67.84	51.50	50.50	50.50
Max value	96.50	94.50	100	98.50	100
Standard deviation	14.440	9.910	15.726	19.673	14.945
Loneliness					
Mean	5.13	5.33	4.90	6.17	5.30
Standard error of mean	0.441	0.882	0.623	0.749	0.326
Min value	3	3	3	3	3
Max value	7	9	9	8	9
Standard deviation	1.246	2.160	1.969	1.835	1.784
Depression					
Mean	6.63	6.58	6.40	8.00	6.82
Standard error of mean	0.885	1.604	1.284	1.966	0.675
Min value	4	3	2	2	2
Max value	11	14	15	13	15
Standard deviation	2.504	3.930	4.061	4.817	3.696

Figure 20: Differences between site at baseline were non-significant at T1 across measures. Differences in depression were significant at T2, depicted in bottom-right panel



6.4.7 Differences between patient groups

This section is a brief demonstration of differences between groups in the changes observed between baseline and the second timepoint. Participants that lived alone and completed two timepoints (n=6) appeared to have a greater reduction in depression and loneliness and a greater increase in perceived social support than those who lived with others (n=13). Samples are small and low confidence is indicated by large error bars – see figure 26. These results are not statistically significant using a univariate model but could be worthy of consideration with a larger sample. Finally, figure 27 depicts change between men and women (n=19), suggesting there may be differences in the support derived from an intervention or how it is observed using these measures.

Figure 21: Change over time by outcome measure, comparing those who lived alone and those who lived with others (n=19)

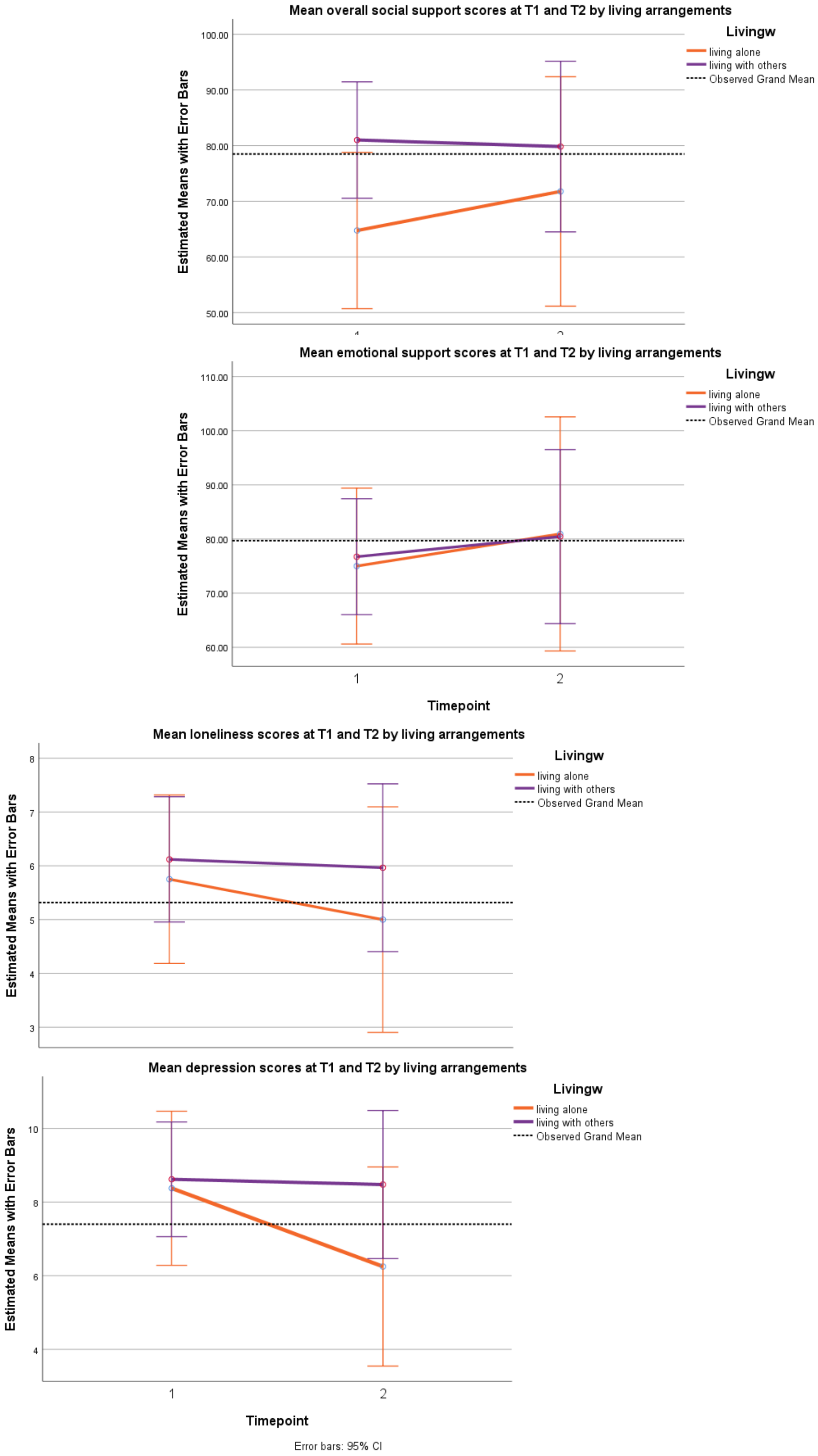
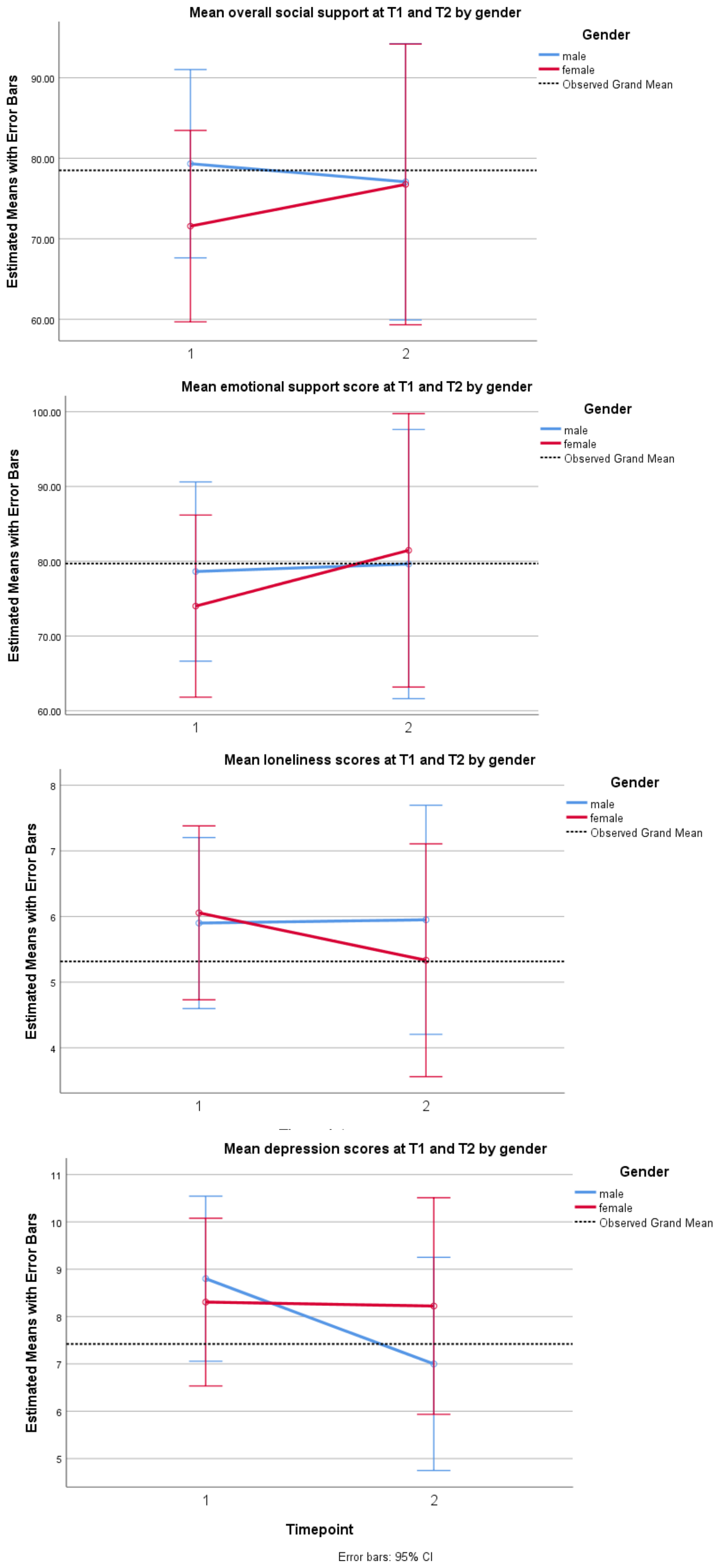


Figure 22: Change over time by outcome measure, comparing males and females (n=19)



6.5 Conclusion

6.5.1 Summary of findings

This chapter observes patent reported outcomes in the domains of perceived social support, loneliness, depression, and health-related quality of life. Health-related quality of life differences between the first and second timepoint were tested with Wilcoxon signed rank test, which is suitable for paired ordinal data (n=19). This showed significantly differences in the domain of self-care (p=0.012) between T1 and T2.

Across the sample in those that provided two or more timepoints, perceived social support increased, and loneliness and depression decreased slightly. Largest changes with the least variation between participants was in emotional support (p=0.165) and loneliness (p=0.104). The smallest change was observed in affectionate support.

Loneliness measure indicated differences between participants by reasons for attrition (p=0.025), those with unknown attrition reason had higher loneliness at baseline than those that died or withdrew due to poor health.

Depression scores suggest that depression did not differ significantly between sites at the first timepoint, but by the second timepoint there were significant differences (p=0.025), which is attributable to unequal dropout rates. Participants who completed the study had a higher proportion of baseline depression cases (scores over 6) than those who died or became more ill. Depression at baseline was indicated in more than half of those who left for an unknown reason or chose to leave the study. Participants in this sample were also less likely to complete the study if they were from more deprived postcodes.

Site 3 contained most of the participants that left due to poor health. As an exercise group, this intervention may be less accommodating to fluctuations or sudden declines in health – although these patients might have accessed the programme again at a later date. Research designs for rehabilitative palliative care in particular may need to be aware that fluctuations in health might have a bigger impact on attendance for exercise groups than for other activities.

6.5.2 Methodological approach

The above findings are presented with caution, as the interpretation of effect from non-randomised studies requires a larger sample than was recruited here. However, it appears that patient reported outcome measures of perceived emotional support and loneliness might be useful in this setting. There were no indicators that the questions caused distress or were burdensome to complete. Although attrition was high, reasons for attrition were identified in most cases, and item level missing data was low. Only one participant withdrew due to distress, which was unrelated to the research. An observational cohort study with a large sample using these outcome measures could contribute to theoretical development and cost-consequence mapping.

However, there were challenges to this approach. In particular, extensive variability was present in time from assessment to first appointment and between appointments. Participants might miss weeks for a variety of reasons, not just for poor health and treatment regimes, but also relating to transport issues, very bad weather, and things happening in their own lives. It may be beneficial to collect more information on the actual amount of hospice services received and to allow outcome measures to be completed at home. Qualitatively, it would be interesting to explore further how the ‘dose’ received within social interventions may be (at least partially) moderated by participants ability and willingness to engage.

Note that recruitment was difficult to predict in this context and obtaining a large sample size over three timepoints would require substantial time and resource commitment. Due to sparse available literature in this area, ethical approval was initially obtained for 100 participants for a feasibility study that could inform power calculations for subsequent studies. Actual number was 30. A mediation analysis on a medium effect size would be reasonably powered if participant numbers reached at least 152.

Personnel changes adds unpredictability to the study: these organisations rely heavily on volunteers, which may mean a small number of staff roles, and a large impact from one or two being off work for any reason. One site decided not to recruit for this study due to personnel changes, but site 4 also reported that follow-up data collection had been affected by recent retirements.

Some participants are 'research-savvy', in that they have previously participated in research or know about research – others less so. Research-savvy (and hospice-savvy?) participants need less decision-making time during the process of recruitment and consent. Research-naïve participants may be more likely to be fatigued/burdened by being approached. How easy or difficult it is for the participant to decide to take part may also depend on their emotional state (especially for people who have never been in a hospice before) and physical state (some people are completely exhausted from getting to and having their assessment). Staff members may be reluctant to bring up a completely different and additional category of decision with some participants, leading to the possibility of selection bias.

Future work towards economic evaluation should collect information on the receipt of formal health and social care services and the costs of informal caregiving. Neighbourhood-level measures are less useful in indicating individual socioeconomic status in rural areas than in urban areas, which is a limitation of using postcodes as indicators of deprivation (Xie, Hubbard & Himes, 2020). An alternative individual-level measure of socioeconomic status could be a housing-based index (HOUSES), which has been shown to predict risk of falls, hospitalisation, and mortality in older patients (Ryu et al 2017; Barwise et al, 2020). This would increase participant burden and not be appropriate to every study, but a more detailed understanding of socioeconomic status in palliative care is necessary to other research questions, particular those exploring resource allocation.

6.5.3 Concluding comments

This chapter reports on the use of patient reported outcome measures to observe change over time for patients attending hospice day services. It has briefly discussed the challenges as well as the opportunities presented by this method.

The next chapter presents a realist analysis using of qualitative data, collected from purposefully sampled service-providers and hospice day services. A much larger longitudinal dataset would have allowed a similar analytical approach to be taken with the quantitative data: using patient reported outcome measures to explore differences between sites, drawing on concurrent qualitative investigation to develop theories of effectiveness, and using longitudinal mediation analysis to explore how variables interact over time.

Chapter 7 : Qualitative Findings

7.1 Introduction

The people involved in delivering and designing social support interventions in palliative care carry an understanding of why it is that they do what they do. In realist evaluation, these explicit and implicit understandings contain clues about the mechanisms within the hospice, and how these might interact with patient context, leading to outcomes. As described in the methods chapter, analysis using these principles allows for the proposal of context-mechanism-outcome configurations that represent tentative explanations of why these interventions might be effective for some patients.

This chapter presents findings from a realist analysis of qualitative data, collected from interviews with hospice service-providers and drawing on observations of hospice day services. Nine hospices were included, across the length and breadth of England, purposefully sampled using insights from the online survey in chapter 5. In total, nineteen interviews were held with hospice staff who provided services facilitating social support for patients with life-limiting illness, or who managed hospice services which included social support, reflecting a large range of staff roles. Table 28 presents details of interview participants, with pseudonyms.

Participants were told they could end the interview or chose to withdraw from the study and had opportunity to ask questions before giving written consent. Interviews took place in the hospice itself, usually in a private office, and often following a tour of the building. Observations of hospice day services by the researcher allowed for an embodied experience of the setting, which facilitated these conversations and led to rich descriptive fieldnotes.

Transcripts of interviews were initially analysed for themes relating to the patient context, mechanisms, outcomes, and salient points of the intervention context. This chapter has sections devoted to each of these areas. By exploring the detail fully, the chapter reveals potential targets for attention in practice and demonstrates the necessity of a context-aware approach to research. The risks and benefits of social support interventions are hinged upon chains of interpersonal interactions and psychological processes, that are not always simple to summarise without losing nuance. This chapter takes time to interrogate the detail of this research topic, in an effort to embrace its complexity. Figure 28 is an overview of this analysis.

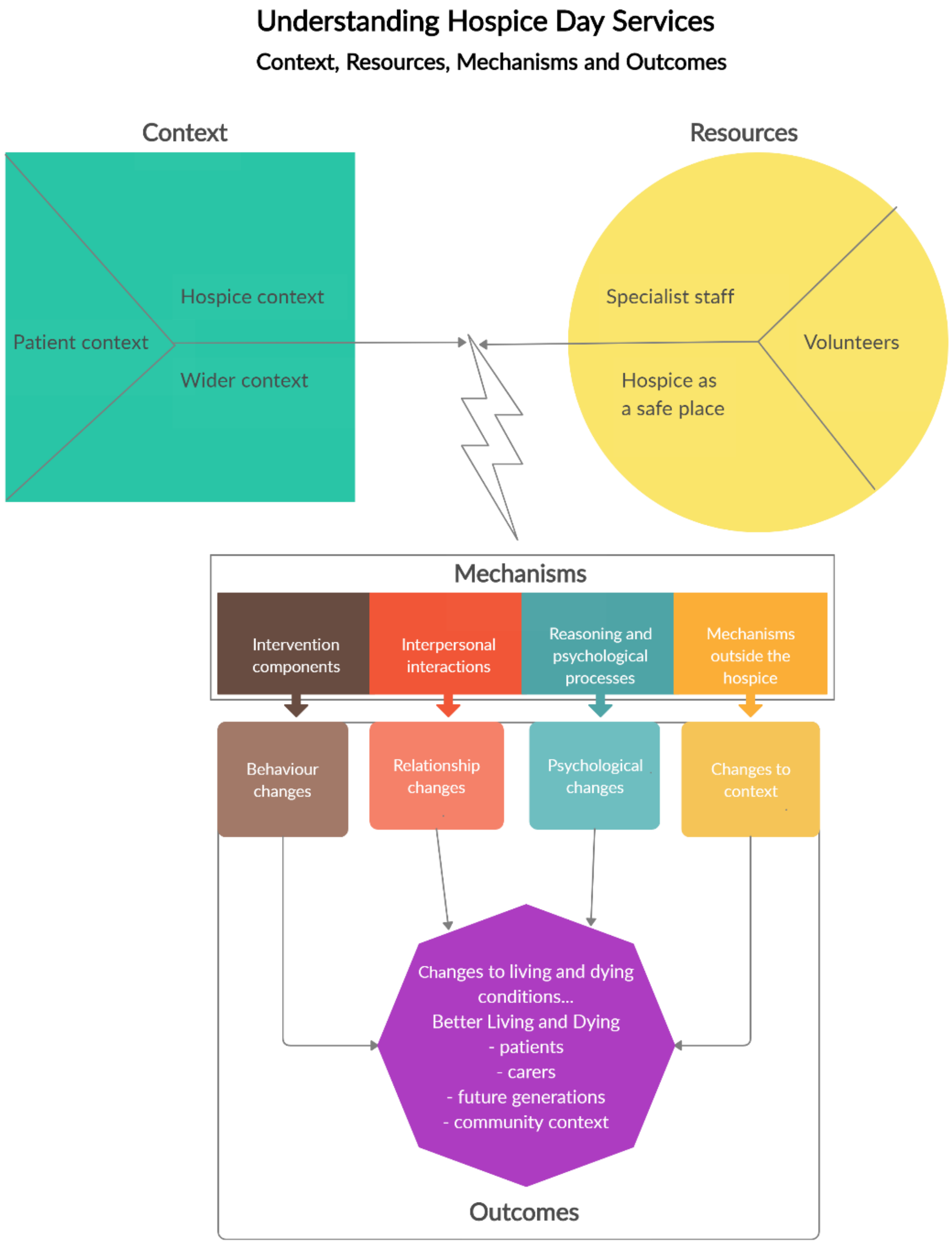


Figure 23: Overview diagram: understanding hospice day services as an interaction of context and resources, leading to mechanisms, then outcomes.

Table 28: Interview participants

Psuedonym	Job title	Time in role or similar	Hospice region	Hospice deprivation decile	Urban or rural location	Gender	Ethnicity
Alice	Support worker	2 years	South Coast	5	Urban city and town	F	WB
Amy	Staff nurse	2 years (20 total)	North-West	7	Rural hamlets	F	WB
Bea	Living well lead	14 years	North-West	5	Urban city and town	F	WB
Carole	Day services leader	4 years	South-West	9	Rural village	F	WB
Danielle	Director of knowledge exchange	8 years	North-West	8	Urban city and town	F	WB
Gemma	Clinical nurse manager	8 years	South Coast	5	Urban city and town	F	WB
Grace	Wellbeing lead	10 years	South-East	5	Urban major conurbation	F	WB
Jill	Creative arts coordinator	15 years	South-West	9	Rural village	F	WB
Jenny	Day therapy manager	9 years	South-East	6	Rural hamlets	F	WB
Katie	Day centre manager	4 years	North-West	4	Urban major conurbation	F	WB
Laura	Sister	19 years	North-West	5	Urban city and town	F	WB
Lisa	Centre manager	10 years	North-West	7	Rural hamlets	F	WB
Lucy	Social care assessor	2 years	North-West	5	Urban city and town	F	WB
Mark	Therapy assistant	6 years	South-East	5	Urban major conurbation	M	BB
Mary	Physiotherapist	10 years	South-East	5	Urban major conurbation	F	BB
Patricia	Day hospice manager	6 years	South-West	10	Rural town and fringe	F	WB
Rachel	Head of rehabilitation & wellbeing	8 years	South-East	5	Urban major conurbation	F	WB
Sarah	Art therapist	2 years (20 total)	South Coast	5	Urban city and town	F	WB
Shauna	Healthcare assistant	18 years	North-West	5	Urban city and town	F	WB

7.2 Patient Context

A thorough exploration of context is presented to begin this examination of hospice day services. The section starts with personal and interpersonal features of the patient context, including a note on the context of carers, before moving on to consider the context of services, and the wider societal context. Figure 29 shows relevant contextual features identified in the personal, interpersonal, and wider patient context.

The patient's context is shaped by the experience of living with illness. Their health context may include disruptive symptoms such as pain, fatigue, and breathlessness, and their lives might also be limited by complex care needs and effects of treatment. Long-term conditions and comorbidities are often, (but not always) associated with old age, which might act to exaggerate the social restriction of illness and increase potential for isolation. Those of a younger age group can have additional emotional challenges to overcome and be vulnerable to loneliness. Emotional wellbeing might be further impacted by experiences of hospitalisation and the healthcare system, including receiving a palliative diagnosis and navigating care arrangements.

Patients also vary in their awareness and acceptance of illness, and of hospices, which could determine their willingness to attend. Patient personality, coping style, and the experience of depression are relevant, as are aspects of the interpersonal and wider context which contribute to potentially isolating and alienating patient experiences. Overall, patients may find themselves in a context of loss as they lose previous routines and opportunities to contribute, and experience restrictions across multiple domains of life. This vicious cycle can become increasingly embedded over time.

> *Amy: "It's all about the losses, the losses of independence, it's the loss of their job, it can be the loss of their relationships. Because nothing's the same as it was before, it's all completely different."*

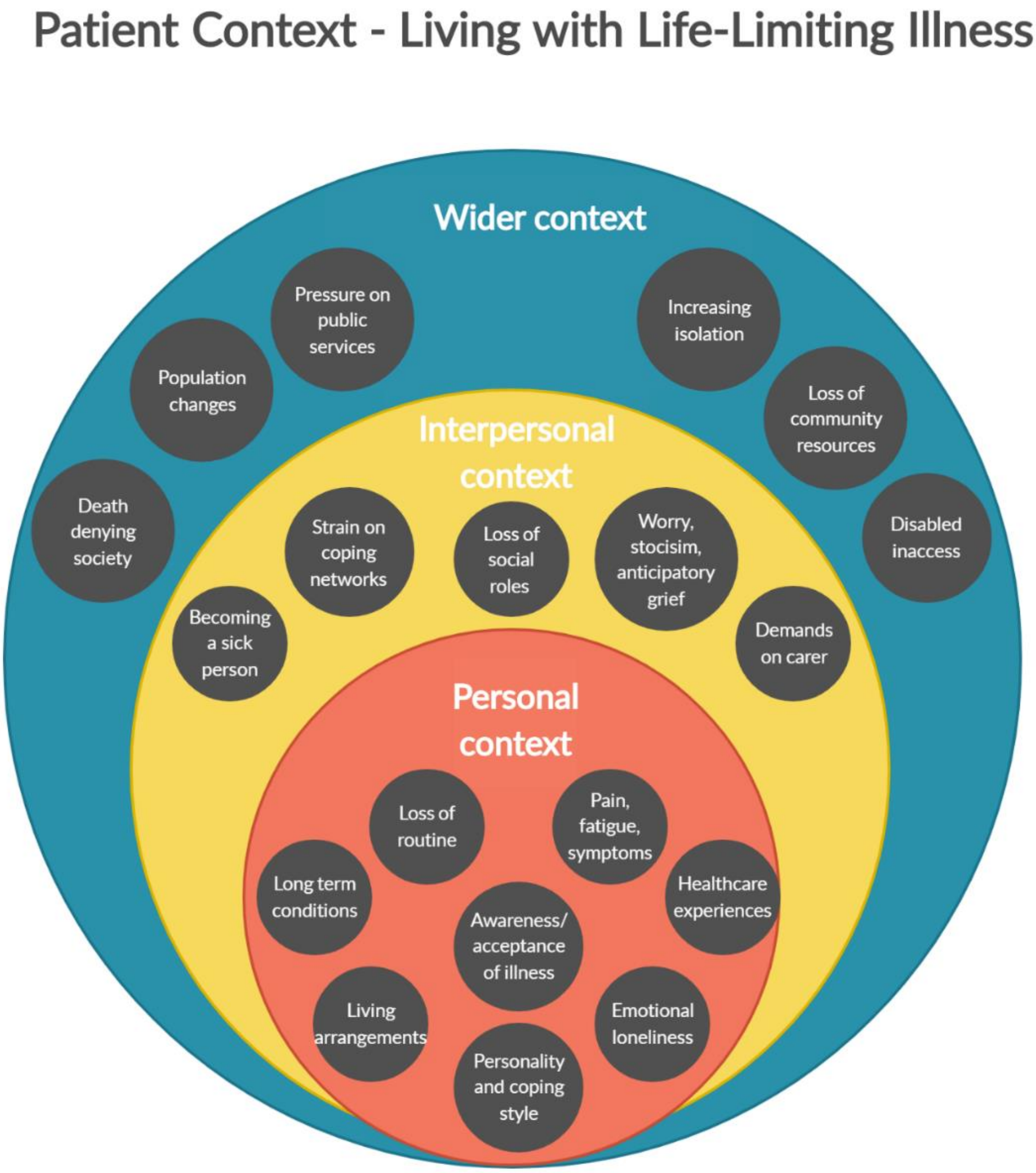


Figure 24: Patient context: summary of interacting personal, interpersonal, and wider factors that might shape the social context of someone living with life-limiting illness.

7.2.1 Health context

7.2.1.1 Illness symptoms

Physical pain, fatigue, and other symptoms can change the social experience of people living with life-limiting illness. Pain and fatigue can particularly impact on a patient's ability to maintain social connections over time, in that they can make it virtually impossible for the patient to pop out to call on friends and contracts the time that might be available for social visitors. Thus the 'work' required to see friends whilst fatigued is substantial. Fluctuations in fatigue add to the challenge – patients struggle to plan activities with other people, knowing they may have to cancel anyway. The making and executing of social plans, key for many friendship groups, becomes an activity that the patient cannot participate in. This can cause friendship groups to break up or no longer include the patient. In this way, service-providers described a path from fatigue to isolation that might be sped up by declines in mobility or loss of driving.

An empathic awareness of symptoms is important for service-providers in supporting patients because these symptoms can reduce patient ability to interact socially, but not their need for some social interaction. Jill, a creative arts co-ordinator in a rural hospice, explains how illness symptoms might change someone's ability to interact with their friendship group.

> *Jill: "Sometimes it's that people get so fatigued when they're ill - you almost have to gatekeep anyway because come the middle of the day you've had it, you're wiped out. If your friends are still working and they say we'll come over in the evening, it's too late. There are all sorts of reasons why you don't see people the way you once did. I think people don't realise how much, not work they put into it, but how much they took advantage of just getting in the car and popping in and seeing someone, and now that's not the case."*

Breathlessness is a symptom of several conditions and an experience that goes beyond shortness of breath – the mental and physical realities of experiencing breathlessness can contribute to a withdrawal from social life. Breathlessness can restrict a person's ability to engage in conversation or enjoy a social meal, and patients can become increasingly anxious of symptoms becoming aggravated whilst out and about. As well as directly limiting participation in social activities, breathlessness and its associated anxiety can deter a patient from personal care tasks such as attending the hairdresser, which may lead to a further loss in confidence to engage socially.

Patients can struggle with any changes to their body and feel conscious of ways in which they might look, smell or function in a different way to how they did before. Weight change is common and can be drastic, and some patients feel disfigured after having surgical treatment - the change presents challenges for body image and self-confidence. A visible sign that the body is functioning in a different way to 'normal' is a constant reminder to the person and people around them that this person is 'sick'. Visible symptoms of illness may also elicit feelings of shame, especially if their understanding of the illness includes self-blame. Illness attributions and body image issues can cause a patient to withdraw from their friends, possibly leading to a downward spiral of low mood and loneliness. Lisa, a centre manager for a rural North-West hospice, gives an example:

> *Lisa: "People have issues around their body image, maybe how the illness has made them look different to how they looked, so they isolate themselves. I have a lady at the minute who body image is a big issue for her. She's withdrawn herself from all of her friends because she's embarrassed about how she looks, and it's a little bit because she feels she's inflicted it on herself by her lifestyle choices, she's embarrassed, so she's withdrawn from her friends. And because she hasn't got that contact with her friends, she feels depressed, it's a massive vicious cycle."*

Fungating wounds and socially unacceptable symptoms are especially difficult to manage or cope with socially. They can contribute to the patient withdrawing from social opportunities, or indeed to members of the social network pulling away. Other individual factors, such as the personality of the people involved, are relevant for whether a patient is able to maintain social contact despite the extensive challenges in their health context.

7.2.1.2 Old age and long-term conditions

The patient's body is not a blank slate in which a life-limiting illness arises. Comorbidity is common. People living with multiple long-term conditions find it increasingly difficult to get out and about while experiencing mobility issues and declining function. This is often associated with old age because morbidity and mortality are more commonplace as we get older. This assumption could have implications for younger patients, because frailty and comorbidity are seen across different age groups, and younger patients with frailty might have different needs and expectations of hospice services. Nonetheless, a person needing practical help to leave the house can still leave the house *if* they have someone available and well enough to assist – older patients are less likely to have adequate practical help available in their close network, for example a partner healthy enough to drive. This can mean that the oldest patients are less able to access services, are more likely to live in isolation, and might become increasingly housebound when not driving. Bea, a wellbeing service lead in an urban North-West hospice, describes how some patients respond to their personal health context of some patients by preferring the reassurance of home:

> *Bea: "Younger people probably do have more friendship support, they've probably got a younger partner, husband, wife, so they can drive and get them out more. I would say that it's more older people - if you're on your own, you can't drive, you don't live on a bus route, you're mobility's poor so you can't get out to the shops, or onto public transport. Your eyesight might be poor, if you're feeling really tired, if you have urgency and need the loo. All those things impact on somebody going out, and they feel a lot safer to stay in, so they'll probably stay in.*
>
> *It's the comorbidities and the implications of those comorbidities that prevent people from going out."*

Some patients are experienced in managing their condition, having lived with it for many years and developing their own approach to health service utilisation (for better or for worse). Self-management practices are shaped within the social network and by historical healthcare experiences. Long-term conditions can be associated with engrained behaviours that can be difficult to unpick without understanding what it means to them in a patient-centred manner. Gemma, a clinical nurse manager on the South coast, gives an example of this interacting with health service use:

> *Gemma: "Someone that's had like COPD like complaints of the chest for a long period of time before they get to us, often people have lived with these conditions 10/20/30 years before they come to us so they feel very safe to go into ED because the ED team know them, the medical warms know them."*

7.2.1.3 Healthcare experiences

Palliative care patients have had challenging healthcare experiences including the traumatic event of receiving a life-changing diagnosis. Interview participants frequently reported how difficult it was for patients to comprehend and face their diagnosis and prognosis at that time, perhaps experiencing ongoing emotional turmoil and fear. Being told that you have an incurable illness, progressing to a palliative stage, is expected to be a negative event - but patients do differ in their responses. Jenny, a day therapy manager and occupational therapist at a rural hospice in the South-East, suggests that distress can arise from anticipating changes in the self – it is difficult to process the knowledge that the (physical) self has changed, is changing, and will continue to change. This a motivating force for people to speak to others who are going through or have gone through similar experiences:

> *Jenny: "The people who are struggling more with their diagnosis, struggling more with the changes in their physical self, their emotional self, they need to talk to people who understand what they're going through."*

For some patients, the diagnosis is unbearable, and it doesn't feel possible that they could live well with their illness. They experience hopelessness and a loss of purpose leading to a sense of isolation from the people around them. In addition, patients occasionally feel a sense of abandonment following the end of curative treatment, when they are left to manage for themselves. Service-providers often gave examples in which patients who were experiencing a near complete crisis in hope were still motivated to seek emotional support. Katie is a day centre manager in an urban North-West hospice; she reports that inadequate support received post-diagnosis contributes to patient distress and might be more common in non-cancer conditions:

> *Katie: "A lot of people have lost hope. One guy, he's one that's recently come in, and at the point when I interviewed him, he was wanting to, he just thought life's not worth living. He'd got his diagnosis, and he didn't know how he was going to manage with it, he just thought it was very bleak. And then he came in, we had a long chat, and it was very emotional, and I got him to come to the centre.*
>
> *Often what feels missing, what I hear from the respiratory and heart failure patients, is that once they've got their diagnosis they feel they've been abandoned a bit."*

Alongside coming to terms with their diagnosis, patients might have to manage multiple ongoing appointments in the health and social care system. This is stressful and takes up time and energy that might otherwise go to more rewarding activity. Many of these experiences are affected by the interpersonal context and the wider context which shapes access to and availability of resources, which will be explained in the next section. Time spent in doctors' offices and hospitals influences the patient's emotional state, self-esteem, and expectations of other services - interview participants described patients losing confidence and/or functional ability following hospitalisation. Service providers contrasted the unwelcoming environment of the hospital to that of the hospice - hospitals operate busy clinics, but patients are not usually encouraged to connect with people in the waiting room. Amy is a staff nurse for a day service in a rural North-West hospice, she considers hospital experiences to contribute to feelings of isolation across disease groups:

> *Amy: "Patients feel that they've very much alone dealing with whatever they're dealing with, whichever disease. They go to appointments at hospitals but that doesn't allow you the opportunity to speak to the person who's sitting next to you or opposite you."*

Healthcare experiences do not have to be negative to have consequences that present a psychological challenge to the patient. For example, diagnosis-specific support groups are useful, but when received alongside an array of other appointments orientated towards the diagnosis, the person can feel solely defined by their diagnosis and other things that matter to them feel lost. Patricia, a day hospice manager in a rural South-East hospice, in her rationale of service structure explains how grouping many different diagnoses together allows for people to connect beyond their clinical label.

> *Patricia: "Disease-specific groups have their place and their benefit, but sometimes it can feel… Say you have breast cancer so you're seen at the breast clinic, and you're seen at your consultant appointments with the person that does breast cancer, and then you go to your breast cancer group, then you go to your breast cancer and secondary's group. So, wow, the whole world is just breast cancer now, and it can feel quite big - it's not that there's not a role for that, but it's that coming somewhere like here, where there is a mixed demographic of neurological, heart failure, cancer patients, different kind of cancers, that it doesn't really matter what your diagnosis is. It's that things are hard, and you are people before you are a diagnosis."*

7.2.2 Emotional context

7.2.2.1 Loss of normal life

The health context shows patients can be experiencing a progressive loss of function and have their ability to participate in social activities to be changed due to their illness. Service-providers made many references to how normal life is disrupted by this loss of routine and activity. Patients may have to stop work, withdraw from social commitments, and cannot contribute as much for others as they did before illness. No longer being able to drive was a milestone mentioned in almost all interviews. When patients lose the ability to drive, it is not just their car that they lose – in rural contexts particularly it can represent a complete loss of independence if there are no alternatives available. Gemma, clinical nurse manager for a South Coast hospice, describes the salience of losing opportunities to contribute to the household:

> *Gemma: "Some of them feel a total burden, some of them get quite agitated and frustrated that they can't do - 'I can't do the gardening anymore, I can't put that lightbulb on, I'll have to ask my wife to do it.' - There's a lot of frustration with just sitting at home, a lot of reminding of the losses that they have to go through… There's a lot of losses there, and it's like well how are we going to fill that time. I'm no longer able to go out to work, I'm no longer able to drive the car and go get the food shopping in, I'm no longer able to do the gardening or put the stuff up the loft to help my wife. So, knowing that there are losses, that is important."*

Our expectations of a normal life are informed by our age and life stage. In general, younger patients could have a harder time accepting their illness - they experience a sense of loss for what they are missing now, and for 'the normal life' they hoped to have in the future. The emotional challenges of life-limiting illness might be heightened in age groups where illness is less common, these people are grieving the loss of an expected future and might find their social network not able to respond. Jenny, day therapy manager, describes how age and illness expectations can relate to emotional isolation:

> *Jenny: "It sounds awful, but when you get to 90, 95, you know, the chances are your contemporaries are probably also quite disabled by then or you've already lost quite a lot of people that are your age. Maybe there's kind of an acceptance, like it's normal at this age to have some level of restriction. Maybe if you're 50 or 60 and your friends and of age contemporaries are still out and about and working, and doing loads, maybe that's a hard thing to accept. I don't know if they feel they've lost the most."*

7.2.2.2 Personality and coping style

Illness experiences and health-related disruption to normal life place an emotional strain on the patient. Their ability to adapt to change and cope with stress is influenced by personality and coping style. These factors of the patient context might also shape their interactions with formal healthcare and approach to hospice services. Interview participants differed in the extent to which they considered their services 'cater for all', but there were regular inferences towards personality differences that could shape patient experience of hospice services and their preferences towards care at the end of life. For example, Bea indicates that expectations of personal control and desire for choice can vary between people:

> *Bea: "Some people, it's not the fact that they've got cancer or a life-limiting condition, it's the fact that they're losing their identity and their control… Some people they chose, even right up until the point of death, that it's for somebody else to sort out. They don't want control over that."*

Personality and coping style might influence which patients access hospice services and have relevance for the person's motivation to engage in groupwork or relationships in the hospice. Palliative care patients who are extroverted or friendly by nature might be greatly affected by social changes accompanying illness; they might be more likely to perceive themselves as having unmet social need which motivates them to attend the service, and once present they might contribute to a more sociable atmosphere . Inquisitiveness, open-mindedness, and curiosity might also make someone more likely to access some hospice services, particularly those providing complementary and alternative medicine.

7.2.2.3 Depression and unprocessed trauma

Depression is common in the context of life-limiting illness, but that is not to say that the experience of depression is homogenous across patients. Interview participants different ways of identifying depression in their practice – sometimes using clinical outcome measures or anti-depressant prescription as indicators, others referring to poor eye contact and social withdrawal behaviours. Jenny, day therapy manager, distinguishes between depression that is measured and depression that is sensed, noting these are not always aligned:

> *Jenny: "We use the hospital anxiety depression scale to measure it usually. I would guess probably 50% at least have depression. Now whether all of those then want to then have medication, or whether some of it is managed just by talking through problems, we do a bit of a mix really. It could be that depression has been something they've been living with for 30 plus years, and it's kind of worsened from their loneliness, worsened from their illness, whatever it might be. Some people maybe won't score highly on the scale, but you can sense there's a hell of a lot of depression. And you know, for them it's kind of normal like, as if you wouldn't be a bit depressed that you've got this life limiting condition."*

Vulnerability to depression during life-limiting illness is determined by life history as well as current context. Pre-existing depression is widespread, and varies according to demographic factors, with some professions appearing to be at increased risk. The patient may have recent and historical life events that substantially shape the emotional context and availability of social resources – they might, for instance, be dealing with a loss of normality following divorce before they receive their diagnosis. Furthermore, neurochemical changes associated with illness and treatment also have impact on mood. There are many contributing factors that may lead to depression and low patient mood, and exploring these can be an essential enabler of person-centred care, as Patricia explains:

> *Patricia: "You have people with long term depression that pre-exists. You have people with work demographics - we now have a whole folder on what support is out there for people who have been in military*

> *service, because actually they come, with or without the diagnosis, they have very specific psychological needs through what they've seen and done. We have people that really struggle with the change in physical ability, those losses of what they can do. You will see that for some earlier on in their diagnosis, for some later on, as the reality of where they really are, they're a matter of weeks from the end and that sadness can become overwhelming. So much of it is losses, the neurological conditions are like being repeatedly burgled. But there are also cognitive changes within diseases that mean you can get apathy and low mood on a biological level, and you're trying to unpick all these things."*

In addition to what they are dealing with in the present day context, some patients are revisited by psychological battles from the past. Unprocessed trauma seems to come to the foreground, possibly because they are approaching the end of their life, or through fearful responses to their immediate situation. This fear can drive inappropriate use of health services and may require therapeutic or emotional support to resolve. In other cases, depression is associated with reduced motivation to seek help, which reinforces loneliness by further impairing the patient's ability to seek out their supportive contacts. This interaction between declining health, loneliness, and low mood leaves patients vulnerable to a vicious cycle, that might be perpetuated by physical features of their environment that restrict mobility and therefore social participation. Katie, day centre manager and occupational therapist at an urban hospice in the North-West, describes practical limitations and emotional challenges that lead to a potentially vicious downward cycle in which depression reinforces social isolation:

> *Katie: "People are hindered because of the environment, where they are and things like that, so there are physical and practical elements of it that contribute to someone being isolated. But then you've got that catch 22 that if they are lonely and their mood drops, they isolate themselves unintentionally. We often hear that described from some of the people that come here - it's easier for them to sit on the couch and not do anything, and that then feeds it."*

7.2.3 Interpersonal context

The previous section suggests how the health and emotional context of patients might reduce opportunities for social support. This has so far focused on the personal – but as we experience change in ourselves, our relationships are also changing. Service-providers described how the patient's interpersonal context can determine the variety and adequacy of social support available and suggested how emotional loneliness might become exacerbated by characteristics of the interpersonal context.

The interpersonal context represents interaction between the multiple personal contexts of each person involved, taking place within a wider context of society and systems (death avoidance and austerity will be highlighted). This section begins with observable features of the patient's interpersonal context and their implications for coping resources, specifically living arrangements, availability of family and friends, and the relevance of other social networks such as organised religion. Palliative care patients can sometimes experience a gradual loss of social roles and the imposition of 'sick person' restrictions over the course of their illness, which might challenge their confidence to be active in behaviour or decision-making. A significant person in the patient's life might also be experiencing a significant shift in roles – this section ends with considering the carer's context and how these might interact with that of the patient.

7.2.3.1 Facing the end of life with no one in your life

Living arrangements form a substantial part of the patient's context and become even more relevant when the patient is less able to leave their home. Service-providers noted many challenges involved in living alone with life-limiting illness, often related to how patient rumination and anxiety are made much worse by excessive time in solitude. People who had been content and unphased by living alone can find that they need more emotional support than they have available to help them process the diagnosis and make decisions about care. Lucy is a social care assessor at an urban North-West hospice. She has met many people facing the end of their life without any supportive relationships:

> *Lucy: "I should imagine its lonely. I've come across patients who've really not got anybody. I had one patient and she'd got nobody, no family, no friends, no nothing at all and she'd been told she'd got 2 weeks to live. I could imagine she was a bit of a loner, but in the time of need, when she did feel poorly, she did cry with me one day. You could never imagine her shedding a tear because she was such a strong person. I could imagine she felt very fearful because she was on her own. Suppose you're really poorly and you've just been given 2 weeks, which she was given, you've nobody to share that information with, nobody to ask shall I go through this or what do I do or can you take care of whatever. She'd got nobody."*

Lucy's example highlights the difficulties of 'putting one's affairs in order' when facing the end of life in solitude - but living alone can increase distress at any stage of illness. When patients are vigilant to new or fluctuating symptoms, they might rely on the evaluations of trusted others to interpret the urgency or severity of a change in health, particularly if they don't feel confident in managing their condition. Help-seeking behaviour that is motivated by health anxiety is more common for patients who cannot easily gain reassurance in their home environment. Service-providers often explained that patients might be more likely to worry and panic when they are on their own, with night-time being especially threatening because help is less available. Pain might also be worse for people with no one to distract them from it. Some patients have abundant friends and family who they might call on – for others, the only trusted person that is available is the emergency services. Patricia draws on her nursing experience to suggest how social isolation can interact with health service utilisation – directly, when individuals arrive at A&E fearful about non-emergency symptoms, and indirectly, when individuals become more likely to engage in self-destructive coping behaviours.

> *Patricia: "Having had experience as an A&E nurse, I know people were just turning up because they're frightened. They do not have emergency symptoms; they do not need to be dealt with at 2 o'clock in the morning, but at 2 o'clock in the morning you're absolutely terrified and they haven't got someone to ring… You will see it in poor health behaviours: people will drink more, people will self-medicate with things, so then they're*

> *more likely to have falls, they will self-harm, they will do all those myriad of things people do if they're socially isolated and there's nobody to talk to. It is worse in those wee small hours. It feels like you might drop through the centre of the earth because nobody cares and you're frightened."*

Social isolation can prevent people from accessing appropriate services at the right time, by reducing motivation to engage or practical ability to participate. There may be unmet informational or tangible support needs – i.e. finding out about a helpful service, and being able to get there. Service-providers also explored the potential long-term effects of social isolation, including physical and cognitive decline. People with and without communication difficulties need to have regular interpersonal interaction to maintain their social and conversational skills – passively receiving 'care' as a task is not enough. The context of care can thus be isolating, even if people aren't objectively isolated at home. Grace is wellbeing lead for a South-East urban hospice and describes how some patients can experience a profound loneliness accompanied by decline in communication skills:

> *Grace: "He obviously was very isolated because he didn't have anywhere to go out, and they just kept him, they looked after him beautifully but he didn't go out in those three months, and he came back having lost the ability, he didn't communicate. Stopped the yes and nos."*

7.2.3.2 Lonely with people around

There are substantial challenges in living alone with life-limiting illness but there is potential for loneliness when living with close and supportive families that could easily be overlooked. Patients might feel they are unable to talk to their families about how they're thinking, leaving them emotionally alone in the decisions they are facing even if surrounded by people. It may be a new experience to be living alongside illness and symptoms that can't be fixed or easily managed. The changing and declining health context of patients will impact on family members, who might not be able to face up to the illness and no longer relate well to the patient. Mark, therapy assistant in an urban South-East hospice, sees this as a potentially isolating experience:

> *Mark: "I think people's families can, probably not deliberately, but they can be isolating, because they're not necessarily understanding of the patient's conditions. And so that maybe could be an isolation factor there."*

Over time, through increasing support needs, misunderstood experiences, and a lack of opportunities to contribute, people with illness can come to feel burdensome to the family. Patients might become tangibly dependent on several family members, requiring practical help with more daily tasks, or aware that such changes are likely in the future. Within contexts of financial stress, people may be even more likely to feel that any emotional disclosures would be a further burden to place on the shoulders of a loved one. This reluctance to disclose how one feels is grounded in concern for the other person – the patient does not wish to add to their worries by sharing fears and dark thoughts about illness and death. Lucy, social care assessor, explains this as an interpersonal context in which the family is not given chance to provide support:

> *Lucy: "They don't want to bother their families, because they are already doing enough for them, that might be taking them to appointments and so on. There's lots of pressures really isn't there, if you're quite dependent on somebody, there's a lot of pressures to put on people – taking time off work, losing money and so on and so on. I think for ill people as well, not only are you going through your diagnosis and what have you, there's the other things that keep going on in life that don't hold back for you, do you know what I mean? Like bills, mortgages, and so on…*
>
> *Sometimes for families, especially if they're living a distance away and they're only making contact by telephone - how are you doing? Yes I'm fine - because you don't want the family to worry, I suppose you're providing false information really. Because at the other end of the phone they think oh they're managing okay, put the phone down and get on. So it's how much people want to actually put onto their families, or not put on…I can only imagine that it must be lonely because sometimes you're trying to put a brave face on in front of your loved ones."*

A life-changing illness affects the entire family, but patients can feel isolated in their illness because they want to protect their relatives from their pain and worries about the future. Service-providers described family dynamics characterised by stoicism and protection, in which patients were reluctant to 'put pressure' on their loved ones to talk about dying. There are instances in which the family themselves might deny the patient the opportunity to talk. These are emotinal topics, but as patients continue to struggle with the challenges in their emotional context, they might feel increasingly distressed and potentially angry within the family dynamic because they lack the opportunities to express how they really feel. A family's discomfort in talking about death, and unwillingness to acknowledge the potential loss of a love one, can corresponds to a scarcity of emotional support for the person with illness. Bea explains how a family's desire to make things better can have an inadvertent silencing effect:

> *Bea: "Family, they want to make everything better, and not everything can be made better, so they tend to say don't worry about that, it's going to be alright. But actually, if a patient is frightened of dying and they mention the word dying, then the immediate reaction from families is going to be oh don't talk like that, you know, you're not going to die, everything's going to be fine. But they definitely can't make that happen.*
>
> *So people just want to talk about, what is it going to be like if I die, or where can I go to die, and you're just seeking information really. And we get asked that question an awful lot, I can't talk to my family because I'll upset them, or my family don't want to talk about it, they think I'm morbid, and actually it's really important to the patient."*

The home environment for those living with other people can be conducive to their motivation for the patient to engage with hospice and other health services. The desire to give their spouse or carer a break was a common first push reported by patients during observations and service-providers during interviews. Patients might perceive their family members to see them more as a task to do than a person to spend time with, with genuinely sociable time feeling a thing of the past given the workload of managing illness. In this quote Patricia describes a sense of meaninglessness arising from receiving care and lacking relaxed companionship:

> *Patricia: A lot of what we see is people who have lost meaning in their life. They haven't just been a sick person, they've done a myriad of wonderful interesting things, and suddenly they're being cared for and they're being done for and they are a selection of other people's tasks and that's not very meaningful. It's often a spouse or a child, that you're very aware that you're adding to their life burden. But there aren't just those people that kind of go no I just want to hang out with you, I just like your company."*

7.2.3.3 Friendship awkwardness & avoidance

Physical changes and illness symptoms can cause the patient to retreat from social situations. Some patients feel unrecognisable after weight loss or treatment, and dodge friends that remind them of their changes. For some patients, social activity might represent the risk of unwanted input, and a driver towards isolation can be the reactions of friends and family members to the diagnosis and changes associated with the illness. Platitudes, motivational clichés, and constant sympathies appear to push some people away from their friendship groups, as Amy, staff nurse, describes:

> *Amy: "As people become more ill, they don't want to go down the pub because they don't like people asking how are you and all that and them having to explain themselves over and over again. It becomes very much of a chore, so they start to avoid those things that they've always done, like going to the pub or having a game of snooker, whatever it might be, so they become more and more insular.*
>
> *They stay at home to avoid those situations and that's where I think the social isolation comes in, because they're literally avoiding people, they've withdrawn… People are irritated by the platitudes as well, the oh come on you've got to think positive, you've got to fight the big fight and you've just got to keep your chin up. You know what I mean, all that, they're just like no."*

Interview participants also emphasised that the social aspects of their service, i.e. being around other people in similar circumstances, was important to patients because so many of their friends had been unable to relate to them since the illness. It seems common for existing friendships to become strained or for friends to withdraw due to their own awkwardness and avoidance. The person has been changed by their illness and by their new label as patient, and this label might be an uncomfortable mortality reminder to others.

Illness perceptions and social embarrassment can contribute to alienation in close friendships - patients can be surprised that close friends move away, but also that acquaintances move closer. Essentially, people who are uncomfortable with their own mortality might feel unwilling to be in the presence of someone that reminds them of dying. Gemma suggests that friends might be withdrawing from incurable illness because they do not know what to say when confronted with death:

> *Gemma: "It might be that they don't what to say, they don't know how to be around that person, they suddenly see them as being quite different. They might have their own, it's really, it makes you reflect on your own mortality. So it might be you don't want to be around ill people because, because I'm living kind of thing."*

Certain characteristics of patient contexts seem to be relevant for understanding how their social network could be impacted by illness. Objective isolation may be more common in older age groups, but younger age groups are still at risk of loneliness, particularly if friendship groups have little experience in responding to illness.

Religion also appeared relevant - formal religious group membership was perceived to be more resilient than other social activities for patients experiencing challenges associated with illness. Jill, creative arts coordinator in a South-West rural hospice, explains that people can still connect on a spiritual level, even when other activities are no longer available:

> *Jill: "We find people perhaps who belong to a church, they sometimes get a bit more support because they've already got a church family and that's sometimes helpful, if it's that kind of group, when it's more about you as a person rather than about what you do, what games you play."*

Some service-providers also referred to how men seemed more comfortable with 'doing', and less comfortable with 'talking', a consideration for them during service design. The influence of traditional gender roles on the availability of social support and the social experience when living with illness could vary between different regions, ages, and communities. Jenny manages hospice day therapy in a rural South-East hospice that offers a mixture of supervised exercise opportunities, gender-specific support groups and informal social activities:

> *Jenny: "Some people might have a really big friendship group but not necessarily people who understand their situation, so yes on paper they've got a big network but are there people that they can actually talk to about their condition? I think particularly men, that are maybe a bit older - they have friends that they do stuff with, so golf friends or friends to go to the pub with or friends to go watch the football with or whatever - but they're not friends that you would sit and chat to, they are friends that are associated with an activity.*
>
> *If you can't do that activity anymore, if you can't play golf anymore, you stop seeing your golf buddies. Because the thing you have in common is the golf. So I think that level of unmet need is possibly there more for the male group, certainly our experience is that, with our social groups, particularly the [coffee morning] group, the vast majority of people that come to that are men. And my perception of that is because they don't have a social network outside of here that they can call upon."*

7.2.3.4 Loss of social roles: Becoming a patient

This section has described how patients might stop doing their usual activities and could find their longstanding friendships or family dynamics to be altered due to changes associated with illness. Through this process, people can lose access to their previous social roles. For example, our chosen profession can be a prominent source of meaning and purpose in our lives. Having to stop work can be difficult for many patients in that it represents a threat to identity that might be quite catastrophic for their self-esteem – as described by Carole, who leads the day services in a South-West rural hospice:

> *Carole: "We had a young lady who was a headteacher and she was diagnosed with cancer. One week she was headteacher in a school, the next week she was unemployed, she was retired. And for her, whenever you used to go round the room, we always have an introduction at the beginning of the day, introduce new people or just kind of touch base, and she used to introduce herself as headteacher, it took her a long time to introduce herself as a herself.*
>
> *She'd never been anything else, she'd barely taken holiday, do you know what I mean? For her that was her life, and she found that really hard. I suppose this is one of the big challenges of getting sick is the roles that you used to have are not there anymore. You either haven't got the energy or you physically can't do it anymore. You are lost, you aren't that person that you always thought you were. It's really difficult without an identity you feel worthless, you feel useless, it's really challenging."*

Service-providers also observed changing roles in the family unit – there's potentially a flip of roles during illness, from caregiver to receiver, that might be challenging for all the people involved. Changing family roles are influenced by internalised expectations of gender - suggesting that feelings of being a burden within the family or reluctant to share emotionally could show some gender differences. Mark, therapy assistant, describes someone who was once a reliable source of advice and wisdom becoming a fragile person to be shielded from exertion, even against their preferences. In this way the change in role can become a loss of status and perceived respect from the family.

> *Mark: "People want to see their grandchildren, maybe their own children, but they're not putting the grandchildren round because they don't want to tire out grandad, that kind of thing. So then that's loneliness, and isolation because they're not seeing that family member. It can be because the role of that person in the family will change, so rather than becoming maybe the head of the family who everyone goes to for advice, you suddenly become the person who is a patient or less well, and maybe people don't confide in that person anymore, that role has now been lost or has changed."*

Life-limiting illness might force people to step back from their active social roles - their chosen occupation, social interests, and position in the family. Alongside losses in function, patients are becoming a sick person in the eyes of the people around them. Family members can inadvertently limit opportunities for the patient to participate in society and potentially accelerate cognitive, emotional, and physical declines by encouraging inactivity. For example, relatives are still experiencing the pressures of life, plus new stresses related to the diagnosis, and may not have the patience or opportunity to enable their relative to still get their own shopping in the context of declining mobility. Expectations of illness can be directly unhelpful when family members explicitly discourage the patient from participating in exercise or complex decision-making, as Mark goes on to explain:

> *Mark: "Sometimes with families they're being kind of protective, they will maybe wrap that person in cotton wool and it becomes negative to the patient because it's like 'I'm still here, and yet I'm being treated differently, I've still got a brain, yes I might be less well but I'm still here'…It sounds really bad what I'm about to say, but maybe their family or their network are treating them like babies, there's 'oh let me get that for you, let me get that you know', as opposed to empowering that person to get that independence back. They want to help, but it's like they're not helping."*

7.2.3.5 Becoming a caregiver

This section has described the interpersonal context, suggesting threats to social relationships that might operate in addition to restrictions in the health context. Emotional loneliness might be related to keeping a brace face, feeling wary to burden others. Being labelled as ‘a patient’ within a supportive family or network can change social status which may lead to experiences of disempowerment, which may be exaggerated through experiences of receiving care. But what about those who are giving the care? Although the patient is the focus, consideration of the carer is essential where one is present.

Both the patient and the carer are adapting to living with illness and the dynamic in this important relationship has a bearing on the patient’s wellbeing. When one person feels stressed or burdensome, this is felt by the other. The demands of caregiving will vary between individual circumstances, and might require extensive tangible, informational, and emotional resources. The salient psychological and emotional challenges experiences by the carer may be markedly different to the patient’s, with expectations of illness potentially contributing to both people feeling misunderstood and frustrated. Added strain at mealtimes and loss of intimacy due to the changing health context can be highly distressing. In some conditions, such as those with cognitive impairment, carers are constantly in a supervision role with no time out from the stress and worries of taking care of a loved someone, or time to process the losses experienced. The relationship is forever changed, and both parties can be vulnerable to isolation.

Service-providers explained that the changes in the relationship, the implications of the diagnosis, as well as the substantial pressures of caring itself, all contribute stress on the carer, which the person with illness can perceive and blame themselves for. Spouses who have been together for a long time can feel like failures if they are unable to cope with these demands, and there aren’t always opportunities to admit when they’re not coping during interactions with relevant healthcare professionals. Within this context, several service-providers referred to allowing space for both parties to share how they are feeling. This can be active interventions specifically tailored for caregivers – with educational groups suggested to be beneficial in addressing potential sources of tension in the relationship. Or it can be as simple as verbal permission to share feelings and reflect on the situation during assessment.

Gemma, clinical nurse manager of a hospice on the South Coast, was one of several service-providers emphasising the value of including the carer:

> *Gemma: We say this, and we always name it in consultations as well, you know. Because the wife's sitting there, kind of keeping it all together, and I say 'now, how are you?' and they get a big taken aback, because they think it's all about him. I'm doing the assessment on the husband, but ask how are you in all of this, how are you managing, and the whoosh the tears, you know, they're struggling and they're feeling guilty because they feel so cross. The wife's sort of screaming and getting really frustrated thinking gosh, because of disease and ill health, their relationship has become this, they're no longer a wife, there's no longer any intimacy, and people name that and they miss that. It's, it's really hard and I think people still want to care for their spouse in ill health but it's a huge part of what we do, supporting them, you know. And by having their hubbies here for the day they're refreshed, they can have some time to process things or reflect about things."*

It is not easy to gain peace of mind whilst navigating the health and social care system, and the responsibilities of illness management, with the looming prospect of further decline and difficult decisions in the future. As Patricia explains, the value of respite and her work in care coordination is partly derived from the trust patients and carers have in the support available at the hospice. The time in which the patient is safe somewhere else could be minimised as a day to tidy the house - but having a genuine opportunity to process the situation and decide what needs to be done might enable them to identify and avoid an upcoming crisis. The priority task might be chores to reduce risk of falls in the immediate living arrangements, reading information about available care choices options, or finding some much-needed emotional support. A few hours break might therefore increase or maintain capacity to provide care, especially important when aspects of the wider context are so stressful:

> *Patricia: "It's not just about those 5 hours that somebody's here. What our carers really get on respite is having somebody else to think for*

> *them, somebody else saying ‘I think you need to be thinking about this now, I think you’re negotiating that so shall I argue with those people for you?’ You’re giving them mental respite from a system that’s really difficult to understand if you’re a healthcare professional, let alone if you’re a very tired person looking after somebody who is sick…*
>
> *Yes, they get to do ‘luxury’ things like hoover the lounge and wash up and do the shopping, or they might get to sit down for 5 minutes and not feel so stressed out. The carers are not just needing straight respite, they’re not like ‘oh I just want a day off’, you’re getting the ability to sit down and think - about how to move forward and have that support…it’s like I cannot manage this situation on my own…it’s that kind of respite from the situation, from the constant onslaught.”*

The process of becoming a carer is just that – a process, not a single event. It can be tempting for healthcare professionals to define a couple as a patient-carer dyad, well before they would consider themselves as such. This is particularly relevant for hospices seeking to support patients earlier in their diagnosis – they might provide informal social groups, sometimes in multiple locations, that are not advertised ‘for carers’ although they are attended predominantly by people involved in providing care. Some patients might derive great confidence from having their relatives attend with them, and service-providers who had permitted family members to join had observed relationship benefits occurring through time spent together in a relaxed new space. Including and supporting the carer is important to the patient’s experience of hospice services, but not all carers identify as carers. Katie reflects on her experience of including family members in a new day centre at an urban North-West hospice:

> *Katie: If I’d had a crystal ball, I would’ve addressed the carers issues. If I’d recognised, if I’d known how important it was for the carer to come with the person - because they’re not necessarily classed as the carer at this stage, because they’re quite early, we’ve got people coming that are husbands, wives, partners erm or even sisters. We had a sister,*

> *the sister ended up becoming a patient as well … They don't even see themselves as carers yet because the person isn't dependent on them."*

7.2.4 Wider Context

The wider context exists beyond the patient and their immediate context and can have a substantial bearing on their experiences, opportunities, and interactions. The wider context was not the focus of interviews or observations, but many service-providers made references to ways in which society and its systems might limit or enable people living with illness. Patient experience and hospice services can be impacted by cultural expectations and the political-economic backdrop. This section is a brief discussion of specific aspects of society and healthcare services as relevant to the patient. The following section will present their relevance to hospice services.

7.2.4.1 Loss of community resources & increasing isolation

Service-providers described changes in the wider context that reduce availability of informal social support for people living with life-limiting illness. Some considered the modern context to be one of increasing loneliness and isolation for people across society, with or without illness. There are two interacting factors that may be more pronounced in rural and/or deprived communities: increasing financial stress and time pressure associated with working and commuting hours reduces the overall time people have to spend together; and smaller, more fragmented families means there are fewer people available to offer care.

Austerity places pressure on formal care and indirectly accelerates the declines in informal care described above. Formal health and social care systems, community organisations, and established institutions are under pressure to use less resources, which in turn places stress on the people relying on those services. Changes to the immediate local surroundings, such as the loss of activity on local High Streets, can become more relevant in a context of declining health, when someone might no longer be able to travel to visit their ‘close’ family members or friends. In this quote Jenny, day therapy manager in a rural South-East hospice, explores factors contributing to increasing isolation:

> *Jenny: “We lead busy lives these days, don’t we, realistically? … I think that’s part of it. Society means we just don’t have the capacity in our lives to keep an eye on people in quite the same way anymore. I definitely think that’s part of the problem with loneliness. There are just less people around. A lot of towns if you walk through them they’re just like ghost towns during the day.”*

Families may live further apart and spend less in-person time together, and many young people move away upon maturity. Housing pressures can contribute to neighbours being less likely to know each other well enough to offer support. Less time spent together corresponds to less trust, lower perception of support availability, and gradually an increasing loneliness. Patricia, day hospice manager in the rural South-West, reflects on her experience and the potentially hidden nature of this loss:

> *Patricia: “There’s all this speeding up, and it’s those slow pointless interactions that we build our lives on and we come to rely on. Whether I’ve got quarter of an hour before I pick up my son, so I talk to mothers, or whether I am scooting in late every day to grab my child and I don’t speak to anybody - I don’t build those relationships, I don’t build that security within my community, I don’t know my neighbours because they’re always working late… It’s all these small little things that once we stop doing for each other we change our view of how scary our society is, and whether we’re willing to go and put ourselves out there.”*

Informal connections in the neighbourhood are important for a sense of safety and security in the community. Shifting expectations of the family dynamic and declining neighbourhoods might be fuelling an increasing loneliness, not just in palliative care or older age groups, but right across society. This explanation paints a picture of a ticking timebomb – isolated professionals that lack a social network to rely on. Existing relationships might not last endure a relocation or retirement, and there may be limited opportunities for new relationships or even informal interaction. Forming and maintaining friendships is not easy. Time pressures were cited as relevant to declining support availability in both urban and rural areas - perhaps in this increasingly isolated and work-focussed society, we lack the permission to reach out to offer support. For Sarah, a hospice art therapist with twenty years' experience from several settings, it is time we recognise a collective responsibility to take care:

> *Sarah: "We all need to take responsibility for the person that lives next door to us, or the one we see in the shops going on their own. I think it's a whole social kind of responsibility. But I think it's easy for us to become a bit lazy and think oh no somebody else is looking after them."*

7.2.4.2 Attitudes towards illness and dying

Our lives are described as being busier than they used to be, with some service-providers suggesting we might also have less patience for people who do things at a less than ideal pace. Unsupportive interactions and awkwardness with friends or family members was described within the patient context. Our cultural expectations and attitudes towards illness and death, and therefore sick people, are a framework for these individuals as they attempt to understand the world around them. Unfortunately, these are sometimes negative or unhelpful perceptions of passivity and fragility, that could contribute to the loneliness experienced by palliative care patients. A cultural aversion to emotional outbursts in the wider context reinforces an avoidance of the illness in the interpersonal context – limiting opportunities for a patient to share and process their feelings.

Service-providers gave accounts of alienating attitudes and prejudice expressed by the general pubic towards people with visible signs of illness or disability. This might be reflected in a deliberate looking away or an infantilising gaze. Some service-providers suggested more exposure to different bodies would help with inclusion – these accounts suggested that celebrity culture and social media leads to a focus on appearance and competition among peers, such that we are reaching a point when everyone is struggling to live up to some unachievable ideal. In this quote Grace draws on her experience working with a young adults' group:

> *Grace: "As a society we like to hide people away, because we don't want to admit that we're going to become ill and die. We want to not see it. It's the surprise on people's faces when we've taken some of the young adults to the festival. It's the surprise that they've come to a festival, oh my God, and they do look awkward, and they do treat them differently, they talk to them more like babies.*
>
> *As a society, we don't like that what makes us uncomfortable. I don't think we've got the knowledge, I don't think we've got the practice, I don't think we like to see it. I think it's something we like to ignore. As a society this image of 'normal' is with the celebrities and Facebook and everything else, we think there's this image of what you should be. Everyone's trying to achieve this perfection image, and even I wouldn't match it. But someone who's in a wheelchair and completely disabled definitely won't get there will they?*
>
> *Even with people that haven't got an illness, it's quite a high level of depression in society. I think that's because everyone's not feeling they're matching up to what the society level is, like the Kardashians and everything else. And the patients would feel that ten times over because they're definitely never going to make that."*

A stigma or taboo surrounding death and dying in the wider context was discussed in some interviews as indicating a fear of mortality. This might be contributing to the distress and loneliness experienced by people living with a reduced life expectancy, and to a lesser extent, anyone with visible signs of illness or disability. Of course, those working in a hospice setting are likely to have a greater acceptance of death than the 'average' member of the public – their personal context shapes their view of the wider context. In some cases, interview participants understood societal death avoidance as contributing to patient distress when receiving a palliative diagnosis. Wishing to talk about death might be seen as 'giving up', which impacts on patient ability to speak about the changes their experiencing – whether to their body, future wishes, or daily life. Through a process of not sharing these changes, they become less relatable and less able to relate to the people around them. Lisa, a centre manager, describes death taboo in the family dynamic:

> *Lisa: "Some people are very open and talk about things, but I mean the death and dying one is the biggest isn't it? These people have all been given a palliative diagnosis, but if you ask them 'have you talked to your family about what you might want for your funeral', most of them haven't. And that's the taboo isn't it, it's the 'we don't talk about that'."*

Membership of a religious group might prevent social decline during ill-health. It is possible that religion helps a society to accept illness and death by providing an explanation of the things beyond our control, as well as an organised social network. Formal religious group membership has declined in recent decades and many people trust professionals in the healthcare service with responsibilities once held by the local chaplain. This might have cultural consequences for the availability of social support, and acceptance of people with illness. Rachel, head of rehabilitation at an urban South-East hospice, highlights the importance of religion as enabling us to face up to existential truths – without it, death and disability become a failure or a spectacle:

> *Rachel: "I think when you step back and you look at society, look at where is time and attention being spent in society, what are kids being brought up into, then I think death and dying and illness is seen as a failure. It's seen as something to be avoided. And the doctors and nurses in the NHS should be able to cure us of it, we just need to push and complain more, and if they don't, they've failed.*
>
> *And when death and dying does come and hit families it's all pretty sad, and quite hushed, and then you kind of bend and go back to normal life again. And it's not the norm is it, to talk about. We're heading for disaster, we complete are. I think we're the first era of people, because it's more than a generation, we have just absolutely lost sight of God completely. God doesn't get a mention, I never hear God talked about on the BBC because there's an assumption that most people don't believe in*

> *God anymore, because he's kind of disproved by science or whoever you want to say. And therefore yes, to die or to get ill is, that's just terrible, that's a disaster.*
>
> *Whereas the basis of Christianity is that suffering and death are absolutely at the heart of it, it's normal. But there's a greater hope within it. And within other religions there is also a theology of suffering, that it's not ashamed and it's not a failure. There's a sovereignty in God that means that stuff is going to happen to you that's our of your control. Whereas now, we live in a culture where everything's absolutely my control. I have rights and if I want something I just need to push harder."*

Death avoidance creeps into healthcare too. The fear of talking about dying within healthcare encounters can sometimes encourage a euphemistic discussion of hospice, which contributes to a misconception of the hospice sector. This is a reason for concern because it has the potential to closedown patients' access to and acceptance of potentially beneficial support. Fear of hospice contributes to reticence to engage and being 'slow to warm up' within services – but these people sometimes become the strongest 'champions' or success stories used by service providers. Several service-providers felt that patients and families aren't to blame for avoiding talk of dying and advanced care planning when even professionals avoid difficult conversations, including Laura, nurse sister of an urban North-West hospice:

> *Laura: "A lot of healthcare professionals still don't talk openly about death and dying and planning for the future and things you're going to do. If healthcare professionals won't talk about things like that, then other services aren't going to, and it can be off putting for patients."*

7.3 Hospice Context

This chapter has so far provided a detailed discussion of the patient context that describes the social world of people living with life-limiting illness and indicates possible targets on which holistic and/or multidisciplinary interventions might act. But which target is most appropriate? The hospice context defines its possibilities and priorities. Each hospice has a history, the staff and volunteers understand the hospice from their own personal and professional context, and each site is embedded in a local network of state and charitable services. The service-providers included in these interviews reflected a diverse range of hospice day services with sometimes differing underlying aims. Features of the hospice context can help or hinder it in achieving effective services, as well as shaping how ‘effectiveness’ is understood by service-providers. This section explains how differences in the organisational context and local surroundings of each hospice influence its service provision and approach to social support. These are demonstrable sources of complexity in the context of the intervention. The following section looks more at what these hospices these services had in common, by describing the resources involved in these interventions offering social support.

The project found hospices at different stages of change and variation in strategic priorities. Hospice service development is driven by wider context challenges and a changing funding landscape, but also by the changing diagnostic mix and needs of patients and an increasing recognition of unequal access to hospice services. For many hospices, the solution is context-driven service development, responding to the local needs and area characteristics, not assuming a one size fits all approach. Service development is supported by a hospice’s local reputation and visibility which might partly determine the resources it has available. Working relationships and collaborations with other providers of a crucial part of this reputation. However, change is not always straightforward - there are many risks and points of contention - with hospices moving away from a ‘traditional’ model without necessarily having an agreed sense of what a ‘non-traditional’ model should look like or aim to achieve. Therefore, the hospice context is increasingly a context of change, which is exemplified by changing expectations regarding patient discharge.

7.3.1 The need for change

7.3.1.1 Uncertain funding landscape

A pressure on public services, associated with austerity and increasing burden of illness, influences the patient and carers context. This same pressure is pervasive in the hospice context, particularly with loss of funding and inadequacy of adjacent community services. An uncertain and changing funding landscape was mentioned by participants across hospices, with finances explored in some interviews more than others. Filling the gaps in local services and fundraising after ten years of austerity is no mean feat. There is a variation between hospices in their local funding, ease of fundraising, and health of community services - all associated with deprivation - which emphasises the significance of the local context rather than just the national picture. There is even variation in service availability and eligibility within a hospice’s patch – this is confusing for patients and hospice staff, and is a significant stressor for those working in the sector. Lisa, a centre manager in the North-West, explains, fundraising is made more difficult by housing crises and generational uncertainty:

> *Lisa: “We’ve got a shortfall in our legacy money in this last financial year, so we were in a deficit, we had to save money. We’ve been lucky in that the CCG has kept the money the same this year, but it’s all becoming conditional. Whereas before it was like ‘there you go there’s the money’, and you kind of had it forever, but it’s not like that now. Plus, looking from the fundraising point of view and the legacies - it’s become more difficult... If you look at society - I have two young children, if I die, I want my money to go to them, I’m not thinking I’ll leave a donation to the hospice. My thoughts are about my family, my children, how are they going to get on the property ladder? And I think everybody’s in that boat, aren’t they? We’re all thinking we want to be helping our children, so legacies will become less.”*

7.3.1.2 Changing diagnostic mix & population needs

Demand for hospice services is only expected to increase in line with medical success stories and increasing societal disability. The details of these changes are important because they indicate how needs might shift with time, both within and outside the hospice. Cancer patients are living longer, there are more non-cancer palliative patients, greater co-morbidity, and increasing frailty. At the same time, there are less healthy and able people available to provide care. Jill, creative arts co-ordinator in the South-West, explains how her hospice is adapting to shifting demographics by offering less intense services to more people:

> *Jill: "We're looking to have bigger numbers. One of the ways is to have a lot of lighter touch services. People might come in and do a bit of physio and then they might be well enough for a while. They don't come in and have the full package right away. We've got coffee morning groups where they can see a nurse specialist, but they're not necessarily coming weekly and having full interventions. There's a lot of that sort of stuff going on and we might need to do that more.*
>
> *The thing we need to keep an eye on is that more people are living to 100, there's going to be higher incidences of patients coming here who've got a cancer diagnosis and they have dementia, or they may have other issues with breathing, with mobility, and now they've got cancer, but actually cancer isn't the thing that's going to finish them off. I think we're going to have a lot more disabled people coming in to the hospice, whereas some of the diseases before they would have died, they are now living for a long time, but they are living more disabled with them."*

Patients at either end of the age range – younger adults and the oldest old – could have their own profile of clinical, social, and emotional needs. Transition patients are people moving on from children's hospices who might have unique clinical and emotional challenges, requiring collaboration and inter-agency communication. Many hospices have successfully broadened their diagnosis mix beyond cancer and might continue to diversify their clientele with an approach based on teamwork and continued learning. Changing population needs are not just driven by medical advances and shifting diagnostic mix, but also by increases in unmet social need. A loss of community resources and increasing social isolation is described above as relating to less informal support for the patient. In this quote Jenny explains how the aims of her role and the needs of her community have changed over the last decade:

> *Jenny: "When I first started here social support wasn't a huge problem for the population we were seeing, because to be blunt, most of them didn't survive the 12 weeks of day therapy. Most of them were dying before they got to the end of their 12 weeks. We've changed a lot of the population we're seeing; we're seeing a lot more people with long-term conditions that are still palliative but have a longer prognosis.*
>
> *People are coming to the end of day therapy, and they're like 'so what do we do now?', because they haven't got that social support. So that's why we've put in more of these social groups, because we saw a need, and we tried to fill it. In another ten years' time if we're seeing a different population, if we are seeing more dementia patients or more frailty or whatever, we might need to think again about how we deliver things."*

7.3.1.3 Achieving equitable access

Some interviews acknowledged a particular 'type of person' accessing their hospices, often related to the nature of the patch and perceived cultural differences between patient groups. There are hospice patients from wealthy suburbs accessing traditional hospice services, and their attendance rewards that culture and satisfies those patients – but these services do not necessarily appeal to everyone and might be off-putting to some people. To use the phrase of one participant, in some hospices it is only people with 'a vested interest' that engage – those who have previously had indirect support from the hospice are less afraid of its associations with death, but this reinforces issues of access. Reaching out to a broader patient population might be more of a challenge for some areas than others, explained here by Lisa, a centre manager in a rural North-West hospice:

> *Lisa: If you look at the clientele that we get, the patient groups. We get people from the town centre you know. We know it's a problem that we can't, that's sometimes the fact of geography isn't it, about where we're situated. Rural areas don't want to access hospice services, and here that's a big problem. It's partly due to that culture, just historically, and it's how do you go about changing that. So, it's actually quite difficult, not that it cannot be done, but it is more of a challenge."*

In a context of population changes and limited funding, how does the hospice appeal to more patients without being inundated itself? Unmet need in the community becomes a legitimate rationale for time-limited hospice intervention, which means restricting some services and enforcing strict policies regarding access and discharge, so that more patients might benefit from attendance. However, opening up access is not straight-forward when access routes rely on healthcare professionals such as GPs. Poor referral pattens from local GP practices can mean that patients are not receiving timely support. Simply opening up the doors to the public or professionals is not enough to overcome misperceptions of hospice work:

> *Bea: "People's perception of hospice is somewhere where you go to die. So, for some people they'll be quite frightened of it, unless they've had experience through a relative coming here… It tends to be the same people that have had dealings with the hospice through as patients. We have had open days here, where we've opened the centre for people, for professionals and the community to come and see what we do here, and they've very very poorly attended."*

Several participants described pressures on GP practices and inequitable access to primary healthcare to be related to factors such as socioeconomic status and available social support. This means that those who might benefit most from hospice support might be least likely to access hospice services through traditional referral routes. Gemma, a clinical nurse manager on the South Coast, uses her experience of community nursing to explain why creative outreach is crucial:

> *Gemma: “Every couple of months I do a weekend, we go out to the patient’s home and get a glimpse of what it’s like to be out there. So, you might go see somebody in the town, you might go to this amazing house with loads of family and all well-educated and well to do, great support. Then you go down the road, and you go to someone who is perhaps not so high on the social-economic ladder, that are completely isolated, don’t see anybody…There are still a lot of people out there that we are not reaching, that are not coming out to the GP practices to see our posters up. There needs to be some creative thinking about how we reach those people, because there’s a lot of poverty, there’s still a lot of poverty out there.”*

The demand on hospice services is only expected to increase in line with medical success stories and increasing societal disability, raising the question of who should be prioritised. Patricia’s interview frequently referred to experiences in emergency department nursing and how this perspective had informed her approach to hospice work. Although the service she operated had strict access criteria, it allowed self-referrals and had abundant local options for signposting. Self-referrals, while unlikely to be sufficient alone, might help open up hospices to more people:

> *Patricia: “When I worked in my previous hospice, they did not take self-referrals and I worried about that. I believe if you’re self-referring you have fallen through somebody’s net, and you should not be allowed to fall through ours. Even if it transpires that you’re not the right person or we’re not the right answer I will then signpost, I’ll even refer you on myself to make that process easier if its most appropriate.*
>
> *I believe that the buck should stop with this department and we should be saying it’s alright, if you are desperate enough that you’re ringing round hospices, clearly something’s not working, and you’re really scared. I think that does a great PR for us, to say on well they did stop, they did give me half an hour of their day and they did get me back on the right track. And by PR I don’t just mean from the fundraising side, what I mean*

> *is that people start seeing hospices as safe and kind places, not just somewhere that people come to die. If you're lost, we will help you."*

Many hospices are developing lighter touch services that can accommodate bigger numbers by not giving 'the full package' to all patients. It is possible that these focused interventions – for example, physiotherapy and art groups - might be more accessible to more people. They are not as time-consuming, have clearer goals, and aren't always marketed towards 'patients'. It remains to be seen how they compare in terms of patient benefit and accessibility for the most clinically-complex patients; but for the hospice context they may contribute to people accessing support earlier on in their illness. Jill, creative arts coordinator, offers a range of groups for people with different emotional needs:

> *Jill: "One of our other groups we've only just started running is for patients who, on the whole, are a bit more well. We are trying to treat it as more of an enablement group, so they come along, and share with people in a similar situation. They are perhaps newly diagnosed so reeling from shock. We use the group to get them into the hospice."*

7.3.2 Context-driven service development

7.3.2.1 Local needs and area characteristics

The context in which the hospice developed, and in which it now resides, informs its approach to service development. We have explored in depth how patient context can lead to personal differences in social support but there are area-level differences in the availability of social support and the extent of social isolation. Changes to services were frequently driven by local patient need and area characteristics, with hospices demonstrating knowledge and responsiveness to the provision of other health, social, and charitable services. In some sites this led hospices to explicitly respond to loneliness and inadequate social support in their area. For example, Katie manages a newly opened day centre at an urban North-West hospice:

> *Katie: "What I've found going to different hospices is that the changes they're making is suiting the area, so that's why I came back and had a look here. Because here the isolation and loneliness are quite high in the Borough. I think heart failure and respiratory conditions is high. Some places, that traditional model, the medical model, it stills suits because they haven't got that facility within the Borough, they haven't got a team of specialist nurses, so they're having to look at ways of capturing those patients that have got complex change in needs, that aren't being met through community services.*
>
> *The hospices need to reflect and shape what is happening within their communities – a lot of hospices have got nurse specialists now, some haven't got bereavement support because it's quite strong in their Borough, others have really fought to get extra funding to do bereavement support cafes in the community. So, it's really the hospices being forward-thinking, and looking at what is within their Borough, so they know they've got the unique approach to the specialism and they can help support what's going on. I think our centre taps into quite a lot of that."*

The size of the patch, how urban it is, and the feasibility of public transport, are influential in what is possible and desirable for the hospices to prioritise. Do they try to get more patients into the building, or get more of the building to the patients? This is a strategic as well as pragmatic issue. Even in areas with good public transport, continued change in this large urban hospice in the South-East is driven by an urge to make services more accessible.

Offering services in multiple locations has practical benefits that reduce distance to travel for patients. There may be some resource implications, but using satellite sites can also serve to reduce the mystery regarding what takes place inside the hospice, by offering crossover activities in more 'normal' locations:

> *Mary: "The idea of having satellites is something to be considered because it makes the journey easier, it makes access easier for patients. Especially if they live right on the edge of our remit. It would just be again*

> *resources, whether we could support that. But I think to have it in more than one places is good."*
>
> *Rachel: "Satellites are the way forward, exactly what we should be doing, borrowing church halls, starting pop up gyms. Buildings are expensive."*

7.3.2.2 Local health, social and charitable services

Many interview participants referred to recent changes they had made or were making as being driven by an awareness the provision of services elsewhere. The availability and consistency of local health, social and charitable services informed their approach to supporting patients and this responsiveness allows hospices to develop unique offerings in their local area, rather than duplicate provision. Changes in local services impact patients, so that what they need from the hospice then changes, whether temporarily (e.g. due to staff sickness) or more permanently (e.g. due to closure of other centres). Since many statutory services are offered on the basis of diagnosis, day hospice managers such as Jenny observe patients with some diagnoses to be more in need of hospice support than others – and notes how this dynamic can fluctuate:

> *Jenny: "We're quite lucky in our area, because if it's someone with dementia that actually just needs to get out and see people, there are quite a lot of groups in our area for people with dementia. It's been looked at in the past, whether we should be providing like a dementia specialist group but actually in their area it would feel a bit like it was doubling up. It's not that we don't see dementia at all, but just the groups that we're running would be challenging for someone with dementia and there are other services elsewhere… I think what's been really important recently, so we get quite a lot of heart failure patients and the heart failure nurse specialist left, and there was quite a gap between when she left and when they've replaced her, and for them in particular having that knowledge that there was somebody about when they'd lost their medical person I think was really important."*

Interview respondents placed emphasis on the importance of collaborating with other providers. Effective working relationships with the local health and social care system informs context-aware service development and are the foundation for essential activities to hospice practice (such as referral pathways and care coordination). The extent of interagency relationships varies between hospices and were not the focus of this study, however these relationships might underline the success of some hospices in broadening their clientele – for example by providing appropriate services for non-cancer patients:

> *Katie: "We're trying to aim for the ratio of non-malignant to malignant as 50/50, and we're actually almost there already. It's great seeing the non-malignant coming in especially because we've done quite a lot of work with the respiratory teams, and we have the pulmonary rehab coming in twice a week to run their rehab group and that's really helped with introducing people that would have never come into the hospice. But because their groups running here, they're actually referring in, so we've got quite a lot of joint working going there."*

There were many positive examples given in interviews or observed during observations that reflecting partnerships with other medical facilities, nursing homes, district nursing teams and equipment providers. There were also examples of hospice practice being limited by ineffective relationships with other providers, including patient transport, that might be impeding patient access in some way. The strengthening of relationships with other organisations is a sign of a modernizing hospice sector, one that is seeking new solutions via partnerships and innovative working; in contrast to earlier models that might have aimed to do everything for the patient. Hospice inter-agency working reaches beyond the statutory system, with independent hospices fostering relationships with national charities that have increasingly aligned mission statements. By cultivating collaborations in the local area, hospices can strengthen their reputation and the impact they make and are better informed on where their resources are most needed.

> *Danielle: "If we're going to make a real difference then utilising the networks and the resources already available in the community and working alongside other charities that are there, it's the way forward. Because Age UK do loads of things as well, they do befriending and they're getting into advanced care planning and all that sort of thing. You don't want it to become a fight, you know, and equally you don't want to be duplicating things."*

7.3.2.3 Reputation and visibility

Reputation and visibility within the community is important because it can determine the availability of volunteers and support for fundraising, as well as improving patient access both directly and via referrers. This is enabled by the working relationships but goes beyond collaborations with professional providers. The reputation of the hospice beyond the people already involved is essential in appealing to different people and overcoming the misconceptions of hospice care that could otherwise be a barrier.

> *Carole: "I think we're very lucky, we've got a good reputation in the area so I think we do well for volunteers, and actually referrers know us, so I think that helps… Some hospices lately have taken hospice out of their name haven't they, I don't know, I guess it's more about your reputation and what people know about you, potentially more than what you're called."*

Many service-providers were active and innovative in their efforts to raise the hospice's visibility with local healthcare providers and within the local community, and in doing so to dispel a wider misconception about hospice services. The level of community cohesion can enable hospice promotion efforts, but this presents another unlevel playing field, because opportunities for hospice collaboration and promotion will be disproportionately concentrated in less deprived areas. In some services with high visibility, there is now a counterweight need to manage patient expectations to prevent later disappointment and distress:

> *Alice: I've had a gentleman not so long ago saying well you're going to sort this, you're going to sort that and it's like whoa whoa we'll do our best here. We got this outstanding report, people have got, you know*

> *quite rightly, high expectations of what we can do and that that can create some issues sometimes if we're not able to achieve all that…*
>
> *I think this is a close-knit community, people always know someone else and invariably you're going to know somebody that that uses this centre. You're going to have a friend of a friend, or an auntie's friend that has died at the hospice. So I think it's really got that community feel about it. You know certainly in terms of sort of fundraising and things, you know and people know the money that they raise is going to the hospice and that is good because my friend's dad died there…I think people are probably moving knowing that they've got an outstanding rated hospice. I know an elderly couple in good health but they say well we'll be alright, you know, we're going to be alright later on because we've got a good hospice and they really think that. That's how people are thinking."*

More insular hospices with low visibility might struggle more with referrals, uptake, volunteering, and fundraising. What was consistent across the sample was an acknowledgement of drastic and continued change in the hospice context and the need for practice to adapt accordingly. Hospice messaging needs to reach the local community if the hospice is to maintain a close connection to the people they are trying to reach. But community engagement doesn't happen overnight, and some service models need to build up gradually to build (rather than dismantle) reputation:

> *Katie: "Other places have got to a point where they've now got enough people coming and they know exactly what is beneficial to the people coming and what they can drop out. We've not built up to that yet. We're at the stage now, we're trialling and if it doesn't work, we don't repeat it… I really listened to somebody that had done this, she said whatever you do whenever you start up, don't get loads of external speakers booked in, because they'll be preaching to an empty room to start with and they'd lose interest. We're trying to get more external speakers in now, because now we're at the stage where people are starting to hear what we're doing and are like oh we'll come in and do it."*

7.3.3 Working in a changing context

This project aimed to capture the perspective of service-providers working in a range of different hospice day services offering social support. In doing so, it reports on hospices at different stages of change. There are pressures in the wider context and local variations that are demanding redesign of hospice services, and there are organisational differences in the urgency and ability of the hospice to redesign its services. Abundant resources and revolutionary leaders are associated with ambitious service redesigns and long periods of embedding change. Some hospices have frequently adjusted their strategic priorities, whereas others have remained consistent for at least two decades. Hospices in less deprived areas might be marginally protected from wider pressures on public services and better able to access resources than hospices in more deprived areas, provided they have necessary reputation and relationships. Urban hospices are advantaged by distance and population density, although this doesn’t always correspond to straightforward public transport.

Change is not easy and service redesign represents a disruption to important hospice work. There are potential conflicts, loss of personnel, and damage to reputation. There is also an apprehension that change could throw out what is good, leaving something worse in its place. This sample is small but the dynamics of change across the sector deserves further investigation.

7.3.3.1 Strategic focus on day services

Day services are gaining increasing attention as a route to service provision that can support the long-term strategy held by many hospices to provide for more people. Attitudes of the senior management team and practical limitations like space and funding determine what change is possible. In some contexts, a strategic focus on day service has led to the development of a large open access group programme, in others it has resulted in much more collaborative working – some hospices embrace both these solutions. Gemma describes how groupwork was initially adopted to reach more patients, but a happy side effect is the therapeutic benefit:

> *Gemma: "That is great group therapy work, you know, and the reason why we kind of started the groups, I don't know if you know but we're growing at such speed… We've doubled the amount of people that we're seeing this year as opposed to last year, the same with the community, so we couldn't carry on as we were, seeing one to one. So say if I was doing a session with you that's a real luxury and if you need it absolutely you'll get it, but if you can go into a group and I see 5 or 6 or 10 of you, you're reaching out to a lot more people within that hour.*
>
> *We had to think, how can we meet more people and so stay doing these sort of services without growing in numbers as staff, we're not going to grow in our numbers because there's no money in the pot to do that."*

Services that offer social support can be specialised palliative care services, representing a group setting with high-intensity clinical and professional input. They can also be open access groups for anyone nearing the end of life, as in the example above. Jenny has been in her hospice for nine years, progressing from occupational therapist to day therapy manager. She is explicit that the social component of hospices services is beneficial in and of itself as she reflects on the strategic change she has experienced:

> *Jenny: "I feel like we're coming round to the idea that actually for some people social is what their need is. And for some reason related to their palliative care condition, that social need can't be met through another means… We just need to acknowledge that actually social needs are in the World Health Organisation definition of palliative care. So why would we ignore that, if someone said they had pain we wouldn't ignore it."*

7.3.3.2 Staff and volunteers managing change

There are substantial pressures driving change, but staff and volunteers are having to manage this change so keeping them 'on board' is essential. Arguably this is the case in many, if not all, settings, but particularly so here - these interventions are characterised by interpersonal interactions, and as such the attitudes and experiences of the staff and volunteers could be crucial components of success. Interview participants clearly loved their jobs, but there was sometimes ambivalence regarding change. There was apprehension and reluctance in more traditional services with the anticipation of increasing structure and activity. Other hospices had already experienced sustained change in management and models of care, with some interviews reflecting on the need to embed and reflect. Many changes had been successful in redesigning services to reach more people, but occasionally staff or volunteers might feel these changes affect the quality of support derived in the setting.

> *Rachel: "it's been really tough to make that change and to bring it into place, a lot of the volunteers have been really resistant, they were not happy. They feel like we've lost the essence of what that place was… They feel that they don't care if we're not reaching lots of people. The few that they met it was so meaningful to them, and it was you know just awful to have that stopped and let it go. So it's been hard. But for me the numbers and our general strategic direction of travel shows me that running that service is not sustainable … The difficulty is when we've stopped stuff there's this mourning and this grieving around it's not the same as it was. And, yes we have thrown out the baby with the bath water, and we lost what was good."*

Strategic change does not instantly translate to substantial change 'on the ground' - ie for the experience of patients. Service development is gradual and can be hindered by various personnel factors including training, staff openness to change, and characteristics of the leadership team. The attitudes and behaviours of the individuals involved are important. Cost-effectiveness can be viewed with skepticism and volunteers who have been reliably served a routine role for many years are not immune to disruption. At all levels, this project observed an enduring concern for the wellbeing of patients that guided the actions of all stakeholders, even when incongruent viewpoints are expressed.

7.3.3.3 Defining who the hospice supports

In the patient context, we described a sense of everything being about the diagnosis, but that not everyone fits into neat little boxes. The preceding recap of population changes paints a picture of greater co-morbidity and more diverse palliative populations – i.e. those neat little boxes are getting even less realistic. There has never been unanimous agreement on who is, and is not, a ‘hospice patient’, but defining who the hospice supports is increasingly contested when demand for services could increase exponentially. Supporting non-malignant disease means supporting longer or less predictable illness trajectories. In these interviews, respondents frequently endorsed a view that early access was beneficial to patients, particularly with non-cancer conditions, because the timescale of support was so challenging to predict. For example, Mary’s position on access could be summarised as ‘better safe than sorry’:

> *Mary: “There’s been lots of discussion about earlier referrals so people can access whatever they need whenever they need it along their trajectory. Rather than trying to play the guessing game, is he or she dying or are they not, when actually you don't necessarily know. So, although we have this question of, do you think that this person would still be with us in a years’ time, you will always have the anomalies of somebody that looks fairly well and then suddenly falls off the cliff edge really quickly. Or somebody that looks really ill and actually they are here two years later and you're like how is that happening? And you get both of those, so yeah to have the contact, to enable that person to access as and when they need, is probably a far better approach than playing that guessing game and then people not having access even til the very, very end when they could actually have had it, and would been really useful to have it earlier.”*

However, interview participants were divided on whether the hospice was there specifically for those with complex palliative care needs and their families (only), or whether the hospice should be a source of support for all people with unmet need from life-limiting illness. This is not necessarily a decision driven by virtue or philosophy, but rather a pragmatic response to resources and demand. For example, we can contrast the positions taken by two centre managers: Katie, in a urban North-West hospice, and Patricia, in a small South-West rural hospice.

> *Katie: "Not everyone fits into that neat box. A lot of your head and neck cancers, they're still undergoing what we'd class as curative, but it looks like they're progressing towards palliative, so they don't know where they fit. It's the psychological side of accepting that they're moving into the palliative side of things, they're not quite ready yet, so we're quite open in what this service is geared towards… The other side, the ones we're meeting that are coming through the service have just been diagnosed, especially with respiratory conditions, they aren't actually unwell enough to access nursing or community services, but they're still left with this condition that's impacting on daily life."*

> *Patricia: "We have to be specific about those with the most complex needs because if we didn't we would be giving lots of input to people that didn't need it, and potentially missing those that really cannot manage in any other way… We keep several folders of resources so that we can signpost people on - we have to focus on people with complex needs that can't be managed by somewhere else. If you're just lonely and you need lunch they're plenty of stuff that I will feel people into and I'll also make sure they've got our phone number so if that doesn't work they can ring back… Otherwise we would be seeing half the country. It would dilute what we do. We would be filled up on a weekly basis and we would be missing the very people are too complex for these other avenues, they are needing that complex management."*

7.3.3.4 Challenges of discharging patients

The context in which the hospice exists inevitably influences the services it provides and the experience of its services for all stakeholders. This is particularly salient when approaching complex psychosocial interventions – by their very nature, these represent the addition of multiple professional perspectives, decision-makers and intervention components to a complicated patient context, at a time when intangible and emotive features of the human experience are especially salient. Factors such as the rationale for service delivery, philosophy of care, and professional context extensively inform the contents of intervention and have substantial bearing on patient experience. This may be especially so around the time of access and at discharge.

We noted above that traditional referral routes alone do not appear to overcome enduring issues of access that can sometimes characterise the hospice sector with a sense of inequity – but getting patients into the building is only part of the challenge of equitable service provision. Hospice buildings do not have unlimited space and resolving issues of access ultimately means facing up to the difficulties of discharging patients. Many have stepdown social programmes or signposting relationships to offer to patients.

There are further points of contention here, situated in the context of inadequate services: when the hospice offers essential support that is not available anywhere else, what happens to the patient when they have used up their allotted time?

> *Grace: "We've got one lady, she's not complex in her care, she's got breathing problems, we are her one day out a week, she's very anxious. It took her a long time to settle in and it took us about a year to get her to really be with the group and five years on she's still here. She comes every week, we've moved her to every other week, but she says if she didn't come here, she'd die and we think she probably would because she doesn't go out at all in the week. She lives in a basement flat, completely alone, her sons live in Italy and she doesn't want to burden them and she's very anxious…*
>
> *Stopping people coming, yes, it kills me a bit. Particularly if I can't find them anywhere else to go. I am really passionate about, I so worry, I*

> *don't like the idea of them being social isolated 'cause I know it could deteriorate – So it's, it's having this pressure, I know it has to be time-limited but then it's really hard doing that talk with them. Which is why I've now decided we'll try and get them into somewhere else in society, even if it's not for a whole day, but so they're linked into something.*
>
> *It's still traumatic, I mean I think the hardest thing I'm going to find is that there's going to be nowhere to find for certain people to move onto. So, you give them this amazing social experience and they lift, and then you send them back and they're back in the social isolation and I think that's going to be the hardest thing."*

Patients with clinical complexity, such as an oxygen requirement, might not be able to find similar services elsewhere. Several service-providers described the process of discharge as traumatic or mentioned specific examples of deterioration after discharge. This brought in the importance of managing expectations during patient assessment. Hospices might offer a low input social activity that patients can continue to attend, even if not receiving other professional components or transport. However, when policies were changing during a patient's time with the hospice, it was difficult to avoid some disappointment or distress.

> *Rachel: "The fact that you get discharged again which should by all accounts be really positive, should mean oh great you know I'm going to go out and live my life, but it's not at the moment. We're in this transition time where it's not, for many people it's not seen as that because we haven't done a good enough job of enabling and empowering people while they're here with us to understand that it's not necessarily going to be forever. We're much more of a service we're here when you need us. But we've never said it like that before"*

7.4 Hospice Resources

Resources are offered by the hospice with an underlying assumption that, when applied to a certain context, these resources create the necessary conditions for mechanisms of personal change that lead to beneficial outcomes for the patient. This analysis defines three domains of hospice resources. These resources are what the social support interventions had in common, and they might be necessary conditions for creating social support between patients. The role that resources play in facilitating mechanisms are described in the next section, which looks in more detail at how interpersonal interactions and psychological processes occurring within the hospice can lead to behaviour change and relationship development beyond it.

Here we give a brief synopsis of resources. These are overlapping, but roughly defined as three – safe space, time-rich people, specialist components. The quote below indicates these resources contributing to an underlying aim of hospice day services:

> *Gemma: "It sounds very simple - we need to give patients the best day. The best day. As in just coming out of where they are, whatever that environment looks like, and obviously everybody comes from all walks of life, and really leaving all that behind and coming into a place where they can feel safe, secure. They can bring up and say anything, raise any concerns. We really have some personal stuff to deal with, but they feel safe and able to do that. Whatever they say, they're going to feel scooped up, if you like, and know that we will do our level best to support them whatever that is. Yes, just to give people the best day so they feel there's a real quality of life, there's a real purpose of their life, you know, they wake up and say right ok we're coming to the club today."*

7.4.1 Safe and accessible spaces

Hospice day services are ideally held in safe and accessible spaces in which people feel included by the physical environment – they can actually get there and be there without significant discomfort. Having back up reassurance from clinical staff may be required for some people with high levels of health anxiety to feel safe. Features of the dining area and importance of welcoming atmosphere highlighted as contributing to safety. Ideally the experience provides a break from feeling a burden. In this was it provides space for patients to talk about and reflect on their personal context, away from family and carers and the home environment.

> *Jill: They find that it's a very safe place, they've got all the professionals around them, nurses, doctors, volunteers, everybody understands about confidentiality. They know that we have a holistic approach to care - so whatever the problem is we will try and address it and if we can't address it, we probably know somebody who can.*

Interview participants explained the value of the hospice environment by contrasting it to the wider context. In doing so, they mentioned features of modern life that became practically inaccessible, such as hairdressers not providing for wheelchair-users, and routine social hangouts that suddenly aren't so simple to visit.

> *Jenny: "Physically they can't get to other places because they're not accessible... Sometimes it's just at that kind of practical level, they just cannot get to where they need to be otherwise."*

7.4.2 Time-rich and experienced people

Staff and volunteers act in a variety of roles, described during analysis as hosts, clowns and teachers. Within the hospice, time-rich personnel offer a different quality of interpersonal interaction to those derived in purely clinical settings; or from family and friends who might be distanced by anticipatory grief and death avoidance. The perception of personnel as being time-rich may therefore rest somewhat on their previous exposure to illness – they are not in a hurry to look away from mortality, as many people are.

These are professionals in terminal illness whereas the patient might not feel like they have any wisdom or insight (because they lack confidence), so the advice and suggestions have credibility (for some people choosing to access these services) – but they are perceived as being less rushed and more holistic than specialists encountered previously. Ideally meeting these experienced and unhurried people provides a break from being seen as a task. It might be important to have not just staff ('people in the job'), but also volunteers choosing to be there and are often very able to be compassionate from their own experiences that have led them to want to volunteer

> *Katie: "That is something that is fed back to me, that everyone's so welcoming when you walk in, and nothing's too much trouble, they feel like they can talk to anyone. The staff they said have always got time, and they feel they can trust, there's that trust. And it doesn't feel clinical, and that's one of the biggest things."*

7.4.3 Specialist components

Intervention components represent specialist and professional input into the setting. This might be educational, artistic, exercise, and clinical care These components were common across sites but there are differences in how these components are used between sites and between patients. That is to say, the hospice context (e.g. organisational strategy, professional perspectives of decision-makers, attitudes of staff and volunteers) interacts with the personal context of the patients. Components varied markedly but there was usually some kind of focal point, providing activity and structure, a reason for attendance and ideally a break from being passive in other contexts. Some sites were much more clinical than others as related to differences in strategy and patient need. Different approaches to art and music therapy reflect different content activities with similar underlying programme theory. The social benefits of these components, for example an association of exercise with empowerment, or goal-setting with autonomy, might vary between hospices even when similar activities and aims are present in publicity documents.

> *Shauna: "My role is really a psychological support for the patients, but also alongside that any practical interventions that might need doing - tell me if I'm being too what's the word technical - so you know things like patients might need syringe driver pumps changing, they might come in very constipated and I might need to give them suppositories, erm quite a lot of our patients have PEG tubes."*

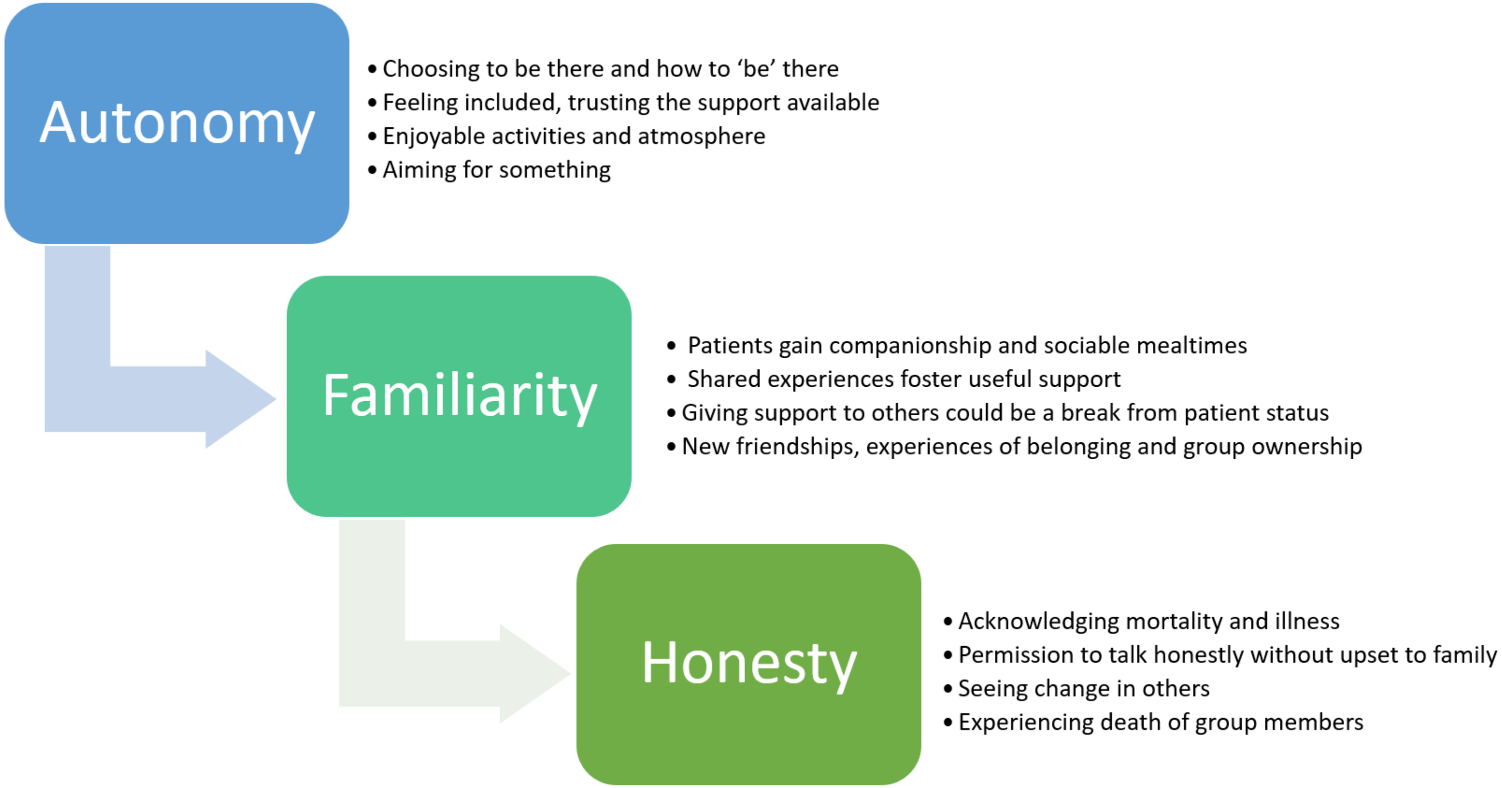
7.5 Mechanisms

This chapter describes complex interventions offering social support in palliative care as a set of hospice resources 'applied' to patient context, which might result in personal and interpersonal (group) mechanisms leading to (somewhat) observable outcomes. Drawing on a realist approach, the intention of this analysis was to draw out the underlying theory of change, or programme theory, from qualitative interviews with service-providers. So far I have explored the context in detail, building a perspective on the potential for unmet social need in this population – palliative care patients in some contexts might experience emotional loneliness, detrimental social support, a loss of fulfilling social roles and objective social isolation. Intervention resources provide a safe space, time-rich personnel, structured activity, and specialist input.

This section proposes interconnected mechanisms representing experiences at the psychological, interpersonal, and group level, that might arise in response to hospice resources, and in some contexts lead to observable outcomes. The analysis found these to be the specific aspects of patient reasoning, interpersonal interactions, and qualities of the setting, that appeared to be the main mechanisms representing the development of beneficial social support in palliative care. Although I am not arguing that these are sequential, one might be seen to underpin the next. As summarised in figure 30, these are related to a patient's sense of autonomy and inclusion, familiarity between patients, and their ability to speak honestly in acknowledging and experiencing mortality and illness.

Initially, interview transcripts were coded for mechanisms related to resources, reasoning, interpersonal interactions, and processes occurring beyond the hospice walls. Mechanisms occurring as 'reasoning' and those occurring as 'interpersonal interactions' appeared to work together, practically overlapping, to the extent that explanatory value and parsimony was gained by considering psychological and interpersonal mechanisms to be entwined. The focus of this research is social support derived within the hospice, so that processes occurring beyond the intervention itself are communicated as proximal outcomes. In the next section I clarify these outcomes and their relevance to achieving the outcome of ‘better living and dying’ for patients, carers, community members and future generations.

Social support in palliative care is essentially a myriad of social and psychological processes and the focus here is on identifying which processes might be necessary to produce beneficial change. The relative importance of these mechanisms and the extent to which mechanisms interact and depend on each other to produce outcomes is likely to vary between hospices and between patients. These mechanisms are enabled by specialist components and experienced staff but are not reduced to these professions. Considering the mechanisms endorsed by these participants demonstrates the complexity and flexibility of these interventions.



- Choosing to be there and how to ‘be’ there
- Feeling included, trusting the support available
- Enjoyable activities and atmosphere
- Aiming for something

- Patients gain companionship and sociable mealtimes
- Shared experiences foster useful support
- Giving support to others could be a break from patient status
- New friendships, experiences of belonging and group ownership

- Acknowledging mortality and illness
- Permission to talk honestly without upset to family
- Seeing change in others
- Experiencing death of group members

Figure 25: Summary figure of mechanisms described by this analysis

7.5.1 Autonomy in the experience

Service-providers communicated in different ways that it was important for patients to have a sense of autonomy or ownership about being there, which included feeling safe there. Both practical and social aspects of the setting are important to patients feeling welcomed and perceiving safety, which encourages them to engage in the space, for example by joining in on conversation or activity. This often includes facilitation from staff or volunteers, particularly if patients require one-to-one assistance with communication.

Autonomy is expressed differently by different people, it is sometimes understood as reflecting personal choice and control, motivating some service-providers to offer patients a wide variety of different choices between or within their services. The type of activities on offer could be off putting or attractive depending on the associations someone has with them (complementary therapy vs physiotherapy; arts and craft vs art therapy and how these might appeal to different people). Although people might have pre-existing expectations of hospice, their first visit and first attendance at the social service can greatly determine their expectations of benefit and willingness to attend in the future – service-providers were conscious of who someone sits next to on their first day and how the arrangement of furniture might be perceived to a new person. Autonomy in the experience could be explored further as an emotional response to practical and relational aspects of the intervention.

7.5.1.1 Choosing to be there and how to engage

Patients choosing to access hospice day services were described by service providers to be people with some kind of unmet need in their daily life. In some cases, they might be sociable people by nature, or they feel increasingly motivated to connect with new people or with other patients through their experiences of illness. Others might find the intervention components appealing or be keen to spend some time in a new place. Overall, this means that the room is (perhaps) filled with people who have chosen to be there, rather than people who are simply paid to be there - and this adds value to the experience of being there.

The patient’s context matters - motivation might well be a belligerent willingness to get out of the house for their carer, rather than enthusiasm to engage with the service itself. It is possible that reticent or quiet patients could derive beneficial companionship from being around others, despite appearing reluctant to engage. Being included in activities and mealtimes might lead to feeling able to relax and to participate in some way. By allowing choice and flexibility, services avoid threatening their autonomy and therefore encourage them to engage at their own pace. This is explored by Patricia:

> *Patricia: "It is the people that will work with you - because they're not prevented from engaging with the rest of hospice care and palliative care if they don't want to come to us. It's something on top of that…Day hospice is really a choice to add extra to life…… its whatever they need from the social side of it, they're all different. Some people will be in the art room from the minute they get in to the when they go. Other people just want to sit in the conservatory, and they want other people there, they don't want to sit alone. They're not doing anything wildly exciting and they might nod off, but they are benefitting from being in a social environment. There's something about a room that feels different with somebody else in it that we often underestimate. I'm happy to be side by side, I don't need to chat to you, I don't need to do your thing, I like that you're there. They feel relaxed, and sometimes there's a comfort in being able to be in a vibrant environment, without having to work at it, without having to engage with what's going on in the background."*

Between services, the choice of when to come and how much choice when present was variable - some patients are allocated a fixed day and given specific times of arrival and departure, whereas others can come more frequently and spontaneously. There are advantages and challenges to both in terms of service delivery, which were very frequently shaped by transport options for the hospice and local community.

Flexibility might be an advantage particularly for patients with fluctuating health and mood, as well as other healthcare appointments - not just practically, but emotionally, because patients feel they can access support if and when they need it. Despite this point of variation, even services with strict access policies or schedules emphasized the importance of choice within the patient experience for intervention success – no components being compulsory.

Furthermore, freedom to move between rooms and to make independent decisions on activities was frequently emphasised by service providers.

7.5.1.2 Feeling welcomed and included

Choosing to be there, of course, requires you to be included in the service. This involves formal access (and referral in some cases), but also practically the steps of being able to get there, safe to go there, and how you are there. There was a broad variation in the functional disability of people attending the groups included in this study, and some differences in the extent of disability that could access the hospice. In general, fellow patients and hospice personnel are at least somewhat ‘experienced’ with illness and might be less likely to express shock, sympathy, or obligations, being themselves experienced with the awkwardness entailed with receiving such messages.

Age gaps (or perceived age gaps) can sometimes make it difficult for a new person to approach the group and feel welcomed, although this was not a ubiquitous issue in every group setting. Some respondents mentioned that gender mix was also a factor. It is possible that diversity in staff and volunteers could make the setting more welcoming to a broader range of people. Several interview respondents explored how a traditional circle layout can look disconcerting for new patients, through associations with aged care and passivity. They were keen to emphasise how activities and atmosphere can encourage a person to feel welcome. Hospice staff, volunteers, and certain patient personalities act as hosts, helping to introduce people into groups and facilitating their inclusion in activities. Inclusion can require staff attention, especially in groups that have broadly different levels of functional ability, and some patients require extra support.

> *Grace: “I think sitting in a room with people treating you like a normal person and having a conversation - I’m very adamant that even people that can’t communicate at all, who are very disabled and can’t, should be included in group conversations. Because it’s just the hearing and it’s being included. We do quizzes and play games and we have a little crafts table. It’s just making sure that they’re completely involved. Because sometimes even here we are guilty of it, if someone’s blind and can’t move,*

> *can't speak, they would get left in a corner, but I really consciously make sure that even if they can't make a card, I would sit them at the table to make sure they're still involved, and I think that's the most important thing, is making sure they're involved."*

7.5.1.3 Enjoying the atmosphere and activities

People attending hospice day services for the first time can be surprised by how 'lively' or 'buzzy' they find the atmosphere to be. This is perceived by service-providers to be an uplifting and welcoming moment - patients might attend the building for a different reason and then find their assumptions about the environment were not what they expected. Atmosphere is therefore important for first impressions — but these aspects of the intervention are difficult to specify or indeed to guarantee in practice. A lively atmosphere might depend on a critical number of patients or volunteers to be present and able to engage that day, for example.

An enjoyable and inviting activity is a good way of getting people around a table, without relying on extroverted personalities. Facilitating and guiding conversations around the table was described in some interviews to be one of the key components of hospice day services. Activity is additionally important because it can enable conversation to develop naturally, without placing pressure on the conversation to 'happen' as would be the case in circle layout. Discussion around the table can become meaningful emotional support or useful information exchange, without having to be guided by a professional agenda. Some service-providers also acknowledged that these conversations might be most useful because topics are free flowing, and the physical or sensory activity might enable deeper communication to take place.

> *Jill: "Sometimes people use it [art] as a distraction from what's going on, and people get very involved. Different bits of your brain are involved when you're doing something with your hands, doing a creative activity - for others it actually helps them to focus on what's happening in their lives. They have difficult conversations, because they're looking at perhaps a piece of clay or modelling, they're more able to say what's really troubling them or on their mind."*

Enjoying the atmosphere and finding new activities might be a stark contrast to other experiences arising since the illness, particularly for people who are not frequently leaving the house except for appointments and obligations. Some interviews suggested that although individual psychotherapy and formal counselling have great value for some patients, they do require emotional investment and are not attractive to everyone. Social opportunities characterised by choice, inclusion, and activity might be less demanding and more relaxing, and thus more appropriate for some patients.

7.5.1.4 Aiming for something

Activity for activity's sake may not be sufficient, and many service-providers emphasised in addition that having a goal or purpose to aim for was useful for patients. Following an exercise programme or working on a project over several weeks is suggested to serve as an escape from rumination on clinical progress.

> *Mark: "Maybe 'cause we're not doctors, you know, we're not based on a ward and it's something different, gives people maybe a different focus as opposed to focusing on their illness, they can just focus on just the task in hand. And so, whether it's coming to the gym, or doing something and taking ownership of it and just aiming for something, it might give them a different way of thinking"*

Aiming for something can also include having a social routine and identifying with a social group – some have 'their day' or 'their centre' and aiming to contribute to this new setting represents a change in activity that provides further opportunities for personal reflection and growth. This ownership can go as far as bringing in relatives to see the centre or meet the group and patients requesting parties in which families and patients eat and mingle together (e.g. at Christmas).

7.5.1.5 Trust in the support available

People with a high level of health anxiety might sometimes need the presence of clinical staff for them to feel safe enough in the space to relax and express themselves. Even with non-clinical social groups, there is a suggestion that the perception of background support being available if needed is important for some patients and/or their carers. Their perception of their own safety might be a prerequisite of their experience of autonomy in the space.

Awareness of staff time and devotion towards care coordination and interagency working could have psychosocial benefits as well as practical ones. Hospice service-providers were observed responding long-term issues in the home, giving assistance with care navigation, and pre-empting emerging crises. The patient might come to trust the hospice is working to their advantage ‘behind the scenes’ and therefore feel relaxed and open to engaging with the social support on offer. Autonomy in the experience could for some patients depend on trust in the support available – a process of patient reasoning, built from the contributions of professionals and non-professionals, volunteers and patients, carers and bereaved. Over time, these experiences build a sense of credibility and trustworthiness in the hospice as a community of people:

> *Rachel: “We want to be much more about a community or a place or a support network that is ongoing but it isn’t always all about the professional specialities, there’s this connection with volunteers, with other people who are also living with the same conditions or problems, meeting other carers and relatives, so that we connect people but we’re not the sole caregivers, the ones that people come to rely on.”*

7.5.2 Familiarity between patients

Hospice resources provide patients with the opportunity to connect with other patients, with group activities supporting comradery and companionship. From a basis of shared knowledge, patients are able to give and receive meaningful support from each other, which can give rise to new friendships and psychological feelings of belonging. Exploring connections based on an equal patient status can give rise to opportunities to act in established social roles that are especially beneficial when experiencing perceived powerlessness in other relationships.

7.5.2.1 Companionship in activities and sociable mealtimes

It is noted above that participation in group activities and conversation, in and of itself, can feel beneficial. Throughout the interviews, a clearly important component of the hospice day service was the opportunity to come and be part of a group doing a fun and/or purposeful activity, having relaxed conversation, maybe reminiscing on things that are important, maybe chatting about the television. This companionship through group activity can be adapted in different services and aims, but its significance might be necessary for the development of familiarity between patients.

> *Gemma: "Coming to have a laugh and a quiz, it is important for people to meet as a group and have some lunch and chatter. They're doing their own bit of therapy isn't it, it's almost like we need to name that. We can glorify it a bit and make it like wow wee you know we've got art therapy, we've got creative therapy, we've relaxation, you know which is fabulous and really important and I think it's really important we do that.*
>
> *But the good old fashioned, you know, stand chatting, having a quiz and playing some scrabble is for those individuals really important for their day. We could never take those things away. Although they're kind of associated with old fashioned day services that people want to move away from, I still think they're important."*

The opportunity to participate in sociable mealtimes is sometimes missing from a patient's usual routine, which can make it particularly valuable for those people to eat a meal with others. Although many of the groups included in this study were not full-day interventions, there were still opportunities for patients to eat together, and this was valued by interview participants. Eating or taking a hot drink provides more opportunities for conversation that might include illness-related sharing or reflecting on the activities and goals of the group; therefore it allows for relationship-building and alleviating isolation for those that usually eat alone.

> *Amy: "They tend to develop their own relationships, we don't have to encourage people to talk amongst each other, they do that, with the group activities. The other thing that we find brings them together is actually going and having lunch together and going into the dining room. So if people are sitting on their own or having a tray [for meals at home], to actually go to the dining room, even if they've not sat next to somebody in the group or talked to them, the lunch is quite social, and that brings people together."*

7.5.2.2 Shared experiences foster useful support

Meeting other people with shared experiences seems to be valuable, in that it might serve as platform for useful advice (informational support) and empathic connection (emotional support). When patients reason that other group members have relevant shared experiences, it gives credibility to the opinions and advice shared within the group. This is particularly useful for motivating behaviour change and acknowledging potentially taboo topics. In this sample, service-providers were all paid staff and therefore professionals in their roles, but many felt that they learn from the patients, rather than the other way round.

> *Bea: "Patients are the experts, and patients are the ones that have been through it and we haven't been through it, so we don't know what it's like. But it's giving them permission to say what it's like and listening to that and valuing that. Patients say that is the biggest thing about coming here the peer group support, because they learn from one another and you're going to learn from somebody that's been through it rather than somebody that's not."*

Some service-providers suggested that clinical similarities between patients were important because it normalises their experiences, as proof it was not just them coping with the illness. In this way it allows individuals to feel less alone in their patient status and possibly more accepting of their situation. This could merit further inquiry, because hospices serving an increasingly (appropriately so) broad and diverse patient population might consider whether some diagnosis, age, or gender specific social opportunities would be useful to facilitate connection between patients if they observe some experiences diverging.

However, as the emotional side of palliative care can be overlapping between diagnoses, the authenticity in sharing first-hand experience is probably more essential than exact similarity. Knowledge received from a professional can feel less relevant to some people than the genuine experiences of trusted peers. There is potential for risk when patients with similar (but never identical) experiences share advice and perceive a high degree of credibility from each other, which mandates a role for some supervision at least in some contexts. In this quote, someone explains how they understand peer support within their service:

> *Mary: "I think the power of the group is that it's less about the professional telling people what they need to know, but more about the group supporting each other and sharing experiences. I think it's more real, truthful, it has more weight to it. It's got authenticity to hear someone else with the same issue, rather than a professional with the lanyard around their neck to say 'oh because you're ill the research shows this or that…To hear it from each other and to share it, it's the whole thing about walking with each other, walking in each other's footsteps.*
> *I think there is something about it you only really know if you're in it. We know that's true in our lives isn't it, if we're going through a hard time and someone says oh I understand and you think no you don't understand, whereas someone who's been through it you know they have understood. It is that shared lived experience."*

7.5.2.3 New connections developing into reciprocal friendship

It was near ubiquitous for service-providers to talk about the friendships arising within hospice day services. Helping patients learn from each other and watching new relationships flourish is a rewarding part of their roles. People accessing these services might be pessimistic about the possibility of meeting new people until they enter the setting – some patients are able and keen to make friends quickly, whereas others might be more reluctant to build trust and require more time 'to warm up' socially. Shared healthcare experiences facilitate friendships, but diagnoses do not have to be identical and the *necessity* of exact experiential similarity is not proposed here. People can build trust through time spent together, in a safe setting with shared goals, since, after all, patients are more than just their diagnosis. Several service-providers observed the beginnings of new friendships as indicated by exchanging contact details and spending time together outside the hospice.

> *Gemma: "There's a huge camaraderie. I think you get to a point of ok I've got this disease now, I'm a certain age, there's probably no chance of new friendships for me - and then they come here and they get new friendships, which is fabulous. They can share and be open about stuff, particularly the chaps, they can get together and talk about wives and the sexual kind of dysfunction bits and bobs, and stuff they perhaps thought they would never be able to share with anyone.*
>
> *It's kind of its safe because they don't really know each other. If I said something about my wife you're not going to hate me because we haven't been friends for 30 years… Is it something about a connection, about friendship? I think it's making that contact isn't it sometimes when you're kind of in the same place. You're both here because you're ill, you've both got a diagnosis of something that brings you here. There is that connection from the off and you can build on that, because it's a safe starting point isn't it."*

Meeting new people who do not know your 'pre-illness' self can be helpful because that person is less aware of the change you've been through, New social connections are perhaps less likely to express shock, sympathy, or obligation-laded questioning than existing friends and families. Patients might struggle with body image when socializing, particularly if they felt guilt or shame (for example about lifestyle choices associated with their illness), but service-providers felt that familiarity between patients and new friendships helped people feel less self-conscious, Furthermore, the space is separate from home life, and new friendships can exist independently to existing relationships, so that patients can share how they feel with more honesty and less concern for (e.g.) family consequences.

> *Carole: "it's a very open space, so people can be who they want to be and then they can put themselves back in their box and go home and be stoic at home if they want to be. I think that is the biggest thing people get from us."*

7.5.2.4 A break from patient status

To the patient, being in a room full of patients feels different from other social settings. Paradoxically, shared illness experiences can allow interpersonal interactions to move passed the illness and towards the person - questions about 'how you're doing today' aren't perceived as an interrogation into symptoms or prognosis, but as genuine queries into how you are feeling as a person. Feeling at equal with each other can be a foundation for meaningful emotional support that can develop into lasting friendships.

> *Katie: "they're able to come here, its feels like a safe haven and they're they forget they've got the condition, well unless they've obviously having the conversations, but they say it's a chance for them to actually feel like themselves again." Katie: "They feel that because people are in similar situations, they feel they are more accepted, it's like its accepted, it's just like an acceptance amongst them."*

Through reciprocal support and trust, people in the group are becoming a team, rather than (perhaps) a lonely patient. The presence of volunteers, rather than just staff, might be helpful in perceptions that they too have chosen to be there. It is proposed that (in some contexts) patients reason that this is a group they belong to, a group that accepts them and their illness-related changes while allowing them opportunities to be who they are 'beneath the illness'.

> *Danielle: "Maybe if you're ill and somebody else is not, that makes you different, maybe it makes you feel weaker. Maybe if you're just talking to people that are ill like you are, the illness becomes smaller, so you talk about other things… if you're mixing with everybody that's in a similar situation, you are talking about the football, because you're not different. I think if you're talking to somebody who isn't ill perhaps you feel less*

> *powerful and weaker, and so if you're on a more level playing field and there's a bit of mutual help there, you can give as much as you can receive."*

Useful and meaningful support encourages a process of trust-building and possibly the development of reciprocal friendships. The process of giving support that is valuable to someone might be as important as the receipt of this support - particularly in the patient's context if other opportunities and social roles have been lost or altered by their illness. This analysis considers that being able to *give* useful advice, meaningful emotional support, or just your time and company, to someone that genuinely wants it, is a valuable (perhaps crucial) component of hospice day services. In the patient context, there might be few opportunities remaining to give support to others, but this is an important human experience that we easily overlook:

> *Carole: "I think it enables some of the patients to give ,and actually I think that's important as a human being, to have something to give. You might've lost your ability to do the washing up and mow the lawn and all those kind of things, but actually if you've felt you've given something to somebody, even words of comfort, or you know you've distracted them for half an hour, or whatever - I think they get a lot from being able to give to each other. I think that's really important. It's one of the few things some of them can still do. So I think they get a lot from that."*

Giving support includes being an experience group member, welcoming in nervous newbies, or cheering on someone with mobility issues as they slowly make their way towards lunch. People are reactive to the health of other people, and patients give extra support to each other when they need it, but this might be perceived differently to the support received elsewhere. Some service-providers discussed how they allow or encourage patients to support each other, and how this was directly linked to their sense of purpose or self. Jokes, banter, and even arguments are opportunities for people to behave in social roles that might not be available for them since their illness. A helpful example is given by Jenny:

> *Jenny: There's an awful lot of laughter, quite a lot of banter that goes on inside the groups, particularly the more male dominated groups, there's a lot of micky taking that goes on. But if that's how people have always been why would that be different now just because they're suddenly Ill? If they've always been someone that takes the micky out of their friends or whatever and that's how they're used to being spoken to as well, I had one gentleman once, I'd been running this group, and he and another patient had a proper argument, like a proper row in the middle of this group, and I thought 'oh my God that was a complete disaster, how did I let that happen, how awful'.*
>
> *So after the group, I spoke to him about it and he was like 'oh it was great, nobody at home will argue with me anymore because they're worried that the last conversation we have will be a big argument'. For him it's actually quite important to have that kind of conversation. So, if it's appropriate and safe and reasonable to do, we let people create their own environment really. The overall environment people do talk about being able to express themselves and able to talk things through… but yes you get like the class clown, you know, there's one guy in particular who privately will tell you he's having an awful week, but in the group he's cracking a joke constantly and he is hilarious, but yes for him that's useful, it's useful to be the class clown for a bit."*

Sociable mealtimes offer many opportunities for people to fulfil personal roles by providing tangible social support for other people in the room. Roles included the class clown, the host, the mum figure, and the cynic. In some services, activities enabled altruism towards other patients, such as those currently inpatient, or to the hospice itself, through craft fayres or other community-facing events. These are opportunities for the patient to give something back to the hospice and seem to further enrich feelings of belonging to a community.

7.5.3 Acknowledging mortality and illness

Acknowledging mortality is considered a salient mechanism that was discussed in interviews and observed by the researcher occurring in different ways in different services. It is described here as psychological and interpersonal processes occurring within the safe space of the hospice and encouraged by patient autonomy and group familiarity. This set of interacting mechanisms is therefore a proposed explanation of how social support in palliative care can lead to increased honesty and acceptance of illness and mortality by patients.

7.5.3.1 Permission to talk honestly

A result of receiving a palliative diagnosis, for many patients, is increased thoughts of death, and their own dying. However, their context might mean the opportunity to speak about these topics honestly is restricted. It could be that attending the hospice group, with others that might be thinking similar thoughts, could provide motivation to come in the first place. Fellow palliative care patients offer valuable firsthand perspectives on the issues they deem important.

> *Amy: "Quite often they're asking what can I expect as I become more poorly and enter the dying phase, and that's a big one, and quite often something that they want to talk about amongst themselves, who else can you ask that's had that experience?... When people come they're always surprised to hear the amount of laughter that's actually going on erm and we can, it's strange but the patients can actually laugh at black humour, and they enjoy the normality of that because quite often they are not able to express those things at home, so this is a place where they can laugh at things that normally perhaps other people wouldn't find that funny"*

Permission to talk at their own pace, or not to talk, and to set the topics of conversation, are likely enabled by the autonomy and familiarity mechanisms already described. Ideally patients perceive they will not be judged for sharing or for choosing to stay quiet. Having permission to speak honestly might support patients in processing the change and losses they have already experienced and expect to experience. By admitting a change to someone else (even through humour), they begin to admit it more deeply to themselves.

> *Bea: "People just want to talk about what is it going to be like if I die, or where can I go to die, and they're just seeking information really. We hear that an awful lot - I can't talk about death and dying to my family because I'll upset them, or they don't want to talk about it, they think I'm morbid.*
>
> *It's really important to them, because if you have been given a life-limiting diagnosis the immediate thing, the immediate thing you do is to jump to death, you cut out the middle bit, you start planning your own funeral. Okay there is a lot in between that, but all they want is reassurance. Someone to say that when the time comes, we'll listen to your wishes and if you want to write them down we have these documents called preferred place of care… They say I can't talk to my husband about this because he just wants to make everything better."*

Allowing conversations to be fairly freely flowing (over activities), these topics can come up without being pushed, although many services did also have scheduled sessions and more direct promotion of advanced care planning etc. People might share deeper worries about families too – like what their partner might do after they've died, or indeed what they would do if their partner did die. Humour is an important process for communication and personal acceptance. A handful of interviews discussed how gender was relevant, in that opportunities for sharing, particularly about more difficult topics, are potentially more limited in a typical male context (this was often referred to as place-based eg 'Essex boys' and 'Wigan men' rather than universal gender statements – and is probably worthy of its own thesis). What is notable here is that permission to speak honestly and freely might produce emotion or humour, but both are potentially consequential.

> *Alice: "One conversation can lead to something else. We had a lovely situation where we're trying to get people to talk about their advanced care planning, what they might like, their funeral wishes, who*

> *they'd like to deal with their affairs when they can't deal with them. I can't think how we started talking about it one day in the lounge, everyone just sort of chipped in. Somebody said well I want egg mayo sandwiches at my wake, and although that made people smile, there was a really serious side to it and people were asking to see the nurse to start going through a more formal process."*

Hospice resources and professional input might support creative and therapeutic expression through other components, including art therapy and one-to-one counselling. It's possible that this work enables some of the sharing that goes on in the social group, and vice versa, so that the interventions components compliment and potentiate each other. Further, hospice staff and volunteers also provide much practical guidance towards making plans, putting documents in place, and making informed decisions. For patients with complex health, this can be a daunting and time-consuming process. Having multiple opportunities to begin to have these conversations with a range of different people and perspectives seems likely to be helpful for people facing the psychological challenges of planning for decline and death.

7.5.3.2 Seeing change in others

Within hospice day services, patients are often declining in health, although some are improving – from week to week, group members witness change in each other and in group membership as some people might die and others arrive. We saw previously that similarities in healthcare experiences are important – and clearly these allow the themes of death and illness to come through freely. But it is also the differences between patients, for example in their health status and prognosis, that help them acknowledge their own condition, experience empathy for each other, and perhaps shift their reasoning on their own situations.

Patients can use social comparison to identify who to reach out to for extra support, whether to seek advice or offer help. Upward social comparisons can give a patient some hope for positive change, and downward social comparisons enable patients to give support. A tactful encounter with a comparable person informs them of how well they are doing and potentially how well they *could* be doing. For progressive conditions, this can be challenging, but might encourage them to find greater acceptance in their current situation.

Seeing change in others might help patients to reframe their own context – when they are the only person they know living with illness, there are fewer opportunities for the patient to reflect on the relative upsides of their own situation. Empathy can serve as a cathartic experience, and for patients to witness change in their peers gives them reason to hope for positive change for themselves (could also give credibility to the intervention).

> *Lisa: "There's always somebody who's more poorly and they'll go, you know, but john's much more poorly he's much worse than I am, and that makes them feel better. That sounds really awful doesn't it, but it does make them realise, it just sort of tends to put things into perspective for them, that they're not really as poorly as - they are poorly obviously, but there are people who are worse. I think when they see that, that just puts things into perspective and then they go home and think actually do you know what, I can still live."*

Seeing people who are in worse health, or seeing people improve their health (eg through exercise), could be useful for motivation to participate in the programme or activities on offer. Opportunities to engage in light competition might be limited at home – so activities that enable people to compete a little might also be part of the enjoyment of some services, the thing that keeps people 'in' – and ultimately a confidence building aspect of participation.

> *Mark: "He is motivated by seeing somebody that he feels is worse, in a worse condition than him, that motivates him to get on and be living his life. But we have heard people talk about the opposite, so person A is able to do this or use the treadmill or whatever and so person B feels like they should at least try, because if that person can do it, then you know maybe I can do it as well."*

A group setting allows opportunities for comparison in different arrangements so that patients can derive hope in slightly surprising ways. Mixed diagnoses groups might well be beneficial in enabling this mechanism, as these might have a broader profile of clinical contexts while underlying themes of emotional concerns are in common. Some experiencing very low mood in that moment, might be more likely to be pessimistic when comparing themselves to others. Seeing people in a worse condition might provide information and motivation to put plans in place or make the necessary changes ahead of time – but these processes might also be distressing, warranting the need for empathy among staff as well as patients and volunteers.

> *Jenny: "it's amazing how often people will say I thought I was bad until I saw them, and that actually gives people quite a lot of strength. Last week I overheard one of the guys who's got heart failure saying to another guy who's got a tracheostomy and the heart failure guy was saying to him, "You're my hero. When I see you and what you cope with, it makes me realise I really haven't got anything to complain about."*
> *And the heart failure guy has got a lot to complain about. But in comparison, he's saying it gives me strength seeing that if you can cope with this, then I can probably cope with what I'm getting. I think sometimes that really helps… On one particular day I was seeing patients and three of the guys I saw all said I can't believe how he copes with it, and he's amazing, and I need to buck up my ideas to cope with it better. Seeing other people who are ill, but not necessarily having the same illness as you, I think is valuable to people…I guess it's all about perception isn't it, so the man with motor neurone disease yes, he was extremely disabled, but he still had a relatively reasonable prognosis. Whereas other people in the group that might have been a bit more able but were in the last couple of weeks of life. It's all about perception."*

7.5.3.3 Experiencing death of group members

Those attending a hospice day service are sensitive to deterioration and decline of others, and are likely to experience death of group members. This serves as a 'reality check', reminding everyone of their own prognosis. Service-providers commented they were sometimes surprised by how open and blunt the group members were, but that it was important to fully acknowledge and mark the passing of patients. The benefits of the relationships built in the setting might be offset by the emotional risk of bereavement, but these opportunities to grieve and acknowledge mortality might be helpful in developing acceptance of their own context.

> *Alice: "We go down to the Chapel and talk about that person, what they remember about that person, which is really therapeutic and people have said that when it's my time I know that you'll do that for me, you don't just kind of just peeter off into the wind you know we're going to remember you, you know for x, y and z."*

Acknowledging the death is important, but could be distressing for some people, and so some services chose to have a limited time for reflection, and/or an optional service or ceremony. Staff are not immune to the loss, and by processing the death together, patients might feel their own passing with be marked with such respect and positivity. Reflecting on the legacy of former group members might allow patients to reflect on what they have given to the space and how they will be remembered. For people living in isolation, their role in the hospice group could be an essential source of self-esteem and so the reassurance that they will be properly remembered and missed could be vital. By experiencing the death of group members, patients might be able to identity and broach their fears regarding the end of life, whilst also perceiving value in their group membership.

> *Gemma: "One person said this has really reassured me because when I die I know I'm going to be remembered and I think we were all quite emotionally affected by that comment, but its real reassurance, its completely voluntary you don't have to attend … but yes it's really important to remember people, for both, for the patient and for the group"*

7.6 Outcomes

The above section describes mechanisms to facilitate patient autonomy, feelings of familiarity and belonging, and a more honest acknowledgement of mortality and illness. The hospice is a safe space that provides resources which support these mechanisms – within this safety, patients can move towards new friendships, personal goals, group membership and perhaps better wellbeing. As we look towards outcomes, we see how social opportunities within a day service can elicit change beyond the walls of the hospice, and how the patient context remains relevant in determining the success of these interventions.

Interview participants described positive changes that might occur for the patient at the psychological, behavioural, and interpersonal level. This section introduces these as proximal outcomes, arising from experiences within the hospice day service, and how these can lead to changes in the patient's context outside of the hospice. Proximal outcomes can interact with each other; and aspects of the patient and/or hospice context can limit the extent to which they occur or how long they last. This analysis identified an ultimate outcome of 'Better Living and Dying', which refers to changes to living or dying conditions that might arise from positive changes in the patient's psychology, relationships, and behavior outside of the hospice, eventually leading to them living more active lives and being more prepared for death (see figure 31). Some interviews also discussed potential changes beyond the patient – occurring in the local community, and for healthcare providers, as well for the family and bereaved. The expression of observable outcomes can be inhibited by certain features of the patient context. In some cases, emergent outcomes of the intervention could influence the intervention context.

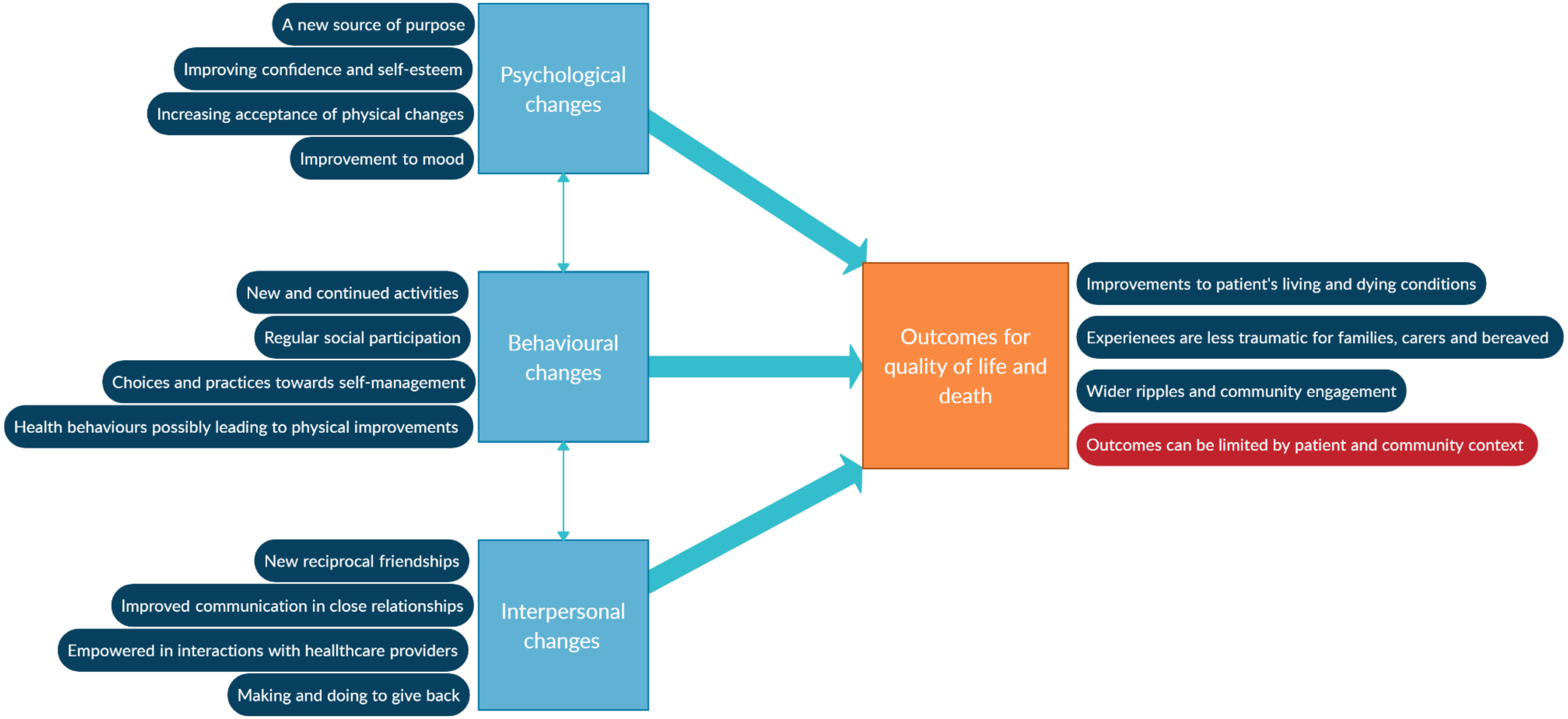


Figure 26: Psychological, behavioural, and interpersonal changes possibly lead to positive outcomes for quality of life and preparedness for death

7.6.1 Personal changes towards acceptance & adaptation

The mechanisms described above elicit feelings of belonging, independence, and purpose, which allow patients to experience a transient sense of normality in their patienthood. These psychological experiences might support improvements in personal confidence alongside a gradual acceptance of physical limitations.

7.6.1.1 A new source of purpose

This could be derived from feelings of belonging in the group, or from aiming towards (and hopefully achieving) a meaningful personal goal. A common idea across interviews was that attendance at the hospice provided something to look forward to. Feeling that other patients ‘get it’ offers a sense of normality that might be absent in their personal context. Despite all their limitations, patients may be learning new things, building new friendships, and witnessing other people’s achievements. These experiences are enabling in that they build confidence, but they also contribute to acceptance by providing the motivation to, for example, adapt activities rather than giving them up all together.

> *Jill: “Sometimes its introducing people to new things and saying you can still learn something, even with all this going on. It can be very, very helpful mentally and psychologically and emotionally and of course, all the others get it in the group.”*

Having something active to look forward to, if it offers a new source of purpose, might also represent a break from the passive routine some patients might experience in their homelives. Those who are isolated or seeing family irregularly, or those who are surrounding by loving and protective relatives, might lack choice and control in their social routine. Centres that allow flexibility in attendance are socially different from other contexts which dictate when the patient must be there. However, even if attendance is weekly or fortnightly, a reason to get out of bed and get ready to see the world is valuable to many patients. Furthermore, the hospice setting can enable the patient to reapproach activities they had previously found a source of purpose or enjoyment, by providing advice for adjustments and encouragement through patient camaraderie. Katie describes why she thinks patients benefit from attending an urban hospice day centre:

> *Katie: “They know they can come down to the centre and access the support that we’ve got here or work on the project that they might be doing. It gives them a bit more focus. I use the words that they come back with. A lot of them describe it as giving*

> *them a sense of purpose again. They feel that they're not being dictated by the condition, one lady said to me she feels she's got her self back… by having the Centre it gives her that sense of purpose to get up in the morning, she knows it's there and it will get her out the house. It means she puts her make up on and she'll get here, and then on a Wednesday if she's been, she knows she can manage til Monday… People have thought they can't do things and then we've shown them that they can."*

7.6.1.2 Mood improvements

Mood improvements were described very commonly, with many factors having the potential to contribute. Time spent in a lively, sociable atmosphere was referred to as 'better than any medicine' by some service-providers. This analysis suggests that autonomy, familiarity, and honesty experiences within a hospice might help patients adapt to the changes they've experienced. Making positive changes requires us to think that positive change could be possible in our circumstances – palliative care patients might be lacking in reasons to hope, but the experiences of aiming for something and seeing change in others might be helpful. Patients may feel less fearful, or have more peace of mind, having shared their fears around sickness and death, and may have benefitted from processing their emotions around mortality within the group, allowing for mood improvements in daily life. Patients experiencing loneliness and low mood might present quite differently in the first meeting than they do after a few weeks with the group in the day service – several service-providers described remarkable shifts in mood following attendance, including reduction of anti-depressant prescription. Mood improvements could be related to long-term personal confidence and perceptions of support after patients stop attending the service. In this quote Carole describes positive psychological changes experienced by some patients:

> *Carole: "They're happy enough and supported enough and confident enough to go and do whatever it is you've identified together that they're going to do."*

7.6.1.3 Increasing confidence and self-esteem

Experiences of social support might encourage an acceptance of physical limitations and hope for positive change. Mood lift makes a difference to functional ability and participation in daily activity, and vice versa, so that patients may experience physical improvements they did not expect, or go on to access other things in society that might not have been available to them before intervention. This suggests that the patients are more able to make positive changes to their living and dying conditions if the intervention improves their confidence outside of the hospice. Note that ‘taking it home’ is not guaranteed, and might be limited by, for example, family attitudes or financial resources. In the quote below, Lisa explains how trying new strategies in a clinically supported space can be beneficial in the long-term:

> *Lisa: “I think for the person that confidence building they do take home, definitely, and that’s what goes back to talking about that safe environment. They know it’s ok to try something here, because there’s that back up of the nurses here or maybe equipment needed to manage a situation, it’s all here. So if they can try something, it means when they go home they might do that again, and not feel so worried about it because they’ve got more confidence…They’ve got to want to help themselves a little bit as well, because they’ve got to be open to using the techniques and trying to utilise it within their daily life, when they go home after, they’ve been taught the strategies of how to do it. There is a lot of empowerment and confidence building and things like that.”*

It’s possible that shifting emphases on empowerment and autonomy with hospice contexts (often discussed in interviews in relation to patient transport and group ownership) might change the quality of confidence-building derived in these settings. Much more work is needed to evaluate this change and to unpick the interaction of empowerment narratives from the accessibility of these services for the most disabled patients. Despite variation in the ethos of these services, descriptions of psychological outcomes were relatively consistent across respondents, although some placed more emphasis on behavioural outcomes and the psychological benefit of having a goal and working towards that goal. In this quote, Mark describes mood improvements and feelings of personal control arising from aiming for a goal:

> *Mark: Once people know what they can do and what they can be capable of, that gives them a bit of a boost. … Its making them see for themselves. It’s not us throwing the seed in there but it’s just us making them see it, ‘cause sometimes you don't necessarily see, especially if you're going through it, maybe a treatment plan, you don't necessarily see the positives in stuff. It’s quite easy to look at the negative… They might be able to do more, might be able to believe they can do more and also they can aim for something, so even if they don't achieve it, at least they can aim to get something, and it gives them a sense of control over their own lives.”*

7.6.1.4 Healthy activity and social participation

These personal changes are reinforced by behaviour changes reflected in adaptation of previous activities, uptake of new activity, and increased engagement in healthy behaviours. Change in practices and personal choices can support increasing activity even if improvements to physical health are not possible, for example greater mobility allowing for ongoing social participation. Group discussions on fatigue management, dietary advice, and adaptations to try at home help the information conveyed by the intervention to be taken on board by the people in attendance.

Experiences within the hospice enable continued activity outside the hospice through practical adaptations and psychological confidence. An individuals willingness to try adaptations, and to overcome the stigma of accepting equipment, could be influenced by the group environment. Some participants specified that willingness to accept equipment is encouraged by familiarity between patients because it helped them emphasis that this supportive item is there because it’s practically useful. In another example, patients learning to recognize and manage anxiety with relaxation strategies, was facilitated through discussing the experience with others, and through the credibility they place in each other, they might be more likely to actually use them when necessary. Being psychologically able to accept this help and willing to try new things is necessary for the patient to benefit fully from the components available:

> *Bea: “It’s about recognising and accepting and coming to terms with a new you really. Erm and probably accepting equipment, which is also a big stigma, you know, if they were to sit down on a perching stool ironing, for example, then they’re going to use less energy ironing.”*

Increasingly, hospices are offering early intervention groups that include some self-management education with the opportunity to build connections between patients. Some groups aim to kickstart friendships that will continue, perhaps with a shared active or creative focus. The idea here is that ongoing support can be derived without hospice resources, improving patient resilience before that is needed. By including people that might not yet be in the palliative phase, people are introduced to the hospice community earlier, and this approach might help deconstruct some negative conceptions of hospice by spreading word of its (e.g.) creative arts or exercise programme.

> *Jill: "So they come to this group for up to 10 weeks and what we try to do is encourage them to continue with the creative activities and meet up outside…. We're suggesting the ones that really get off on perhaps the clay work, we might suggest to them, they have their own clay. They might not have a kiln but there's plenty of people that do pottery round here. So that's one thing but it could be that we suggest well you only live there, you live there, instead of spending money on a taxi to come here, why don't you meet up and do card-making? So, there are ways we try and encourage people to keep that creative space going."*

The earlier the access, the earlier the patient can begin to regular engage in healthy behaviours, which might then improve their functional and social trajectory as the illness progresses. Continuing exercise or art and potential social participation outside the hospice is context-dependent, but there were many examples of solutions in even rural contexts.

7.6.1.5 Self-management and resilience

Overall, an increasing acceptance of illness can encourage changes in response to limitations and confidence to try new things despite these limitations. Psychological acceptance might be observed behaviourally through adaptation and planning. Supportive relationships can improve a person's resilience to cope through low mood and symptoms. Increasing equity in social exchanges can improve mood, and the social context also allows for the learning of skills in self and illness management.

> *Lisa: "It isn't just about having company; it's about having all those other things. It's about having ways to manage if you're feeling lonely, or if you're feeling low in mood, or if you're feeling that the symptoms get really bad when you're on your own."*

Home visits are also a feature in identifying potential hazards or opportunities for improvement and encouraging the patient to address these – something as simple as a hallway light, perching stool, downstairs bed, or extra help tidying up might make a big difference. Ultimately the patient is more resilient at home than they would have been otherwise, but in hidden ways. Trying to prevent hospital admission might be as direct as this, but there are also indirect effects of these social opportunities in supporting the patient's confidence to manage with their illness.

Ideally hospice is a life-changing experience that breaks a vicious cycle established from illness-related loss. However, a few service-providers spoke of anguish around designing suitable discharge procedures, wishing to maintain psychological and behavioural gains for existing patients whilst effectively withdrawing their support to allow more patients to benefit from complex multidisciplinary services. In this section we see that continued health behaviours and fulfilling activity might be arising alongside and within continued social participation, which may improve resilience in illness by adding more sources of support to the patient context.

7.6.2 Interpersonal changes in roles & relationships

This analysis has described how interpersonal interactions occurring over time in a safe setting, from a basis of shared experience, could lead to the development of new friendships, characterised by respect and honesty. Confidence is built through familiarity with other patients, enabling the person to feel less 'a patient' and perhaps also able to better communicate within their existing relationships. A notable feature of complexity here is the time spent together, which is not always guaranteed in the 'non-traditional' service models.

> *Carole: "You almost have to come a couple of weeks to see it, but we call it magic, we don't know what the magic is but the magic definitely works - I think it's the relationships they build."*

7.6.2.1 Lasting new friendships

New friendships are identified by service-providers as patients being in touch with each outside of the hospice, and in some situations last far beyond the length of the intervention (including, for example, inpatient visits further down the line). Some interviews suggested a sense of matchmaking pride from service-providers – this is part of their role of facilitating social support – empathizing enough with everyone to foresee who might get along. If these friendships are indeed lasting, they provide a continued support of support after discharge – this support is not based on sympathy or obligation, but rather a willingness to listen and understand during the bad days.

> *Bea: "They can only stay here for three groups on this service and then they're discharged, very often the problems are still ongoing. We've helped them but the problems will always be there. So they've set up their own support groups, they've made lots of friendships and if they're having a bad day they don't need to say that they're having a bad day, people know, and they just support each other."*

Service-providers that had limited the use of patient transport reported that experiences on ‘normal’ patient transport had been beneficial by boosting their confidence to maintain activity and friendships, even after discharge from the service. Although not available for all patients, arrangements that reduce transport might be enabling the development of some of these friendships. There is a risk of conflict that places pressure on staff during changes to procedure.

> *Grace: “We’re encouraging people to make their own way, which has been quite a challenge, but we’ve got some people that are sharing cabs now, or husbands taking them and picking them up. So that’s forcing them to build friendships outside of here, and continue their friendships outside of here, which I really try and encourage now… I’d say that particularly this one group that we’ve moved on, they are all fairly mobile, so they didn’t need transport anyway. It’s almost made them a community I’d say. If anyone dies, they go to all their funerals, they go and visit people in hospital, so it’s really a proper friendship group.”*

7.6.2.2 Improvements in existing relationships

There are direct benefits from carers having a break, particularly when caregivers are able to use the time effectively. But the benefit for existing relationships here goes beyond respite. Through doing something new, conversation might be opened up, and experiences at the hospice give people something else to talk about when they get home. Some caregivers attend with the patient – for the carer it is a break from the stress of being solely responsible for someone, and therefore still might be a change from the patient-carer dynamic at home. During time spent in these services, people might practice conversations with other patients or peers, this rehearsal in a safe space builds confidence to then try more honesty with their loved ones.

> *Lisa: “It’s about talking, sometimes talking to family about certain things. They might say I can’t tell my husband that, oh I can’t tell my daughter that or I can’t tell my son. So it’s giving them the confidence to do that, and sometimes it’s how you say it isn’t it. But yes they do sometimes try it out with each other… we can help facilitate that if needs be or talk to them about what they’re actually worried about, and just open that up a little bit, what their concerns are or do you think maybe that your daughter’s already*

> *thinking this but you are both protecting each other, and it's just opening that up and it not being like a taboo"*

Adapting to the new strains of illness within relationships is supported by advice and coaching from hospice staff and fellow patients. People might need to allow partners and friends to take on more tasks and accept that they might not do it in quite the same way.

> *Bea: "Because nothing will be done in the same way as what they would do themselves and it's about changing their mindset to say actually yes. But the other partner is learning to be able to take those rules and responsibilities on, they won't be in the same way or perhaps as well as what you would do, but actually they're gaining some skills under the belt."*

Through identifying and working towards a goal in a group setting, patients gain functional ability as well as confidence to participate in social activity. Examples could be getting into a car, being able to play with grandchildren, or better stability standing and walking to see friends. Some will directly facilitate patients getting out of the building to join a local gym, which represents a less secluded arena for people to further develop social confidence by participating in healthy activity alongside people who might not be patients at all.

7.6.2.3 Interactions with healthcare providers

Improvements to mood and knowledge about illness increases personal confidence in self-management ability, and that might also correspond to chances to interactions with healthcare providers. Several interviews reflected on patient empowerment as having the potential to change use of other services, perhaps relating to avoiding a crisis or improving symptoms. Some offered explicit guidance on getting the most out of healthcare consultations and when working with social services. Even without formally addressing this area, beneficially psychological outcomes and improved communication within the family might also correspond to improved communication within the clinical encounter.

It's possible that hospice experiences could help to improves healthcare communication during interactions with clinicians. Crises could be avoided, alongside wellbeing improvements, care coordination and effective care planning – when these outcomes are achieved, there is a potential for substantial difference for the local healthcare system. Some hospices contribute substantially to care coordination and might be able to, for example, shorten length of stay or the wait for patients' notes in the event of an unplanned hospitalisation. They might directly highlight to patients that there is an alternative to their current care trajectory, talking to patients about how they could improve the care they receive, right up until death:

> *Gemma: "We'd say you've been into A&E, crickey, three times in the last week, and the last time they maximised your steroids, they maximised your antibiotics, and it was no benefit, you're still very breathless. So then, you know, you're coming to the end of life. Often there comes a conversation where actually hospital is not worthwhile. In that situation, we put the care plan together, A&E know, 111 know, 999 know, family know, patient knows.*
>
> *If that situation were to happen again, we give the alternative - ok stop phoning 999, 111, phone us here at the hospice. And then our nurse would come out, and administer Lorazepam or something to relax you, some morphine to slow that breathing down. If we knew it was more end of life, then we can give supportive care in their own home, or they can come into the hospice."*

7.6.2.4 Giving back to others

Overall, hospice experience is different from the interpersonal context described earlier. Patients might be able to fulfil previous social roles and talk about interests other than illness, in a setting in which they feel relaxed. The activity within the space challenges assumptions about the passivity of illness and the morbidity of hospice – perhaps enabling patients to better express themselves, and more clearly reflect on mortality. Many of those who have benefited from hospice intervention feel motivated to give back specifically to the hospice itself – as a charity, it enables this transition from patient to advocate through, for example, accessible fun runs and Christmas fairs. Making and doing to give back the hospice is useful beyond its fundraising potential. Opportunities to give back to others might be a crucial ingredient in alleviating patient loneliness, particularly when thoughts of dependency and decline are fuelling distress.

> *Katie: We haven't actually had to instigate it, that sense of purpose that it generates for those that are not working - they've lost that role and they've learnt about finding crafts they can do and they've created these items, and they took it upon themselves to do a garden fayre and selling what they made and it was just fantastic.*

> *They did it all, so again it was empowering them, it was enabling them to organise, and they were responsible for it and had a sense of purpose… it's very much they come up with ideas and run it by us… I think the people in the room feel that they're giving something back, that has been interesting, they're helping us."*

7.6.3 Outcome: Better living and dying

Defining a specific route to 'better' living and dying is not congruent with the person-centered philosophy of the hospice movement. The outcomes that matter are, generally speaking, the outcomes that are right for the patient. The service-providers in this project commonly used patients' ability to perform activities of daily living and participation in meaningful wider activities as indicators of 'better living', with patients' agency in their care plan, acceptance, and support at the end of life and possible bereavement care as corresponding to 'better dying'. Some participants placed much more emphasis on how patient-level outcomes can ripple into the community supporting changes in the wider context towards 'better living and dying'. It would be interesting to explore these concepts with patients, to explore their perspectives and experiences more specifically, rather than those of the service-provider.

This chapter has considered in detail numerous aspects of context, mechanism, and outcomes, leading to an overall outcome of 'better living and dying'. At the end of this section, the chapter turns to configurations, which explain how this broad array of context, mechanism, and outcomes might fit together.

7.6.3.1 Changes to living and dying conditions

Hospice resources provide practical and professional input towards symptom management, care coordination, and advanced care planning that is facilitated by social support via the mechanisms discussed above. In doing so the hospice helps patients to look ahead and thus make preparatory changes as needed. Input from hospices help families to navigate the system and get the outcome they want, which helps them avoid negative outcomes and a loss of agency in the healthcare interaction. Changes to living conditions might enable patients to participate more in health behaviour and meaningful activities. Changes to relationships (new and existing) increase the resilience of the network around the patient. Furthermore, improving opportunities for reciprocal support and empathy could increase acceptance towards dying and allow for adaptation to illness.

Person's context is important in what they want at end of life and the people around them contribute to this goal being achieved. Patients arriving at hospice day services might have had a particularly difficult spell of healthcare experiences affecting their function and confidence. In some cases, the hospice appears to be acting as an NHS safety net, preventing hospital admissions for otherwise frequent attenders by managing symptoms and supporting the carer. In other cases, it is an active rehabilitation service, providing physical, emotional, and social rehabilitation opportunities after lengthy illness and treatment experiences. Subtle changes in self-management might avoid hospitalisation but evidencing this is challenging.

> *Lisa: "A lot of what we do is preventative, keeping people well, managing symptoms so it doesn't turn into a crisis, and carers feel supported. We do a lot of care planning, advance care planning and looking at the future… We quite often will see them come here off the back of multiple hospital admissions, and then our job is do the confidence building and the monitoring of symptoms, have you got things in place, what would you do if this happened again, and not just about the patient but the family too."*

Seeing patients in similar or more advanced conditions to their own might inspire care planning ahead of time. The challenging experience of being confronted with one's possible future could deconstruct avoidance, enabling the necessary consideration of one's mortality to identify preferences and opportunities for agency towards the end of life. These are emotionally-laden processes - people can need time to understand these decisions and their implications, perhaps in a place separate from usual home life. The time-limited aspect, so tricky to negotiate around discharge, might be sometimes seen as a necessary motivator for people to face up to difficult topics and make these changes to living and dying conditions:

> *Rachel: "This idea that its coming to an end after a certain amount is why it's so key, that it doesn't become the respite in of itself, that it's almost like a therapeutic intervention to help people to set up their lives better.*

7.6.3.2 Outcomes for families, carers and bereaved

Discussions within the hospice environment help allow plans to be put in place and care to be coordinated – these can both allow for hospital avoidance and increased support for the family. Support for patients can reduce stress for carers and families, particularly if the patient is in less distress or is more active in life. Furthermore, lack of emotional expression within families might increase distress during bereavement, but hospice experiences might allow for increased communication within the family and the renewal of long-term bonds.

> *Katie: "Her sense of worth just increased and she started doing more, she was laughing again…I saw her husband and he just said I feel like I've got my wife back."*

Occasionally service-providers witness a family member seeming to shift in their behaviour towards to hospice as they become more accepting of the illness themselves. Distressing experiences towards the end of life might lead to complex and difficult bereavement, and thus avoiding these experiences could have outcomes for families and carers. There are lasting changes within the family and beyond, that might be triggered by hospice groupwork, and could contribute to better outcomes throughout the family by encouraging more active coping and trust in services ahead of future life events.

> *Patricia: "It will really change the trajectory of whether that family feel they can trust the health service. I would also challenge that then stops those families from presenting badly as well. Because if you've had an awful death with one of your family members, you will have less trust in the health care services, you will be more inclined to ignore your own symptoms, because you're frightened of dealing with a health care service that managed it badly.*
>
> *So then you yourself will present late, there will be fewer options to fix you, and you will self perpetuate onto your younger family who have the same. It goes round and round. It's not just about preventing that one interaction with A&E, it's about changing people's health behaviours.*
>
> *Because if you're not frightened, because I did well by your husband and your dad, then you'll tell your GP when you're frightened there's something going wrong with you, because you think people will stump up good, and you will see the benefit of telling somebody there's a problem earlier, rather than when you were in crisis."*

Experiencing a loved ones 'bad death' is a personal experience that at a population level becomes a determinant of poor mental health, via complicated bereavement, and physical health, via help-seeking behaviours. Therefore achieving 'better living and dying' has the potential for generational ripples within the family and community.

7.6.3.3 Community changes and wider ripples

Some interviews referred to community engagement approaches that increase social opportunities for patients whilst potentially challenging a societal stigma of towards hospice and visibly sick people. Early referral clinics and open access groups for the newly diagnosed might have ripples into the community, changing hospice reputation and introducing more people to hospice support. Different amounts of community engagement between sites might reflect different amounts of 'openness' in their strategy as well as different opportunities in their local context. Supporting patients to access 'normal' leisure groups and transport through discharge contributes to this effort by increasing the visibility of illness within the local area.

> *Rachel: "I wonder whether hospice's being these places of perceived death and dying is because it has been so closed. People have come in and then we've done stuff within here, that isn't out there. I think we have got a need for the doors to be open and show what we do out there, and I think part of that is releasing people back into the community to do the living with disability, in illness, back out in their own communities. That is a good thing. I think maybe hospice have done a disservice by bringing it away."*

Projects working with schools, or with work experience pupils, was a route to increase inter-generational contact and energy in the space, increasing the confidence of both groups and leading to highly rewarding interactions. Working with local clinicians and medical students to demystify their communication around death and dying was also considered helpful. This hospice runs a restaurant separately to the main building, which is a resource for community signposting and casual social support:

> *Danielle: "we wanted it to be a kind of community engagement really, to demystify hospice care, to bring people into the grounds for many different reasons. To really break down those barriers to hospice care, so if at any point people did need hospice care they would think oh well actually it's a really nice place…"*

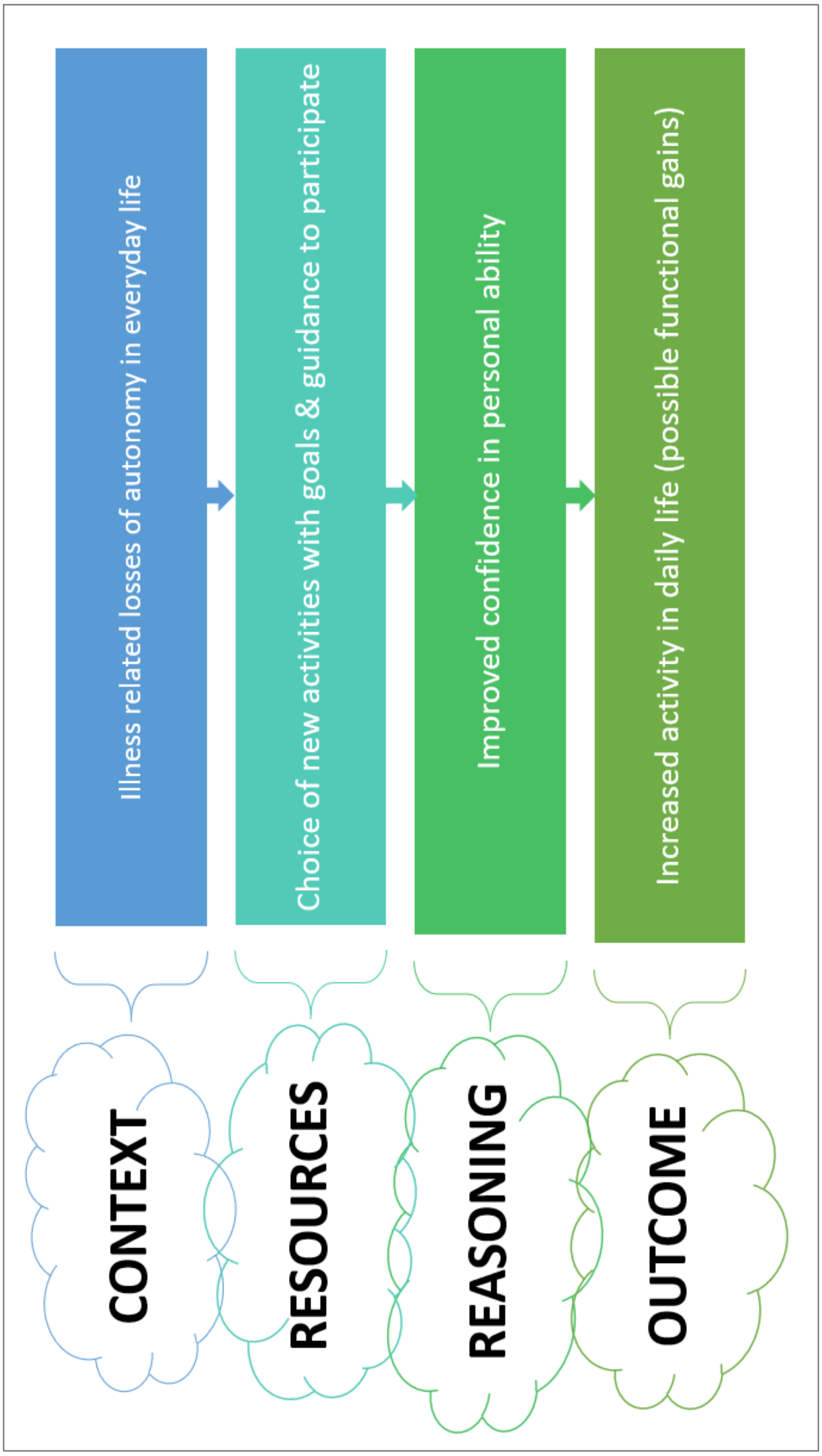
7.7 Context-mechanism-outcome configurations

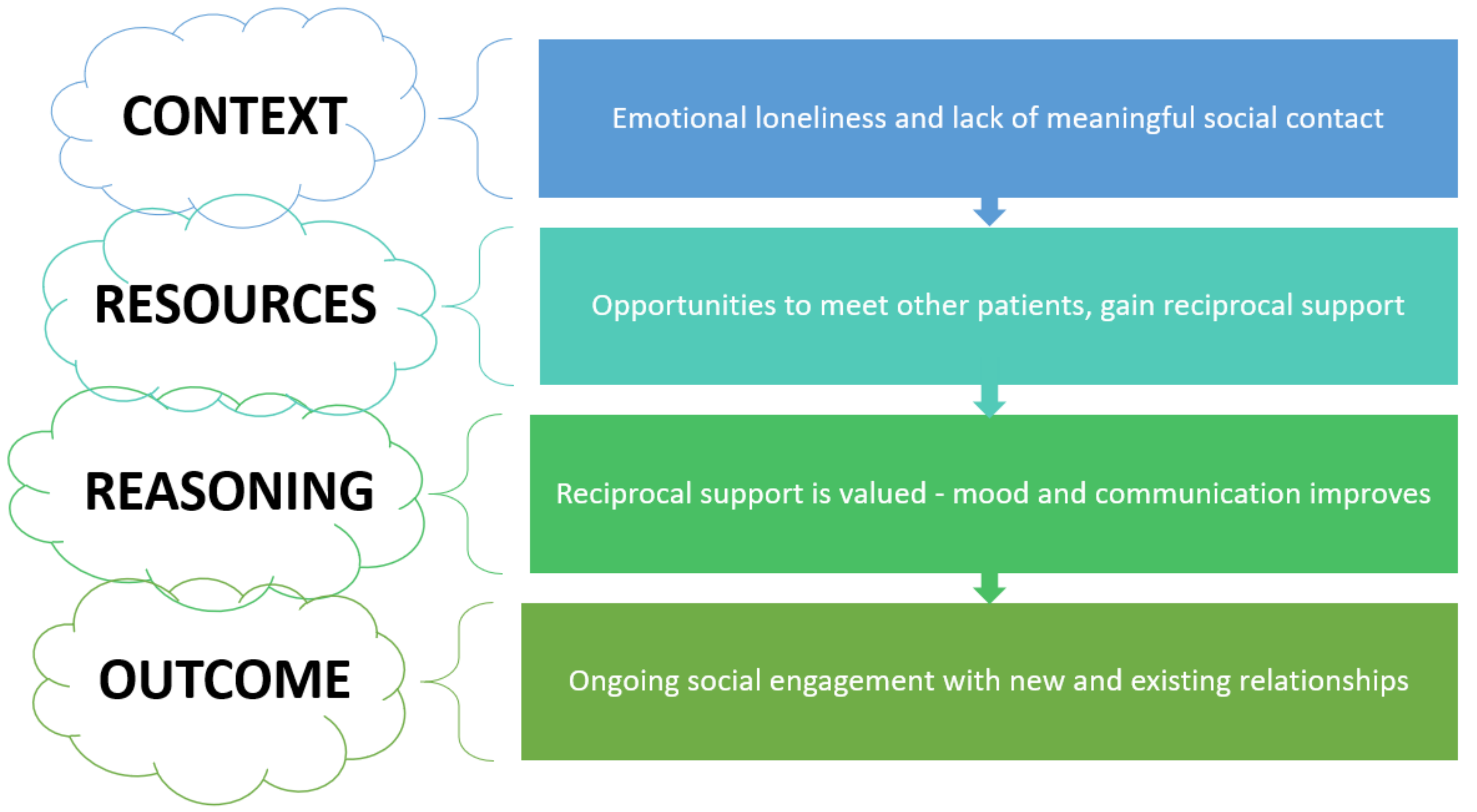
This section proposes configurations of context, mechanism, and outcome; reporting on an exploratory and explanatory analysis underpinned by the principles of realist evaluation. Early configurations are demonstrated here. These configurations could be empirically tested through observation of psychosocial variables and if possible, the application of mediation analysis. They could be elaborated further though additional qualitative work with patients and/or their caregivers, or the previously bereaved (using realist interviewing strategies in which emerging explanations are explored explicitly with the participant). The subsequent discussion chapter develops these configurations to contribute an initial programme theory of social support in palliative care.

The figures indicate specific patient contexts and interpersonal interactions that might in some circumstances ‘fire’ to produce positive change in stated areas of the patient’s psychosocial experiences, and possibly their observable behaviour (see complexity section below). As discussed in the method chapter, identifying a salient feature as either context, mechanism or outcome reflects the focus of the research question rather than an objective classification – interventions of different disciplines and evaluations of different scope will have different interpretations of what ‘counts’ as a mechanism or an outcome.

Figure 32 presents three context-mechanism-outcome configurations. In these figures, mechanisms are communicated as both resources and reasoning, reflecting how these components were approached differently during analysis: ‘resources’ shows what the hospice offers, and ‘reasoning’ shows how the patient internally responds. This interaction of hospice resources on psychosocial state might subsequently produce a behavioural (and therefore observable) outcome, implicating the role of time.

Figure 27: Configurations depicting a theoretical explanation of how applying hospice resources to patient contexts might influence patient reasoning, leading to specified outcomes.




CONTEXT
Emotional loneliness and lack of meaningful social contact
RESOURCES
Opportunities to meet other patients, gain reciprocal support
REASONING
Reciprocal support is valued - mood and communication improves
OUTCOME
Ongoing social engagement with new and existing relationships


CONTEXT
Death avoidance and stigma of illness
RESOURCES
Safe space gives permission to talk about 'difficult' topics
REASONING
Increased acceptance of own situation/mortality
OUTCOME
Change in behaviour
(eg) towards planning for/preventing decline

7.7.1 Complexity

This section briefly refers to points of complexity. Observations between different services were very helpful in showing different contexts at least for different hospices, if not for different patients. At this level of investigation there were notable examples of the ways in which outcomes might be limited by patient context, which bring in complexity to the causal chain proposed by the above configurations. Some interviews indicated emergent outcomes, in that the outcomes of the intervention can change how it operates or its context. Transport and discharge are issues of contention and perhaps risk: in different contexts they might operate as mechanisms towards beneficial change, in others mechanisms of exclusion and disenfranchisement.

7.7.1.1 Outcome limited by context

The effectiveness of an intervention could be understood as its ability to elicit interpersonal interactions that lead to long-lasting positive change. This type of effectiveness can be curtailed by enduring features of the patient's context that limit the possibility of change beyond the hospice setting. Motivation to engage with a service is drawn from the patient context – the living environment can influence the acceptability of an intervention and the patient's attitudes towards its components. For example, Mark theorises that the impact of an outpatient exercise programme is more noticeable when there are encouraging family members who provide motivation and prompt adherence to at home activity:

> *Mark: "It's nice to see when someone you know was hardly walking and really unwell, fatigue and everything, and then you've worked with them and they've like really turned things around. But I think what happens with some people is when you have someone who has a support network as well, like as well as coming here, they might have family or friends, that makes a massive difference. If they have like someone who can maybe push them at home to do things, then they're more likely to do things. For instance, if you give someone a home exercise programme to do, if there's someone there to hold them accountable, that can make a difference."*

The patient's economic context might reduce the observable benefit of an intervention, particularly because financial resources can be required to attend, or to adapt fully in response to the illness. Some hospices assist with patient entitlement to benefits or accommodation modifications, but they are limited in the amount of change that can be achieved. Furthermore, decision-making in an emergency is often up to the family members, rather than the patient, and if these people are not sufficiently ‘brought along’ with any changes, and equipped to deal with a crisis, then improved outcomes are less likely to be achieved. Shauna outlines this complexity in the process of avoiding a hospitalisation:

> *Shauna: “But you see the thing is, it’s not the patient that has the power at that point, it’s the relatives. If the relative is panicking in that moment because they’re very symptomatic and an ambulance is called, that’s what’s going to happen, they’re going to go to A&E. Unless that patient is able to convince the paramedics – ‘No, I don’t want to go to hospital’ then that’s where they’re going to end up, unfortunately. And what happens so many times is the patient does through to A&E and they end up on a ward and get a hospital acquired infection and they die in the one place they didn’t want to die… If the family don’t feel supported enough to keep the patient at home, they will always end up in A&E, because where else are they going to go?”*

Socioeconomic resources and cultural norms are relevant to social support in palliative care – this project grappled with disentangling their influence but notes their interplay. These forces shape the patients’ opportunities and vulnerabilities, their perception of the world, and people’s perceptions of them.

7.7.1.2 Outcomes changing intervention

These are emergent outcomes that add complexity by potentially changing the intervention content or its community context. There was an emphasis placed in some services on group ownership – the group being in charge of the group, and making decisions on topics or activities included. In some cases, this also supported community engagement, getting the hospice’s name out there while increasing patient opportunities to give back.

> *Katie: “A lot of the groups that we have set up have been in response to what people have said they’d felt they need as well… Erm so, we were going to be called Knit and Natter and they decided Wool Warriors… When we do the reviews we try and get ideas for future groups, and like that’s where they’ve come up with the fact they liked it when the solicitors did a talk about future planning. So, we’ve decided to do a workshop on it to bring in advanced care planning as well. And then a lot were asking about weight management, so we’re going to do an education session but trying to link*

> *in to what's going on in the community for them to then access. Because one of them, erm quite a few of them actually were fearful of going to like weight watchers"*

Encouraging patients to actively support the hospice or input into service design is suggested to be beneficial to them. However, changing interventions adds complexity to evaluation efforts, and shifting its aims might affect the volitions of other stakeholders. Volunteers and staff are responsive agents to change, and may be attached to their role, particularly regarding 'being nice' and pampering patients. Within teams, there might be unexpected emotional significance towards changes made to longstanding services. Allowing group members to make some decisions does seem likely to improve motivation for the people involved, but given the established access issues, more investigation is needed to see how this process might help or hinder context-informed service development.

7.8 Conclusion

This chapter presents an exploratory and explanatory analysis of qualitative interviews that is underpinned by the principles of realist evaluation. Hospice resources provide patients with the opportunity to connect with other patients, with group activities supporting comradery and companionship. From a basis of common of experiences, patients are able to give and receive meaningful support from each other, which can give rise to new friendships and psychological feelings of belonging. These experiences in common can be related to illness and body changes, but often there is more shared knowledge about the local area and years gone by. Mechanisms facilitate patient autonomy, feelings of familiarity and belonging, and a more honest acknowledgement of mortality and illness.

It was important for patients to have a sense of autonomy or ownership about being there, which included feeling safe there. Both practical and social aspects of the setting are important to patients feeling welcomed and perceiving safety, which encourages them to engage in the space, for example by joining in on conversation or activity. Opportunities to take a break from patient status and act in established social roles might be especially beneficial for patients experiencing powerlessness in other contexts. Within the safety of the hospice group, patients can become agents, moving towards new friendships, personal goals, group membership and perhaps better wellbeing.

Social interaction, group activities, and working towards personal goals can be valuable for self-esteem. These are opportunities to express agency and individuality as well as to gain the specified resources from each other. Having permission to speak honestly might support patients in processing the change and losses they have already experienced and expect to experience. Practices around death management (of group members, and towards care planning or legal preparation) might elicit acknowledgement of their own attitudes towards dying that is psychologically meaningful and opens the door to behaviour change.

Group, interpersonal, and psychological processes are entwined – together they contribute to the patient's motivation and their ability to participate in activities of independent living, including regular and meaningful social contact (i.e. to 'live well'), as well as to communicate, plan, and achieve, their end of life wishes (i.e. to 'die well'). These processes are enabled by the safe space, specialist components and experienced staff, but can't be reduced to these components. There are also potential changes beyond the patient – most notably for the family who have care and bereavement experiences that are less difficult than they might otherwise have been.

Social opportunities within a day service can elicit change beyond the walls of the hospice, but the patient context can limit the expression of behaviours, such that outcomes of day services are not expressed. Financial resources, attitudes and behaviour of family members and close social contacts, and cultural norms in the local community are highly relevant to social support needs and experiences for people with palliative care needs. Societal issues of inaccessibility and death avoidance could contribute to patient loneliness.

Chapter 8 : Discussion

This chapter will summarise and discuss findings of the previous three chapters, drawing on existing psychological literature and recent research. Exploring reports of patient and family experience in relation to the core mechanisms and suggested outcomes leads to the development of an initial programme theory for social support in palliative care and allows for contribution to the conceptualisation of social support. Reflecting on the insights gained and the challenges experienced from this methodological approach allows for guidance to future researchers.

8.1 Summary of Findings

An online survey was used to understand what services are currently offered by hospices to facilitate social support. Questions were asked on hospice characteristics and the services provided. Responses were received from roughly half of the eligible hospices in the United Kingdom and Republic of Ireland. Respondents were day service leaders or equivalent roles, who each respondent identified a maximum of 8 services that they felt offered social support to patients. Multi component interventions such as palliative day care were most common. Although these tend to offer medical care with stated aims that focus on clinical aspects such as symptom control and monitoring, 70% of survey respondents considered these multicomponent interventions to be the ‘most social’ service at their hospice. There was a huge variety of activity groups identified, as well as formal support groups, and informal social activities. Over a third of the services identified were described as drop in by the respondent. Outcomes were not routinely collected by 73% of the services reported in the survey. The survey concludes that most hospices offer at least one service in which patients might obtain social support, but there is site level variation in aims, personnel roles, transport provision, and the number of spaces available.

Patients who were about to start attending or had recently started attending a service that facilitated social support were recruited to observe patient-reported outcome measures in domains of perceived social support, loneliness, depression, and health-related quality of life. Although thirty patients were recruited, only nineteen completed the second timepoint, and this dropped to five patients completing the third and final timepoint. Between timepoint one and two, five patients died, one stopped attending due to health decline, two chose to stop attending, and three withdrew for unknown reason. This is a very small sample and attrition is high so the following results should be interpreted with caution.

Collecting the reasons for attrition was a very useful aspect of this study, helping to establish that the reasons for attrition was most often death or decline – these were palliative patients. However, some did choose to stop attending. In this sample, those who chose to leave the study appeared to have higher self-rated health, and self-rated health decreased very slightly over time for those that stayed in the study. Comparing participants by attrition reason showed that patients who died appeared to have a higher perception of social support, less loneliness, and less depression at baseline. This was not significant for perceived social support or depression but approached significance for loneliness. Those with an unknown attrition reason appeared to have higher loneliness, lower perceived social support, and were more likely from a deprived postcode.

Most participants reported moderate or several pain, and moderate or severe problems with mobility at baseline. Problems appeared least common in the dimensions of anxiety & depression, and self-care. However about one quarter did describe themselves as being moderately or severely anxious or depressed, and just over a third experienced moderate or severe problems in self-care. Differences between the first and second timepoint showed significant differences with problems increasing in the domain of self-care between T1 and T2. Trends were for problems in the domains of mobility and daily activities to decrease between timepoints, and for problems with pain and anxiety and depression to decrease slightly, but these were not statistically significant. Correlations between timepoints were significant at the 0.1 level, suggesting this measure might be used in palliative care to describe patient context and compare populations, rather than necessarily as an intervention outcome.

The mean change for overall social support for these nineteen participants was positive, but this was not a significant difference in this sample. The subscales were affectionate support, emotional support, tangible support, and social interaction. Change was not observed in the affectionate support subscale: the mean change was (slightly) negative. This also showed the least variation between people. The emotional social support subscale showed the largest mean change between the two timepoints, a high t-value, and p-value <0.5. This demonstrates that change between first and second timepoint was largest in the domain of perceived emotional support (n=19). A similar pattern was seen in the available data at timepoint 3. Tangible support and social interaction subscales showed slight positive change. Loneliness was observed to decline between T1 and T2 (n=19) and this appeared to be significant. Depression was observed to decline overall between T1 and T2, but variation was high, and the result was not significant.

Change in psychosocial domainsmight have been different for patients who lived alone, compared to those that lived with other people, and between male and female patients.

Nineteen service-providers took part in qualitative interviews. Their different job titles included nurses, support workers, art therapists, physiotherapists, social workers, and managers. The interviews explored the hospice services and the interviewee's perspective on the significance of social support for palliative care patients. All sites had a minimum of one full day participant observation of services, up to 3 days when a large variety of services were available. Observations of hospice day services by the researcher allowed for an embodied experience of the setting, which facilitated these conversations, and led to rich descriptive fieldnotes. The observations were important for me to appreciate some of the less tangible differences between services, particularly the pace and atmosphere. It was also my main opportunity to informally chat with patients and volunteers.

In realist evaluation, certain aspects of context interact with the hospice resources to 'fire' and produce mechanisms of change that might lead to observable outcomes. The interviews with service-providers were analysed for context, mechanisms, outcomes, and these were then constructed into configurations. The analysis led to a very detailed description of the patient's social world, detailing relevant aspects of the personal, interpersonal, and wider context; proposes a set of interconnected mechanisms at the psychological, interpersonal, and group level; and suggests how proximal outcomes arising from experiences in the hospice day service can lead to changes for the patient outside the hospice.

The patient's context is shaped by the experience of living with illness. Their health context may include draining symptoms such as pain, fatigue, and breathlessness, and their social lives might also be limited by complex care needs, medical appointments, bodily changes, and the effects of treatment. A difficult health and emotional context disrupts normal life and it can exacerbate loneliness when there is miscommunication and disempowerment occurring in existing relationships. People losing access to their previous roles in society can be increasingly treated as a passive sick person. In the wider context, inaccessibility, loss of community resources, pressure on public services and death avoidance can all shape the patient's access to social support. Overall, the palliative care patient is at risk of a vicious cycle of increasing loneliness and social isolation. The patient's interpersonal context shapes the variety and adequacy of social support available to them – it determines the need for intervention and shapes the outcomes of that intervention.

Identifying what the interventions had in common was an important step in understanding what was being offered and how this could be explained in terms of mechanisms. These resources are overlapping, but roughly defined as – a safe and accessible space, time-rich people who are not avoidant of illness and dying, and specialist components delivered by clinicians and other professionals. In providing these resources, the hospice enables mechanisms – within this safety, patients can move towards new friendships, personal goals, group membership and perhaps better wellbeing. The mechanisms are proposed to, in some contexts, lead to observable outcomes. These are: a patient's sense of autonomy and inclusion, familiarity between patients, and the ability to speak honestly in acknowledging mortality and illness experiences. The mechanisms are enabled by the hospice resources but can't be reduced to these components.

Proximal outcomes arise from experiences within the hospice day service. Feelings of belonging, independence, and purpose could allow patients to experience a transient sense of normality in their patienthood, improvements to personal confidence, and a gradual acceptance of physical limitations. These psychological changes are reinforced by behaviour changes, such as the adaptation of previous activities, uptake of new activity, and increased engagement in healthy behaviours. Changes to routine and personal choices can allow for increasing activity even if improvements to physical health are not possible, for example allowing for greater social participation.

Interpersonal interactions occurring over time in a safe setting, from a basis of shared experience, could lead to the development of new friendships, characterised by reciprocal support, respect and honesty. The day service may be an important opportunity for patients to gain resources they might need to reduce isolation by encouraging activity outside of the intervention. Time spent together is relevant to the expression of outcomes and might be threatened by an appointment-based model.

Improving opportunities for reciprocal support and empathy could increase acceptance towards dying and allow for adaptation to illness. Changes to living conditions might enable patients to participate more in health behaviour and meaningful activities. Changes to relationships (new and existing) increase the resilience of the network around the patient. This means that social support indirectly facilitates symptom management, care coordination, and advanced care planning - thus leading to better living and dying conditions by helping the patient look ahead, with the hope and confidence they need to make changes.

This analysis describes an ultimate outcome of ‘Better Living and Dying’, which refers to changes to living or dying conditions that might arise from positive changes in the patient’s psychology, relationships, and behavior outside of the hospice, leading to them living more active lives and perhaps being more prepared for death. There are also potential outcomes beyond the patient – within the healthcare system and for the family who could have caring and bereavement experiences that are less traumatic than they might otherwise have been.

8.2 Discussion of Findings

8.2.1 The social side of the hospice

This project was informed by previous qualitative work indicating that social interaction was at the core of palliative day services. Focussing on social support across a number of day services revealed details of the patient and provider context and indicated possible mechanisms of beneficial change. The thesis proposes interconnected mechanisms representing experiences at the psychological, interpersonal, and group level that might arise in response to hospice resources and in some contexts lead to observable outcomes. Experiences described in the below research of in advanced illness patients and their relatives are broadly supportive of this analysis but help to add further depth and detail.

This thesis suggests that being in a bound space can have consequences for feeling safe and supported as a group, and thus psychologically able to share with the group. The day care centre is an area or space that is supportive and responsive to its clients (Kernohan et al, 2006). Patients and carers derive confidence knowing that the staff had made a definite choice to work in day hospice and to work specifically with them and others like them. Staff were perceived as unhurried – ideally patients feel listened to, looked after, and fully accepted (Hopkinson and Pollitt, 2001). A qualitative evaluation of palliative day care concluded that patients feel safe and reassured and carers can relax due to the presence of experienced healthcare professionals with specialist knowledge (Low, 2005).

Opportunities to connect with other patients as equals are helpful to alleviate emotional loneliness in the home environment (Hyde, 2011). Patients might feel they can be more honest with each other, and a sense of humour can develop that might not feel possible in other relationships. Important emotional support can be derived from the social side of an intervention with a different focus, such as rehabilitation, (Wathall et al, 2020). In order to benefit fully, patients and carers might need the time and opportunity to build trust, a process which is supported (but not shortcut) by a shared sense of community (Hyde, 2011).

Gathering to eat together is meaningful for patients who do not have the opportunity elsewhere. A communal lunch can serve to break down hierarchy between staff, volunteers, and patients (Lawton, 2000).

Commenting on a mixed methods evaluation of a peer support intervention for breast cancer survivors (Pinto, Dunsiger, Stein & Kamson, 2017), Rini et al (2018) raise the possibility that opportunities for helping other people along their own illness journey is actually an intervention for improving the health and wellbeing of (in their case) illness survivors through a peer mentoring role. Acknowledging that these benefits may be nuanced and difficult to capture experimentally, they argue for research design informed by social and behavioural theory; and for better understanding of differences between those people who do and do not take up a peer mentoring role. However, in this study, only 10% of cancer survivors initially contacted were interested in the opportunity for mentorship. Most peer mentors were white, educated, with a good income. The relevance of demographic similarity in the processes of peer support might vary by context, however practitioners and researchers facilitating peer support might need to be aware that (for example) being a “poor young terminally ill person” can be a different experience to being middle class and middle aged, but much research has focused on a narrow segment of society (Williams, 2004).

Although not the focus of this analysis, volunteers are a group of people that benefit from the hospice day service whilst contributing to its social side. Volunteering seems to serve as a light-tough psychosocial intervention following bereavement, potentially after lengthy caring duties and associated isolation. Volunteers could be attending the service regularly for a decade or longer, but there are few that would describe this an unhealthy dependency. Volunteers do bring management challenges, such as awareness of professional boundaries, and making them feel valued in a culture of change. (Low, 2005). However, continued opportunities to support others could possibly prevent future decline for these individuals, by maintaining access to ‘giving’ roles.

Within hospices, volunteers contribute a substantial amount of time, with costing estimates reporting 28-38%, but some raising questions on whether this resource is used effectively and how their contribution can be made more sustainable (Mitchell et al, 2020). Hospice volunteers can be a conduit of community engagement – their presence in the building is a normalising one that brings in community news and energy and allows the hospice message to be promoted out in the community via their networks (Morris et al, 2015). However, this approach alone is unlikely to resolve issues of hospice access because diversity in volunteers tends not to be representative of the community served (Morris et al, 2015). The role of volunteers in contributing to patient perceptions of safety and how these processes might different between social and cultural groups is perhaps unexplored at present.

Note that safety within an intervention goes beyond clinical/physical, to include perception of social and emotional safety. It is not guaranteed. Enduring inequities and discrimination in healthcare could be interpreted to mean that what could be perceived as ‘safe’ for one group of people might be more threatening to others (e.g. a clinical nurse uniform; watercolour painting). Developing this theory would benefit from work with patients, who are best placed to explore their own experiences of safety in a hospice day service, especially if recruitment methods were able to contact patients who had declined the intervention after one or two visits.

8.2.2 Addressing patient loneliness

The mechanisms described in this thesis include familiarity between patients, suggesting that shared patient status and experiences are a substantial component enabling psychological acceptance and behavioural changes. Shared experiences could be illness-related, but over time they also share more positive memories of things done together in the day service. There are pressures to existing relationships during long-term illness and distress that could be helped by alternative avenues for emotional communication. The social support derived in the hospice setting can increase capacity to change the situation in existing relationships as well as providing potential for new friendships. Exploring positive experiences in preparing for loss, social support mediates personal growth through increased opportunities for proactive coping (Rogalla, 2018). Since patients experiencing distress may perceive themselves to have lost their role or purpose in life since illness, they could benefit from opportunities to reconnect with previous roles in a new social setting.

Patients with physical symptoms can avoid reporting psychological distress to healthcare professionals (Mosher et al 2015). The strain of coping with symptoms, case management, and medical professionals commonly emerge as sources of psychological distress during psychotherapy in serious illness (Bekelman, Knoepke & Turvey, 2019). Conflict in interpersonal relationships and effects of treatment, particularly fatigue, mood swings, and physical weakness, increase feelings of being a burden and not having control (Sparla, Flach-Vorgang, et al 2016). Sparla and colleagues describe how an avoidance of talking about dying within some families results in a lack of emotional support addressing (for example) worries about deterioration, or thoughts of guilt about cause of illness (Sparla, Flach-Vorgang, et al 2016). Religious social networks can offer collective support with emotional and practical assistance through advanced illness, although belief in God and an afterlife/fate might actually increase feelings of self-blame and depression in some contexts (Mosher, Ott, Hannah et al 2015).

The mechanisms proposed describe autonomy support, group membership, and emotional support, potentially occurring at different times for different patients, and/or developing over time to accentuate each other's effects. This suggests that the emotional loneliness described by Weiss (1974) can be relieved without a new attachment figure, within a context that can also relieve social loneliness by offering new group membership for those that need it. Differentiating between the experiences of social and emotional loneliness may be helpful (Weiss, 1974), but separating the 'cures' could be unhelpful. Loneliness is affected by the type of contacts that are missed and the capacities to change the situation (De Jong Gierveld, Van Tilburg & Dykstra, 2018).

Miller (Miller, 2005) noted that some drop outs cited distress from hearing other people's stories as a reason for withdrawing, and that drop outs had significantly higher levels of baseline social support. This suggests that baseline social support may influence participant's experience of an intervention and its acceptability to them. Patient context might motivate or disable the patient in attending and engaging with the intervention. People who feel lonely or keen to meet with other patients might be experiencing confusion in their sense of self and seeking social clarification. Giving support to people 'in the same boat' is related to seeking truth about the self (Richman et al, 2016)

Yalom (1975) depicts the 'great strengths' of (eg) Alcoholic Anonymous to be understood through the conviction developed by group members that 'they can be understood only by someone who has trod the same path as they'. Through shared experiences and honest communication, each group member becomes a living inspiration to the others. This phenomenon goes beyond dyadic empathy and is paramount for hope. Attending and eventually belonging to a new social group has the effect of changing the social surroundings of the patient, if only for a few hours a week at first. Time spent listening to others broadens perspective on current experiences, essentially offering a resource to gain new meanings in life, or to rediscover meanings lost through illness. Shared identity can reduce reactivity to acute pain and the subjective experience of stress (p.270, Haslam et al, 2018). Retaining and developing social identities is considered an essential component of hope and wellbeing for people living with neurological disease (Soundy, Stubbs & Roskell, 2014)

Depressive symptoms appear to escalate as people draw closer to death, a pattern shaped by diagnosis and sociodemographic factors, but the antecedents of depression in palliative care are not well known (Kozlov et al, 2020). Social identity theory considers reducing social disconnection as a route to improved health – observing improvements from group intervention to be associated with increases in people's social identification within groups (Haslam et al, 2018). This hypothesis is yet to be explored within palliative care, but research might draw from social identity theory to foster social wellbeing and develop interventions that perhaps reduce depression towards the end of life.

Finally, the cultural context appears relevant to loneliness. It is suggested that sensitivity to loneliness and social exclusion is higher in collectivist-oriented communities, whereas individualistic communities are more characterised by autonomy and choice in interactions (Lykes & Kemmelmeier, 2014). This thesis did identify that autonomy in the experience was potentially crucial and this was indicated by the emphasis on choice – choosing to come, what to engage with, and how to present when there. Social exclusion is described in the loss of social roles and experiences in an inaccessible physical world occurring in some patient contexts. It is possible that people's worldviews become more communally minded as they move towards the end of their life. It is also possible that educating others, giving informational support, increases autonomy and agency via increased self-efficacy in illness management - thus could be rewarding even from an individualistic perspective. Autonomy in the experience could be explored further as an emotional response to practical and relational aspects of the intervention.

8.2.3 Beneficial social support

The emphasis on reciprocity in the friendships within the hospice indicates that relationships without reciprocity have the potential for detrimental social support through perceptions of dependency. Feelings of being a burden to others can be distressing to patients and might motivate their participation in an intervention so that they can 'give their carer a break'. Experiences of self-perceived burden might be alleviated by restoring reciprocity in the caregiving relationship or by reframing caregiving as an opportunity to give (McPherson et al, 2007).

Coping together allows for 'invisible' support, whereas one person obviously helping another is unhelpfully 'visible'. For someone who is receiving help regularly as a patient, opportunities to give help might broaden their perception of what they can offer to other people – thus reciprocal friendships inside the hospice might have real benefits for other relationships. Passing on help to others can be psychologically beneficial by restoring self-confidence after receiving help (Alvarez & Leeuwen, 2015). Self-compassion is thought to be activated by showing compassion towards others (Breines & Chen, 2013).

Reciprocity increases opportunities for gratitude at the individual level and allows for the development of a group identity based on mutual respect. Continued participation in the group increases opportunities to reminisce, or simply be reminded, of previously enacted actions related to perceived gratitude in others. Reminiscence is an opportunity to go back to altruistic and identity defining moments and perhaps to gain benefit, when physical resources can no longer sustain the performative task - because it is easier to recall than perform helping behaviour (Ko et al, 2019). In this way, being altruistic and remembering ways in which one has been helpful to others could serve as a resource for identity.

A prospective longitudinal study of older married adults (US, n=846) reported that giving social support was more important than receiving social support for longevity. Giving instrumental or emotional support had a beneficial effect on mortality, controlling for physical health, mental health, heath behaviours, and socioeconomic status. Giving and receiving emotional support were highly associated within couples; however, the effect of receiving support on mortality was affected by dependency and giving support to others. The authors conclude that the benefits of social contact might be associated with the giving, and not receiving, of support (although it remains possible that giving support is an indirect indicator of health). Importantly, interventions designed to help people feel supported may need to re-emphasise what people can do to help others, because giving social support to others could reduce the negative impact of dependence (Brown et al, 2003).

People who are able to maintain multiple social identities have continued opportunities for giving social support which appears to support wellbeing post-retirement (Steffens et al, 2016). It is possible that having numerous relationships containing experiential similarity increases a person’s opportunities for emotional expression – honest communication as a proactive coping mechanism; and agential expression – giving tangible or informational assistance to the other person. Altruism and reciprocity experiences are worthy of further exploration in life-limiting illness. Note that dishonesty in relationships leads to psychological feelings of inauthenticity (Ryan & Ryan, 2019), but that patient context might have many factors that discourage honest self-expression. Reciprocity during instrumental support is considered to foster self-esteem, but effects may have gender differences (Irby-Shasanmi & Erving, 2020).

8.2.4 Confronting mortality, together

Terror management theory proposes a dual process model by which humans defend themselves against the terror of their own death (Solomon, Greenberg & Pyszczynksi, 2015). When thoughts of death are outside conscious awareness, we allay death anxiety by bolstering our cultural worldview (comprised of shared symbolic concepts of the world that will persist after death) and our self-esteem (derived from meeting the expectations of this cultural worldview, so that personal value might also persist after death) (Greenberg, 2012). When thoughts of death are within conscious awareness, we engage in proximal defences that include thought suppression, denial, and avoidance (Pyszczynksi et al, 1999).

This theory aligns well with a description of death-avoidance in the wider context presented by this thesis, but terror management is not so straightforward when people are faced with death, when it is necessary for psychological health that mortality be accepted further. In the palliative care context, it is not always possible (or indeed appropriate) to push death out of conscious awareness with the defensive thoughts and behaviours described by Pyszczynski. 'Distal defenses' might remain as buffers against distress, i.e. sharing symbolic concepts and fulfilling cultural expectations as a way of bolstering self-esteem. Drawing insights from terror management theory, it is important social spaces are sensitive (or at least not downright hostile) to diverse cultural worldviews.

Patient loneliness towards the end of life could be understood as an unmanageable terror related to the existential condition, rather than the social surroundings (Yalom, 1985). Existential aloneness can feel an irresolvable chasm of disconnection. Yalom argues that the distress of dying people is at "being abandoned, even shunned, by the world of the living". Patients were described as protecting others with an airy façade, avoiding morbid talk, which increasingly created a gulf between their inner fears and outer communication. Things have changed a little, but death denial for avoidance and protection is still at play in our society. Denying limitations represents an inauthentic life characterised by constant frustration and anxiety. Permission to speak what has been denied is thus a therapeutic opportunity in that more honesty with others enables more honesty with ourselves (Cooper, 2015). Being able to voice one's concerns openly within a space gives rise to feelings of being "a part of" rather than "apart from" (Yalom, 1985).

This thesis highlighted group processes of familiarity and belonging as mechanisms supporting psychological acceptance and personal growth. Analysis discusses group cohesion, communication, interpersonal learning, and general themes reflecting togetherness; but there is clear value too in the separation of members, the meeting of people from entirely different life courses and social networks. Members learn what they can and cannot obtain from others – including escape from death (Yalom, 1985).

Considering the possibility of our non-existence due to death can change the construction of meaning in life (Vos, 2014). Finding meaning in life can be a struggle when sources of self-identity are threatened by the illness or its consequences, but opportunities to redefine the situation and express love or gratitude are helpful (Prince-Paul, 2008). Permission to acknowledge mortality might help to alleviate personal fears about death eg fear of illness-related changes, pain and symptoms, fear of decline and events toward the end of life, fear of losing autonomy in decision-making, fear of being separated from others, and fears of not existing, of the unknown of non-existence (Black & Csikai, 2015; Strang, 2014).

Time spent in new physical and social surroundings can open us up to the possibility that other meanings in life could be possible. Other people's death can have a mirroring effect on our own life, encouraging greater appreciation of caregiving and acts of solidarity (Drillaud et al 2020). Life matters in that it is finite, and thus it is essential that hospices don't shy away from the death of group members and 'water down the tragedy of life.' (p.89, Yalom, 1985).

This analysis proposes that the management of existential anxiety might be enabled by giving support to other people. In the context of mortality salience, processes of performing (and recollecting) altruistic and other identity reinforcing behaviours (legacy making, role enacting) could be protective against psychological distress. There will be individual differences in the extent to which psychologically protective processes require interpersonal interaction. Social connection broadens perspective beyond one self, which is paradoxically a route to insight and acceptance of one's own experiences and condition.

8.3 Key Contributions

8.3.1 Social support in palliative care: initial programme theory

The project used realist evaluation to produce a theory-driven understanding that could be useful for both research and practice. This was developed from initial configurations presented in the previous chapter, using insights from literature discussed below. It is just a theory, a proposed explanation for change, each component and assumption can be further refined and tested. The initial programme theory presents opportunities for future empirical work to refute the proposal, contributing further to theory development.

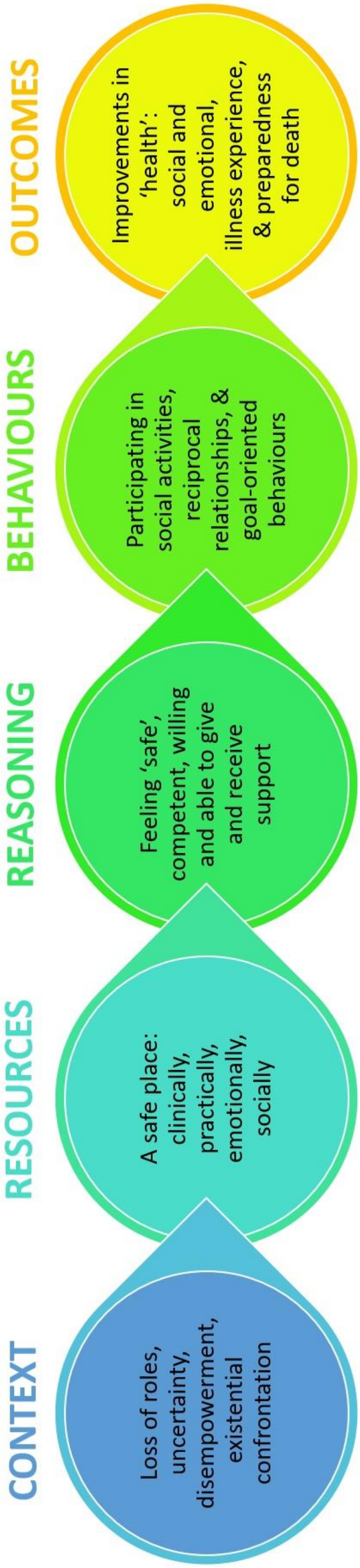
This causal chain includes features of context, intervention resources, patient reasoning, patient behaviours, and outcomes across multiple domains. Outcomes lead to improved health (understood holistically) and enable better living and dying experiences for patients and families, with possible 'ripple' effects for future generations, wider network contacts & involved healthcare professionals.

Objective physical health gains are possible for the patient, but this is a model of how there can be meaningful improvement for the patient and their families even without changes to physical health. The effectiveness of an intervention could be understood as its ability to elicit interpersonal interactions that lead to lasting positive and lasting change. However, note that the effect of hospice resources in creating 'safety' will be different for different people and that there are notable examples of the ways in which outcomes might be limited by patient context, which brings in complexity to the causal chain proposed.

As shown in figure 33:

- Context: loss of social roles and agency from illness related changes, uncertainty about the future, emotional loneliness in relationships, existential confrontation with mortality and isolation.
- Hospice resources creating a safe place: clinically, practically, emotionally, and socially
- Reasoning in response to these resources is that the patient is feeling 'safe' and competent, being willing and able to give and receive support from others
- Behaviours: Participating in social activities, reciprocal relationships, and goal-oriented behaviours
- Outcomes: Improvements in 'Health' – i.e. mental health, social functioning, illness experience, and preparedness for death.

Figure 28: An initial programme theory for social support in palliative care



8.3.2 Defining social support

In this thesis, social support is defined as a resource gained from other people to meet our needs. But it appears that sometimes, what is needed is an opportunity to give support to others. So, social support could instead be defined as a resource for coping with challenges of living (with or without life-limiting illness). Feelings of having the right support needed to face current challenges and those anticipated in the future can allow for feelings of autonomy and empowerment. In contrast, feelings of powerlessness, or being isolated, in facing the current challenges can increase loneliness.

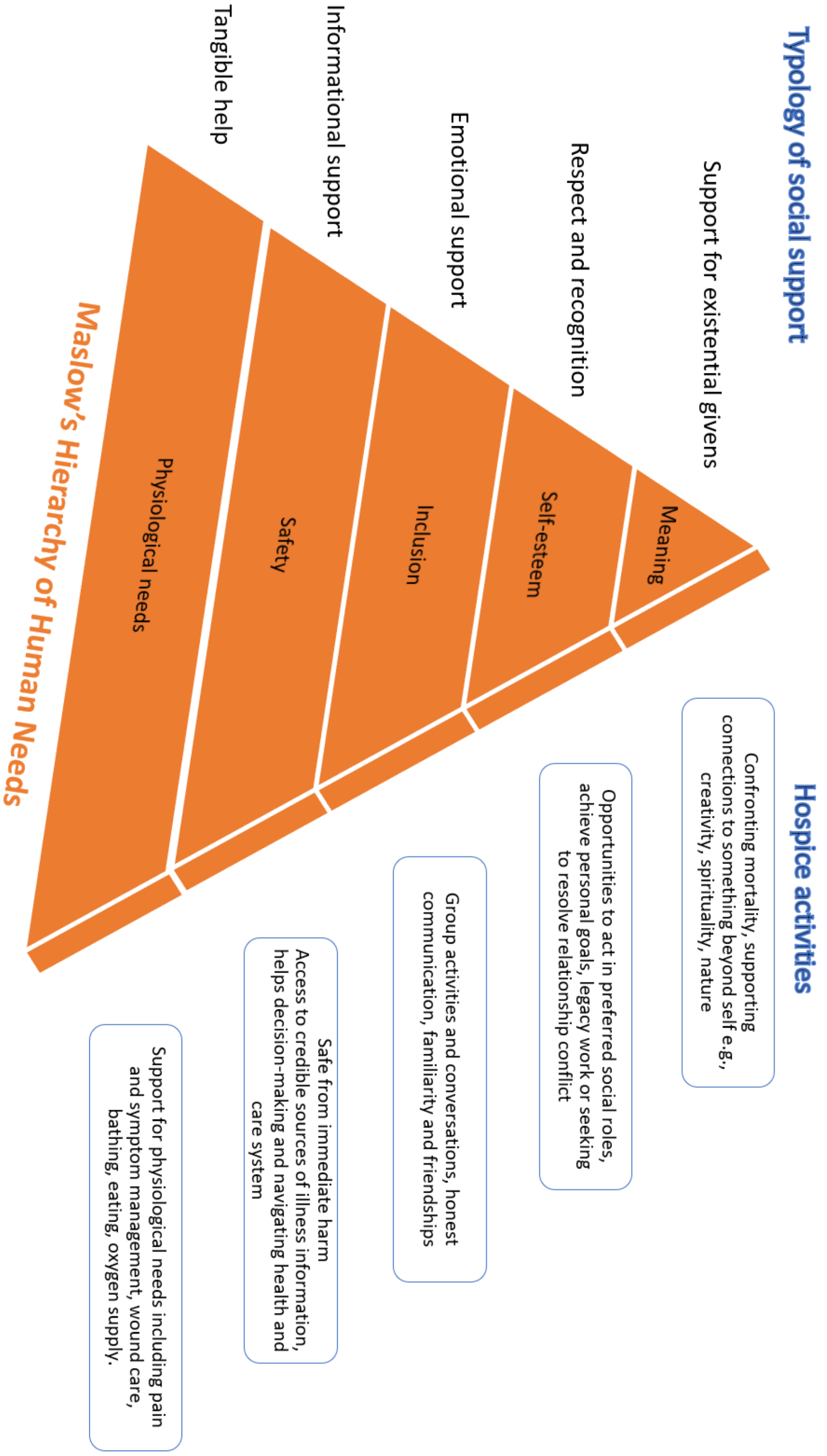
This thesis has established how social support is contextual – it relates to a particular person in a particular setting at a particular moment in time. The project describes the personal, interpersonal, and wider context to all be relevant. The hope for intervention is that the availability of social support and our perception of social support can change over time and makes a difference to experiences, behaviour, and outcomes. Defining social support in this way describes how coping is a relational process, not one that occurs in isolation, while still allowing the person to be positioned as the agent of their own decisions, including care.

In the context of illness, challenges include negotiating the healthcare system, managing existential anxiety, illness-related anxieties, and the relational impacts of illness. A source of credible information and authentic emotional support can be the resource that allows for individuals to express their agency in coping and adapting to stress and change. Inadequate or detrimental social support can impact negatively on opportunities to participate, as well as on self-esteem and coping behaviours. The availability and adequacy of social support can be reduced by illness experiences, leaving work, living alone, having an aging social network, the length of time spent with declining health and function, and having visible signs of illness. Continued loss of social support puts people at risk of isolation, which has negative consequences to health, symptoms, and function – making it harder for people to obtain the support they need.

Social support both allows for and is produced through participation. Even people with very limited function can be enabled to participate in care decisions, in activity choices, in meal planning, to identify their own personal goals and better able to communicate their preferences. Being a passive recipient of care is more likely to lead to feelings of loneliness and less likely to lead to feelings of autonomy, compared to someone with more opportunities to participate in their self-management. Self-management should be understood as process that occurs within a social context – if an intervention that is able to offer useful tangible, informational, emotional, esteem, and existential support to people, it could change their social context in such a way that the person is better equipped for present and future challenges.

Drawing from humanistic psychology, a hierarchy of human needs could be used as a framework to further the conceptualisation of social support needs (see figure 34). This helps to go beyond ‘it’s context-dependent’ to describe how different human needs can create challenges that often require support from other people in some way, and how these needs can be understood to relate. The bottom of the pyramid is most essential: physiological and safety needs tend to dominate experiences if unmet, so that it may be less possible to achieve inclusion, self-esteem, and meaning. This figure relates a typology of social support to the different support/relational needs and suggests different activities of the hospice day service as components offered to help. It is not intended to be a strict absolute as a hierarchy, but to identify a ‘re-usable conceptual platform’ that could support middle-range causal explanations answering the question ‘what works for whom’ (Pawson, 2013).

Figure 29: Presenting a typology of social support with a hierarchy of human needs (Maslow, 1943) shows how different support needs could relate to different hospice activities



8.4 Discussion of Methods

8.4.1 Realist evaluation

Realist evaluation, particularly the use of the context-mechanism-outcome configurations, is useful to explain crucial context factors and potentially observable outcomes, as well as mechanisms, in a relatively parsimonious manner. It has descriptive value on what's happening 'in the room', but there is more to the knowledge gleamed. Knowing what matters about the context can reveal upstream intervention targets and guide practice by indicating what type of patient context would indicate a need for increased social support (e.g., living alone or with interpersonal avoidance). Knowing more about how social support can benefit patients indicates proximal outcomes operating in a causal chain prior to more distal observed outcomes relating to quality of life or survival. These conclusions are potentially transferable to other populations, pending further investigation.

Complexity aware evaluation can endeavour to explore the ways in which complex interventions are embedded and evolve within their social contexts (inc spatial, political, geographical, cultural, systemic). This lens is useful for numerous reasons, eg - understanding the non-linear and unpredictable nature of change, identifying socioeconomic aspects of context that may impede or enable intervention aims, developing interventions in ways most beneficial to all stakeholders (Orton, 2016). However, defining the edge of context is tricky and risks overwhelming research efforts/introducing bias by allowing research to be guided by hidden assumptions rather than explicit decision.

The answer to the question of 'what matters' will inevitably vary according to who is asking - warranting a section on research reflexivity, but also serving as a warning to those approaching realist evaluation methods. Whilst allowing myself to be led 'by my nose' to some extent through published studies and texts, my intention was for the project to be useful for practitioners and for illuminating further research questions. Practically this meant that I tried to maintain a focus on:

- exploring the significance of social support for palliative care patients
- demonstrating the potential for realist evaluation in psychosocial palliative care
- developing a programme theory for social support interventions in palliative care

8.4.2 Realistic health economics

Multidisciplinary team-working in palliative care enables a spectrum of professional expertise and multimodal therapeutic options, at potentially but not necessarily high cost (Fernando & Hughes). Group interventions might be considered simply as a saving on staffing cost per patient. But describing hospices as solely the roles and actions of paid staff would risk missing the magic entirely. Volunteers and family members are active and can derive psychosocial benefits from providing services (Claxton-Oldfield, 2015). Importantly, patients are not passive receivers of services - this project identifies that contributions made by patients might be necessary mechanistic components of the intervention. Additional complexity emerges as hospices support more people for longer, and it becomes increasingly illusive to define people connecting with the hospice as strictly a patient, carer, volunteer, or bereaved person.

Furthermore, immutable features of the patient’s context that prevent the expression of observable outcomes mean that the proposed chain of outcomes does not always occur - but whether this means that individual patients and other stakeholders did not ‘feel the benefit’ of the intervention, at a psychologically and clinically meaningful level, is a different question. Therefore although the proposed chain of outcomes might improve care, due to complexity in the patient context, healthcare expenditure is not a proxy for care quality, patient satisfaction, or illness management. Inequalities in disease outcomes are driven by disparities in the availability of linguistically and culturally accessible healthcare and technology accessibility looks to become an increasing barrier for some groups. (Lund, 2020). Healthcare administrative data may be highly useful for some research questions but it is not sensitive to the social determinants of health and cannot underpin decisions guiding resource allocation - an explicit health equity framework is more appropriate (Williams et al, 2020).

This thesis describes the significance of social support in achieving changes to living and dying conditions. Achieving these outcomes in practice can also include an array of specialist components, for example physiotherapy or home visits that might provide practical equipment and improve patient function (as well as fatigue management, this may be geared towards fall prevention - walking sticks, or managing breathlessness - handheld fans). In approaching economic evaluation, the temptation when calculating cost per patient would be to include only these specialist ‘costly’ components - but this definition of the intervention would ignore the social support component arising between patients and facilitated by skilled hosts. Patients and volunteers contribute their time freely to the space, and may benefit from doing so, but their contribution is not automatic. This analysis underscores the dangers of a reductionist approach to these holistic interventions, by demonstrating the *value* of things that may not come with a clear price-tag.

Working in a context-sensitive manner demonstrates hospice services to be adaptive and responsive. They are valuable for study precisely because they can vary according to the ethos of each organisation, local patient need, and characteristics of the local area. Their diversity is their richness – or to put it another way, the magic is in the complexity. Viewed with a realist evaluation lens, obstacles for traditional economic evaluation become clues for programme theory development. We can learn many lessons from thoughtfully designed comparative research that is able to consider what works, for whom, in what circumstances, without relying on resource-intensive controlled trials.

8.4.3 Research reflexivity

This research recognises description to be a constructive process including the researcher and thus making the researcher's position clear is part of documenting a transparent process. Active consideration is important as a tool to deepen explanation, but also as a basis for responsible choices (Mortari, 2015). As a novice in the field, I had a lot to think about – before, during, and after entering research locations, developing my ideas of the researcher's role, and trying to predict the unpredictability so as to foresee my own responses. The process of writing notes after fieldwork and interviews was hugely beneficial in consolidating my observations and bringing awareness to how my own emotional and physical sensations were relevant to my perceptions.

Researching end-of-life issues can provoke general anxieties about mortality, with experiences having emotional repercussions that can linger into later stages of work (Borgstrom & Ellis, 2017). During this project I experienced several bereavements, including the sudden illness and loss of a family member during the second year of the PhD, which no doubt shaped the project – not just its timescale, as I was just about to begin data collection at the time that I instead was called to the Midlands to care for my father and helping him to achieve his wish to die at home (in relative solitude, I would add). My interest in palliative care had perhaps been started after my Granny's peaceful hospice death following a long and gradual decline to cancer, but I no way felt an expert. After my dad's death, I felt I knew even less. Working alongside my own sense of grief, I realised I had perhaps had a rose-tinted view of the hospice sector.

Researchers can struggle with their own emotions in their field, they can be a helpful sign of one's humanity, at the same time as feeling like an embarrassing indicator that one is not cut up to the job

(Woodthorpe, 2007). Over the last four years I've become more aware of my own health and body, experiencing restrictions to my own mobility through a knee injury and back pain, which again deepened my connection to these topics in a way I might not have expected when I started this project in my mid-twenties. This year, the pandemic has brought social isolation and connection into an almost painfully sharp focus. While I accept the role of acknowledging and seeking to bracket our emotional responses as researchers, particularly during the analytical process, I consider these life experiences to have developed who I am as a person and therefore who I am a researcher.

I considered myself to be a non-expert, entering a setting in which the experts (such as patients) might perceive academia and confer expertise, authority, or perhaps even related to funding of the hospice itself. This influenced my attitude in approaching services and the people within them – I tried to get people to explain things to me, not the other way round. I entered observations with a willingness for the unexpected, which requires 'thinking on your feet' or reflection-in-action, and approached fieldnotes with a list of things to consider, which is reflection-on-action (Schon, 1983). However, clear lines were necessary, for safety and ethical reasons – so, while I might sit unaccompanied with a patient on a visible garden bench, I would not be interrogating them for the benefit of my research questions, or indeed providing them with advice on their own relationships, for example. I should add that these lines were clear to me from counsellor training and voluntary experience, which provided skills in listening and hearing that were no doubt useful to this project.

Chapter 9 : Conclusion

The availability of social support and the perception of that support can be highly relevant for the experiences and outcomes of people living with life-limiting illness. For people living with life-limiting illness, there are difficulties obtaining adequate social support and the available social support might not always be helpful in coping with illness-related challenges. This can leave people feeling isolated in their experience, even within a close-knit family. The illness itself can increases the need for support from other people, putting pressure on existing relationships, so that, for example, those requiring a lot of practical help from their partner or children might feel reluctant to make additional emotional demands. People living with life-limiting illness can be at risk of loneliness and social isolation, which can increase their distress, perpetuate low mood, and accelerate loss of function.

An interplay of physical, mental, and social health underscores the way in which social rehabilitation might lead to positive change in physical health and mental health. The significance of social support in achieving positive outcomes of some models of specialist palliative care may have been under-acknowledged. This thesis describes how opportunities to meet other patients can aid in adapting to a new normal, emotionally and practically. Developing friendships within a hospice day service directly increases social resources to cope with illness. There may also be benefits of increasing opportunities for palliative care patients to give support to other people. Intervening to provide social support has the potential for detriment, particularly if social experiences inadvertently increase loneliness or decrease feelings of autonomy or competence. Recording outcome measures of perceived social support, loneliness, and depression could allow insight into social and emotional wellbeing and perhaps risk of suffering.

Resilience in self-management and resources to adapt are determined by an interplay of personal, interpersonal, and wider context features. Through living with illness, patients experience a disruption to their lives and can be stripped of their ability to contribute socially, either through functional limitations or social responses to illness. The patient’s context determines their capacity and motivation to manage long-term health conditions, by shaping access and availability of necessary resources (including emotional and physical energy, knowledge and confidence, time, money, and sense of self-responsibility). Socioeconomic resources and cultural norms are relevant to social support in palliative care – this project grappled with disentangling their influence but notes their interplay. These forces shape the patients’ opportunities and vulnerabilities, their perception of the world, and people’s perceptions of them.

This work reports that social support in palliative could improve emotional support and decrease loneliness for some patients. It highlights that people living alone might respond differently to hospice day services. Gender could be relevant too. We did not test how depression of clinical severity might interact with outcomes. The impact of day services could have differed between hospices, but sample size was insufficient to compare between sites. Recruitment was unpredictable and people from areas of high deprivation were less likely to complete the study.

There are unresolved questions in the conceptualization of social isolation and loneliness, and their relationship to each other and to health domains. The psychosocial challenges of long-term complex morbidity may vary between and within groups. It’s unclear the extent to which hospice intervention can establish self-sustaining friendships without service input, particularly in contexts of clinical complexity or local deprivation. Practical challenges, including funding and transport, add complexity to evaluation and challenges to service provision. Societal issues of inaccessibility and death avoidance could contribute to patient loneliness and thus the need for these interventions.

9.1 Recommendations for Practice

People whose lives have been profoundly changed by life-limiting illness find their emotional and relational context to be changed, as well as their physical health. Overall, this thesis would encourage interventions that provide opportunities to give support, or act altruistically, not just to receive support.

New connections based on an equal status provide a basis for meaningful emotional support, that might develop into reciprocal friendships given sufficient time spent together. Slow social time, casual chitchat, and eating meals together are important opportunities to build trust and the perception of safety in a space. Giving support to other people might be helpful to alleviate existential loneliness; to the extent that altruism, reminiscence, and humour serve as resources for identity. Hospice groups should not shy away from acknowledging deaths of group members. Practices around death management (of group members, and towards care planning or legal preparation) might elicit acknowledgement of their own attitudes towards dying that is psychologically meaningful and opens the door to behaviour change.

The issue of meeting a variety of individual client needs depends on staff that possess appropriate breadth and level of skills and knowledge - this could become more salient when broadening the scope of access to services through a range of diagnoses, ages, and cultural backgrounds. This analysis presents an argument for context-aware service development - there is no one size fits all approach. Service redesign is not risk-free, but hospices are learning lessons from each other, and this thesis hopes to contribute to that process in some way. Changes to discharge procedures can cause genuine distress for patients, volunteers, and junior staff.

Community engagement, particularly death acceptance initiatives, might be upstream interventions to challenge a cultural avoidance of dying and illness. Working with schools, community interest companies, faith organisations, and local events might increase the reach of hospice messaging, broaden its appeal to volunteers, and ‘power up’ community empowerment. Initiatives working in partnership with community organisations are under-researched but may be potent in improving outcomes for numerous stakeholders, particularly if they elicit feelings of altruistic belonging. Involving service-users in decision making can allow for interventions to be embedded in their context rather than applied to it (Gardiner et al 2018).

People living with illness may have had their opportunities for social support dramatically altered by the present context of the COVID-19 pandemic. Outside of anyone in their household, many will be limited to interpersonal interactions taking place via technology (telephone, web-based messaging, and video calls) or, mobility permitting, spending time together outside. Unfortunately, patients living alone or with limited social network within their local area may have experienced isolation and declines in function this year. Over time, safe outdoor spaces and gardens might become a more important feature of hospice services in order facilitate social support for people living with life-limiting illness.

In the short term, activity packs appear a potentially valuable, low-cost component, that could be beneficial for patients who have built up a connection to the day service they attend, through knowledge that other people like them are participating towards the same (possible altruistic) goal. Regular telephone calls and opportunity for emotional expression, even if irregular, could make a difference especially if the social support is perceived as offered freely, rather than a professionalised ‘must-do’ task. Group video calls might include a programme of activities through ‘Zoom’, a way for patients to maintain an existing regular activity or conversational opportunity within their routine. These are valuable, commendable, and appropriate responses to an unprecedented situation. They may not be adequate substitutions in the long-term because they are not designed to foster new connections. Switching modalities might have implications – especially because the disembodied nature of interpersonal interactions through technology might mean that group processes are less facilitative of acceptance towards the changing body. This is an area for further investigation.

9.2 Recommendations for Research

This project suggests that psychosocial domains such as perceived emotional support and loneliness could be used as patient reported outcome measures for social support interventions in palliative care. Health-related quality of life might be more appropriately used as a tool to describe personal context. This was feasibility work that suggested these measures were feasible and acceptable. Cost-consequence study comparing different models requires the piloting of any cost-collecting approach to establish its feasibility and level of participant burden.

Personal contexts shape the availability and need for different types of social support, as well as opportunities to participate in research or access hospice services. Neighbourhood aspects, age, gender, and access to economic resources are influential in shaping the availability and need for support. Research could explore more with a larger sample the differences in experiences for patients with different contexts, especially: people living alone; people who meet criteria for depression at baseline; people of different ages or genders; and people living with deprivation.

Data collection in this project focused on the setting of the hospice and had less access to patient context. I also had very little contact with people who did not enjoy the service they attended. Solutions to mitigate loneliness include those that provide safe opportunities for people to socialise, however the experience of an intervention from the perspective of a lonely person is often overlooked (Lim, Eres & Vasan, 2020). Future work is important to seek out these perspectives.

A necessary next step is to explore patient experiences and responses to the proposed programme theory. Future research could explore themes of altruism, mortality awareness, reciprocity, and belonging, with palliative care patients. The role of volunteers in contributing to patient safety perceptions and the outcomes they might gain is perhaps unexplored at present.

Recruitment from a hospice context is likely to be unpredictable due to a) clinical and emotional vulnerability of patients, b) personnel changes or insufficient resources within the hospice or referral chain. Obtaining a large and representative sample in this area of research requires sufficient resources to enable the continued participation of patients beyond those who are ‘research-savvy’ and easier to reach. Research design should seek consent to follow up with patients who stop attending.

Collecting reasons for attrition was beneficial and is recommended for future work. Differences between attrition groups can be explored and could contribute to theory development. An additional recommendation would be to allow outcome measures to be completed at home to improve follow-up rates, adapting design so that outcomes of those who do not continue to attend are also observed. A mixed methods study might also invite these participants for interview to understand their experiences.

The information in this study indicated Site 3 contained most of the participants that left due to poor health. As an exercise group, this intervention may be less accommodating to fluctuations or sudden declines in health – although these patients might have accessed the programme again at a later date. Research designs for rehabilitative palliative care in particular may need to be aware that fluctuations in health might have a bigger impact on attendance for exercise groups than for other activities.

In a larger longitudinal study, a realist analytical approach could be taken with quantitative data: using patient reported outcome measures to explore differences between sites, drawing on concurrent qualitative investigation to develop theories of effectiveness, and using longitudinal mediation analysis to explore how variables interact over time.

9.3 Recommendations for Policy

Palliative care patients are at risk of increasing isolation, and emotional loneliness even if not socially isolated. Poor health and living alone are personal risk factors, occurring at the micro level. Discrimination and social discomfort, as interpersonal processes, can occur at the meso level. But we must not forget the macro risk factors - population aging, economic instability, individualisation, and inadequate/declining community resources. These macro risk factors in the wider context, can (and should) motivate public health interventions to prevent and/or alleviate the social isolation and loneliness currently associated with living with life-limiting illness.

Social support interventions in palliative care respond to a patient loneliness that might be reinforced by cultural attitudes towards illness and avoidance of death. This should motivate policy to create more intergenerational spaces, improve death awareness, and endorse the inclusion of differently-abled bodies in society. A fragmented community, composed of death-avoidant and alienated individuals, is not well-equipped for illness and dying. But community resources can be built, and rebuilt. Upstream policy level changes to prevent distress at the end of life would include those that improve community cohesion, provide more social and accessible spaces, and reduce inequality in healthcare.

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Appendix A. Definitions

Palliative care

Palliative care supports people with life-threatening illness to live well, despite the physical, psychological, social, and spiritual problems of living with illness (World Health Organisation, 2014) The objective of palliative care is to prevent and relieve the suffering of patients and their families, through treatment of symptoms and the simultaneous care of psychological, spiritual, social, cultural, and situational needs (Krikorian et al, 2011).

Hospice

Hospices provide palliative care services including clinical, psychological, spiritual, and social support to more than 225,000 people in the UK each year (Hospice UK, 2018). Many hospices operate as independent charities, giving them a greater flexibility than providers within the NHS. Current practice is not well-documented, but hospice support is increasingly provided within day or outpatient services, or in patients' own homes.

Social support

Social support is defined as the resources gained through interpersonal interaction. Extensive research in the general population has indicated that social domains including actual and perceived social support are associated with quality of life and other positive outcomes. Inadequate social support arises in a situation where the person is lacking meaningful and sufficient social contact to meet their social needs.

Loneliness

Unmet social needs are a precursor to emotional or social loneliness - the subjective perception of inadequate social support. Social isolation, i.e. the observable absence of social relationships, and the subjective sense of loneliness do not necessarily correlate; but have each been demonstrated as detrimental for health in the general population. This thesis focuses on social support and considers that qualities of the relationship and the interaction, including the subjective experience, are likely relevant in the extent to which the social support meets the social needs of the people involved. Negative social experiences can perpetuate loneliness experiences just as

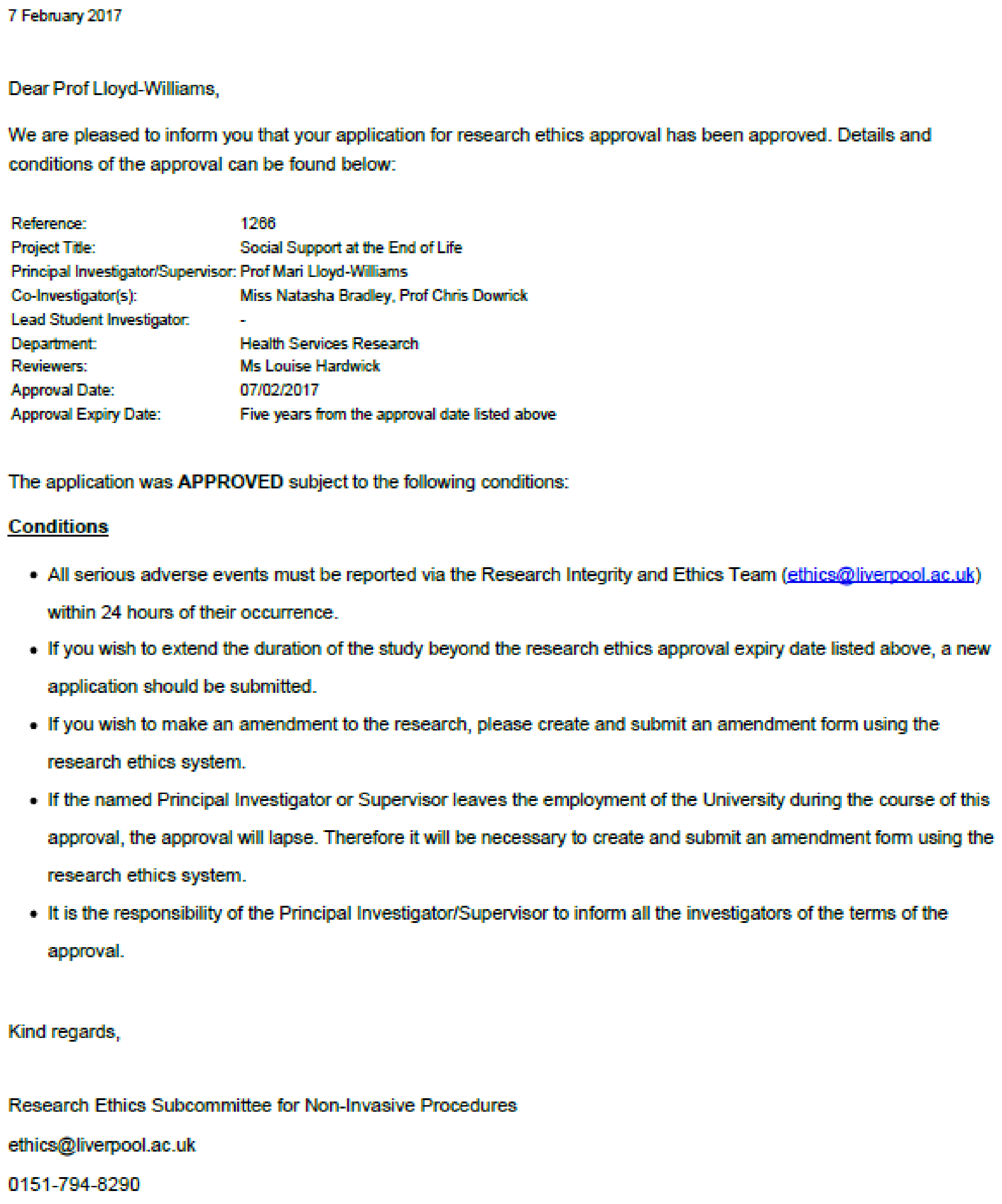
Holistic

Hospices provide holistic support to people with life-limiting illness. This means that their care moves beyond responding to the illness, i.e. focusing on symptoms and prognosis; seeking instead to respond to the person as an individual and family member. Holistic support recognises that there are multiple domains that can contribute to patient suffering – thus holistic hospice-led care usually includes clinical, psychological, spiritual, social, and family needs.

Quality of life (QOL) and health-related quality of life (HR-QOL)

Quality of life is composed of multiple interacting domains - there is more to life than health and thus more to quality of life than health-related status and time remaining to live. This thesis defines quality of life as a holistic concept, whereas health-related quality of life focuses on clinical condition and physical ability.

Appendix B. Ethics Approval



7 February 2017

Dear Prof Lloyd-Williams,

We are pleased to inform you that your application for research ethics approval has been approved. Details and conditions of the approval can be found below:

Reference:	1266
Project Title:	Social Support at the End of Life
Principal Investigator/Supervisor:	Prof Mari Lloyd-Williams
Co-Investigator(s):	Miss Natasha Bradley, Prof Chris Dowrick
Lead Student Investigator:	-
Department:	Health Services Research
Reviewers:	Ms Louise Hardwick
Approval Date:	07/02/2017
Approval Expiry Date:	Five years from the approval date listed above

The application was **APPROVED** subject to the following conditions:

Conditions

- All serious adverse events must be reported via the Research Integrity and Ethics Team (ethics@liverpool.ac.uk) within 24 hours of their occurrence.
- If you wish to extend the duration of the study beyond the research ethics approval expiry date listed above, a new application should be submitted.
- If you wish to make an amendment to the research, please create and submit an amendment form using the research ethics system.
- If the named Principal Investigator or Supervisor leaves the employment of the University during the course of this approval, the approval will lapse. Therefore it will be necessary to create and submit an amendment form using the research ethics system.
- It is the responsibility of the Principal Investigator/Supervisor to inform all the investigators of the terms of the approval.

Kind regards,

Research Ethics Subcommittee for Non-Invasive Procedures

ethics@liverpool.ac.uk

0151-794-8290

Appendix C. Survey of Hospices

Contact details

*1. Your name:

*2. Job title:

*3. Contact telephone number:

*4. Contact email address:

*5. Please indicate here if you are happy to be contacted to take part in the next stage of the research. You can withdraw from the research at any time.

○ Yes

○ No

NEW QUESTION

About the hospice

*6. Hospice name:

*7. Hospice postcode:

8. **Approximately** what percentage of individuals does the hospice support that have the following primary diagnoses?
(optional question)

Cancer
Respiratory disease e.g. COPD
Neurological disease e.g. MND, MS.
Heart disease
Renal disease
Mobility issues/frailty
Dementia
HIV/AIDS
Other

*9. What percentage of funding is currently provided by statutory sources (e.g. the NHS or local authorities)?

0 **50** **100**

*10. Does the hospice offer **transport** for people attending its services?

○ No

○ Yes (provided by volunteers)

○ Yes (provided by paid staff)

○ Yes (provided by a different organisation)

*11. Does the hospice offer services to people who **do not** have a life-limiting illness ?

○ Yes

○ No

○ Not sure

*12. Is the hospice linked with any **compassionate communities** projects?

○ Yes

○ No

○ Not sure

*13. Does the hospice offer any services that take place **outside of the hospice building**? i.e. in a different location such as a library or community garden. Please tick all relevant options.

☐ No

☐ Community centre, library or other non-religious building

☐ Religious building such as a church hall

☐ Outdoors - e.g. a community garden or park

☐ In people's homes

☐ Other (please specify – free text box)

*14. Does the hospice ask for **payment** towards any of its services? Please tick all relevant options.

☐ No

☐ Set charge per session

☐ Optional donation per session

☐ Charge for transport

☐ Charge for lunch/catering

☐ Charge for some activities

☐ Other (please specify – free text box)

What roles are carried out at the hospice?

*15. Please indicate whether the roles below are provided by **paid staff, volunteers** or **both**. If a service is not available at the hospice, please select 'not applicable'.

	Paid staff	**Volunteers**	**Both paid staff and volunteers**	**Not applicable**
Doctor				
Nurse				
Physiotherapist				
Occupational therapist				
Psychotherapist, counsellor or other mental health support				
Pharmacist				
Social worker				
Chaplain/spiritual worker				
Hairdresser or beautician				

	Paid staff	Volunteers	Both paid staff and volunteers	Not applicable
Creative activity leader				
Other activity leader				
Complementary therapist				
Mindfulness or meditation practitioner				
Catering				
Cleaning				
Administration tasks				
Befriending				

How does the hospice offer social support?

We are looking for information on any services that are currently managed by the hospice that offer people living in the community the opportunity to spend time with other people. These can be any hospice or community-based services - for example day care, respite, community centres, empowerment centres, support groups or group therapy, creative/craft groups, diversionary activities or community engagement activities.

Please state any services that you think may be relevant to our research. You may state up to eight different services, but please enter at least one.

*16. Service 1

17. Service 2

18. Service 3

19. Service 4

20. Service 5

21. Service 6

22. Service 7

23. Service 8

24. Do any of these services operate as a '**drop in**'? Please tick all relevant boxes, or 'none'.

☐ {{ Q16 }}

☐ {{ Q17 }}

☐ {{ Q18 }}

☐ {{ Q19 }}

☐ {{ Q20 }}

☐ {{ Q21 }}

☐ {{ Q22 }}

☐ {{ Q23 }}

☐ **None**

25. Are any of these services **organised** by volunteers, carers or patients? Please tick all relevant boxes, or 'none'.

☐ {{ Q16 }}

☐ {{ Q17 }}

☐ {{ Q18 }}

☐ {{ Q19 }}

☐ {{ Q20 }}

☐ {{ Q21 }}

☐ {{ Q22 }}

☐ {{ Q23 }}

☐ **None**

*26. In your opinion, which of these services offers the **most** opportunity for social support? You will be asked some more questions about this service.

○ {{ Q16 }}

○ {{ Q17 }}

○ {{ Q18 }}

○ {{ Q19 }}

○ {{ Q20 }}

○ {{ Q21 }}

○ {{ Q22 }}

○ {{ Q23 }}

Note: conditional formatting was used during survey design. Here, {{ question number }} is replaced by respondent's answers to Q16-23 & Q26

*27. What is the hospice's stated **aim** in offering this {{ Q26 }} service?
(free text box)

*28. **When** does this service take place? (tick boxes)

	Morning	Afternoon	Evening
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			

*29. What is the **typical number of people** that attend this service per session?

○ 0-10

○ 11-20

○ 21-30

○ 31-40

○ 41-50

○ 50+

*30. What is the **maximum number of people** that can attend this service per session?
(free text box)

31. How do people find out about this service? If they are formally referred, please state how.
(free text box)

*32. Please give detail of any **exclusion criteria**. If none, please state 'none'.
(free text box)

*33. Is there a **discharge policy** or a limit on how long people can attend?

○ Yes

○ No

34. Please give detail on discharge policy (if applicable)

Maximum number of sessions:

Maximum time frame:

Other discharge policy:

*35. What (if any) **outcomes** are measured? If possible, please indicate how frequently and by who. If none please state none.
(free text box)

36. Do you have an **estimate of cost** to provide any of these services? (eg per patient, per session or annually). If this information is not available, please select No.

☐ {{ Q16 }}

☐ {{ Q17 }}

☐ {{ Q18 }}

☐ {{ Q19 }}

☐ {{ Q20 }}

☐ {{ Q21 }}

☐ {{ Q22 }}

☐ {{ Q23 }}

☐ **No**

37. If yes please state below
(free text box)

Final questions

38. Do you have anything else you would like to tell us about services offering social support at your hospice?
(free text box)

39. Do you have anything else you would like to tell us about the hospice or its services more generally?
(free text box)

40. In the space below, you may provide an URL for any promotional material or further information
(free text box)

41. In the space below, you may upload any promotional material or further information
(file upload)

Appendix D. Participant Information Sheet (Patient)

Academic Palliative and Supportive Care Studies Group,
Institute of Psychology, Health and Society,
Waterhouse Building (Block B),
1-5 Brownlow Street,
University of Liverpool,
Liverpool.
L69 3GL.

PARTICIPANT INFORMATION SHEET

Title of Study: Social Support in Palliative Care

You are being invited to take part in a research study. Before you decide whether or not to participate, it is important that you understand why the research is being undertaken and what it will involve. Please take the time to read the following information and feel free to ask us if you would like more information or if there is anything that you do not understand. You may also wish to discuss this with your family, friends or doctor. We would like to stress that you do not have to accept this invitation and should only take part if you wish to do so.

Thank you for reading this information.

What is the purpose of this study?

Social isolation and loneliness is a significant issue in our society. The project aims to explore different forms of social support, focussing on services that offer people living in the community the opportunity to gain social support. In a context of increasing demand and decreasing resources within health and social care, it is important for research to consider how services are provided and how they can show that they are effective.

Why have I been chosen to take part?

We are looking for participants that are about to start or have recently started attending one of the services that we are studying. You have been referred to us by a member of staff at [insert service]. We would like to ask you to complete some written questionnaires over 12 weeks, to give us information about your experiences attending the service.

Do I have to take part?

It is up to you whether you decide to take part, it is entirely voluntary. You can choose to withdraw from the study without being affected in any way. This information sheet is yours to keep.

What will happen if I decide to take part?

If you do decide to take part, you will be asked to sign a consent form. You will be given written questionnaires to complete and you are allowed to ask someone to help you complete the questionnaires. You will be asked to fill in the questionnaires now, in 6 weeks, and again in another 6 weeks. The questionnaires will be returned to the researcher in pre-paid envelopes provided with the questionnaires.

What are the benefits of taking part?

There are no direct benefits to you for taking part in this study. By taking part, you will help us to find out more about what is important and effective about social support. A summary of findings will be available to participants.

What if there is a problem or complaint?

If a problem arises please contact Natasha Bradley of 0796 901 5126 and we will try to resolve the problem. If you remain unhappy please contact the University Research Governance Officer on 0151 794 8290, providing the name of the researcher and the name of this study (given at the top of this letter).

Will the information I give be kept confidential?

The information that you give us will be confidential and stored securely. Every person taking part in the study will be allocated a unique number so that no information that might be used to identify you will be stored. Only the research team will have access to the data that is collected. It is likely that this research will be published in journals and presented at conferences, however all participants will remain anonymous.

What will happen if I decide I do not want to continue taking part?

It is not a problem if at any time you decide you do not want to carry on taking part in the study. Your participation is voluntary and you can withdraw without any consequences to you. You will be asked to contact Natasha Bradley to tell her that you no longer wish to take part.

Who do I contact if I have questions about this study?

Please contact Natasha Bradley on 0796 901 5126 or Natasha.bradley@liverpool.ac.uk.

Appendix E. Consent Form (Patient)

-

Title of Study: **Social Support in Palliative Care**

Researcher(s): **Natasha Bradley**

Supervisor: Professor Mari Lloyd-Williams

Please initial box

1. I confirm that I have read and have understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw without giving any reason, without my rights being affected. In addition, should I not wish to answer any particular question or questions, I am free to decline. ☐
3. I understand that, under the Data Protection Act, I can at any time ask for access to the information I provide and I can also request the destruction of that information if I wish. ☐
4. I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications. ☐
5. I understand that any concerns about me or someone else being in potential danger will be addressed in line with University of Liverpool Guidelines. ☐
6. I understand and agree that my participation will involve completing questions at three time points, I consent to my answers being stored securely for data analysis. ☐
7. I agree to take part in the above study. ☐

Name of Participant Date Signature

_______________________ ________ ______________

Name of Person taking consent Date Signature

Appendix F. Participant Details

Name: ____

Telephone: ____

Home postcode: ____

Please describe your current living arrangements:

☐ I live alone

☐ I live with other people: ________adults and _____ children

Please give your age: __________ DOB: ________________

Please indicate your gender:

☐ Male ☐ Female ☐ Prefer not to say

Please indicate your ethnicity (please tick one box):

☐ White ☐ Asian

☐ Mixed ethnicity ☐ Black

☐ Any other ethnic background ☐ Prefer not to say

What country were you born in? ______________________________________

Do you have any long-term health conditions (*e.g. arthritis, cancer (please specify), dementia, diabetes, epilepsy, hearing loss, heart disease, osteoporosis, motor neurone disease, Parkinson's, renal disease, respiratory disease/COPD, stroke*)?

Please list in the space below:

____

____

____

____

Appendix G. Participant Question Pack

Participant ID:	**Date today:**

☐ Week 1-2

☐ Week 6-8

☐ Week 12-14

This pack contains 36 questions in two sections. Each section opens with a brief instruction. Please choose one of the multiple choice answers for each question.

It is important that an answer is given for each question. You can choose not to answer any of the questions, in this case please tick ‘declined to answer’.

Primary researcher: Natasha Bradley

07969015126

Natasha.bradley@liverpool.ac.uk

Part 1: Social support

People sometimes look to others for companionship, assistance, and other types of support. How often is each of the following kinds of support available to you if you need it?

1. **Someone you can count on to listen to you when you need to talk**

None of the time ☐ A little of the time ☐ Some of the time ☐ Most of the time ☐ All of the time ☐

Declined to answer ☐

2. **Someone to give you information to help you understand a situation**

None of the time ☐ A little of the time ☐ Some of the time ☐ Most of the time ☐ All of the time ☐

Declined to answer ☐

3. **Someone to give you good advice about a crisis**

None of the time ☐ A little of the time ☐ Some of the time ☐ Most of the time ☐ All of the time ☐

Declined to answer ☐

4. **Someone to confide in or talk to about yourself or your problems**

None of the time ☐ A little of the time ☐ Some of the time ☐ Most of the time ☐ All of the time ☐

Declined to answer ☐

5. **Someone whose advice you really want**

None of the time ☐ A little of the time ☐ Some of the time ☐ Most of the time ☐ All of the time ☐

Declined to answer ☐

6. **Someone to share your most private worries and fears with**

None of the time ☐ A little of the time ☐ Some of the time ☐ Most of the time ☐ All of the time ☐

Declined to answer ☐

7. **Someone to turn to for suggestions about how to deal with a personal problem**

None of the time ☐ A little of the time ☐ Some of the time ☐ Most of the time ☐ All of the time ☐

Declined to answer ☐

8. Someone who understands your problems

None of the time A little of the time Some of the time Most of the time All
of th☐e ☐ ☐ ☐ ☐

Declined to answer ☐

9. Someone to help you if you were confined to bed

None of the time A little of the time Some of the time Most of the time All
of the☐e ☐ ☐ ☐ ☐

Declined to answer ☐

10. Someone to take you to the doctor if you needed it

None of the time A little of the time Some of the time Most of the time All
of the☐e ☐ ☐ ☐ ☐

Declined to answer ☐

11. Someone to prepare your meals if you were unable to do it yourself

None of the time A little of the time Some of the time Most of the time All
of the☐e ☐ ☐ ☐ ☐

Declined to answer ☐

12. Someone to help with daily chores if you were sick

None of the time A little of the time Some of the time Most of the time All
of the☐e ☐ ☐ ☐ ☐

Declined to answer ☐

13. Someone who shows you love and affection

None of the time A little of the time Some of the time Most of the time All
of the☐e ☐ ☐ ☐ ☐

Declined to answer ☐

14. Someone to love and make you feel wanted

None of the time A little of the time Some of the time Most of the time All
of the☐e ☐ ☐ ☐ ☐

Declined to answer ☐

15. Someone who hugs you

None of the time A little of the time Some of the time Most of the time All
of the☐e ☐ ☐ ☐ ☐

Declined to answer ☐

16. Someone to have a good time with

None of the time A little of the time Some of the time Most of the time All
of the ☐e ☐ ☐ ☐ ☐
Declined to answer ☐

17. Someone to get together with for relaxation

None of the time A little of the time Some of the time Most of the time All
of the ☐e ☐ ☐ ☐ ☐
Declined to answer ☐

18. Someone to do something enjoyable with

None of the time A little of the time Some of the time Most of the time All
of the ☐e ☐ ☐ ☐ ☐
Declined to answer ☐

19. Someone to do things with to help you get your mind off things

None of the time A little of the time Some of the time Most of the time All
of the ☐e ☐ ☐ ☐ ☐
Declined to answer ☐

20. How often do you feel that you lack companionship?

☐ Hardly ever ☐ Some of the time ☐ Often
Declined to answer ☐

21. How often do you feel left out?

☐ Hardly ever ☐ Some of the time ☐ Often
Declined to answer ☐

22. How often do you feel isolated from others?

☐ Hardly ever ☐ Some of the time ☐ Often
Declined to answer ☐

Part 2: Wellbeing and health

For these questions, please choose the answer which comes closest to how you have felt **in the past 7 days** (not just how you feel today).

23. I have blamed myself unnecessarily when things have gone wrong

Yes, most of the☐e
Yes, some of th☐e
Not very often ☐
No, never ☐ *Declined* ☐
answer

24. I have been so unhappy that I have had difficulty sleeping

Yes, most of th☐e
Yes, quite ofte☐
Not very often ☐
No, not at all ☐ *Declined* ☐
answer

25. I get a sort of frightened feeling as if something awful is about to happen

Yes, definitely and quite b☐
Yes, but not too badly ☐
A little, but it doesn't worr☐
Not at all ☐ *Declined* ☐
answer

26. I have felt sad or miserable

Yes, most of th☐e
Yes, quite ofte☐
Not very often ☐
No, not at all ☐ *Declined to answer* ☐

27. Things have been getting on top of me

Most of the time and I haven't been able to cope a☐
Yes, sometimes I haven't been coping as well as ☐l
No, most of the time I have coped quite well ☐
No, I have been coping as well as ever ☐ *Declined to answer* ☐

28. The thought of harming myself has occurred to me

Yes, quit☐en
Sometim☐
Hardly ev☐
Never ☐ *Declined to answer* ☐

For these questions, please choose one answer that best describes your health **today.**

29. Mobility – do you have problems in walking about?

☐ I have no problems in walking about
☐ I have slight problems in walking about
☐ I have moderate problems in walking about
☐ I have severe problems in walking about
☐ I am unable to walk about

Declined to answer ☐

30. Self-care – do you have problems washing or dressing yourself?

☐ I have no problems washing or dressing myself
☐ I have slight problems washing or dressing myself
☐ I have moderate problems washing or dressing myself
☐ I have severe problems washing or dressing myself
☐ I am unable to wash or dress myself

Declined to answer ☐

31. Usual activities (e.g. shopping, housework, family or leisure activities)

☐ I have no problems doing my usual activities
☐ I have slight problems doing my usual activities
☐ I have moderate problems doing my usual activities
☐ I have severe problems doing my usual activities
☐ I am unable to do my usual activities

Declined to answer ☐

32. Pain/discomfort – how is your pain or discomfort today?

☐ I have no pain or discomfort
☐ I have slight pain or discomfort
☐ I have moderate pain or discomfort
☐ I have severe pain or discomfort
☐ I have extreme pain or discomfort

Declined to answer ☐

33. Anxiety/depression – do you feel anxious or depressed today?

☐ I am not anxious or depressed
☐ I am slightly anxious or depressed
☐ I am moderately anxious or depressed
☐ I am severely anxious or depressed
☐ I am extremely anxious or depressed

Declined to answer ☐

34. In the last 6 weeks, have you visited hospital for A&E (casualty)?

☐ Yes (more than once) Total number of visits: ____________

☐ Yes (once)

☐ No

☐ ined to answer

35. In the last 6 weeks, have you stayed in hospital overnight?

☐ Yes Total number of nights: ____________

☐ No

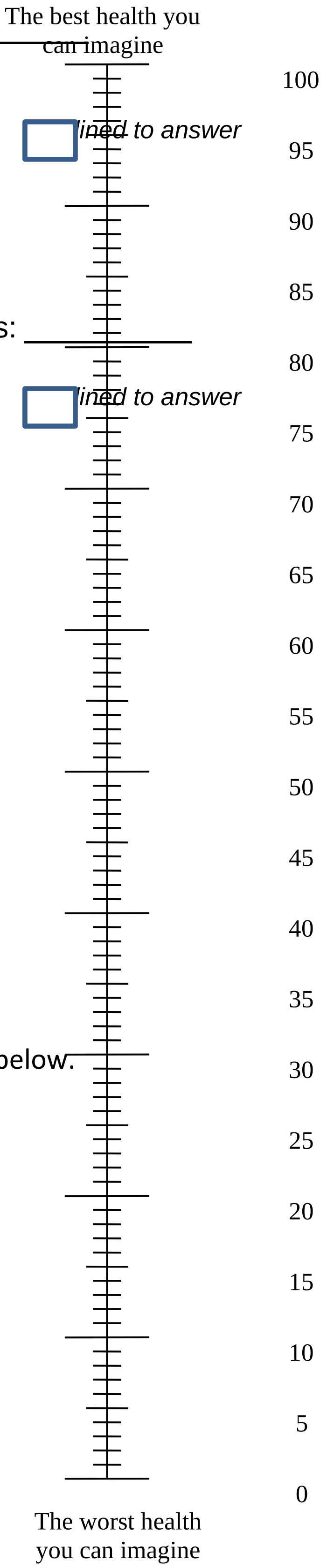
☐ ined to answer

Final Question

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the <u>best</u> health you can imagine.
  0 means the <u>worst</u> health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = ☐

Declined to ☐ er



Thank you for contributing your time in completing these questions.

Appendix H. Participant Information Sheet (Provider)

Academic Palliative and Supportive Care Studies Group,

Institute of Psychology, Health and Society,

Waterhouse Building (Block B),

1-5 Brownlow Street,

University of Liverpool,

Liverpool.

L69 3GL.

PARTICIPANT INFORMATION SHEET

Title of Study: Social Support in Palliative Care

You are being invited to take part in a research study. Before you decide whether or not to participate, it is important that you understand why the research is being undertaken and what it will involve. Please take the time to read the following information and feel free to ask us if you would like more information or if there is anything that you do not understand. You may also wish to discuss this with your family, friends or employer. We would like to stress that you do not have to accept this invitation and should only take part if you wish to do so.

Thank you for reading this information.

What is the purpose of this study?

Social isolation and loneliness is a significant issue for older people and for people living with a long-term illness. The project aims to explore how hospices can provide opportunities for people living in the community to gain social support. In a context of increasing demand and decreasing resources for health and social care, it is important for research to consider how services are provided and what is important or meaningful about these services. This research is aiming to gain a detailed understanding of some hospice services through observation and interviews with service-providers.

Why have I been chosen to take part?

We are looking for participants that are involved in providing a hospice service that offers the opportunity for people with life-limiting illness to interact with other people. We have asked the service manager to identify potential participants and give them this information sheet. We would like to hear about your experiences, to help understand the ethos and uniqueness of the service itself, and to hear what you think is important about social support in advanced illness.

Do I have to take part?

It is up to you whether you decide to take part, it is entirely voluntary. This information sheet is yours to keep.

What will happen if I decide to take part?

If you do decide to take part, please contact the researcher Natasha Bradley (0796 901 5126, Natasha.bradley@liverpool.ac.uk). Natasha will discuss the study with you and give you the opportunity to answer any questions before arranging a convenient time for the interview to take place. The interview will take place at the service and last approximately one hour. You will be asked to give written consent to take part in the research. Natasha will audio record the interview with your consent, so that she can concentrate on what you are telling her without having to take notes. You will be asked questions about your experiences at the service and what you think is important about social support. You can choose to withdraw from the research, without giving a reason, at any stage before the commencement of data analysis.

What are the benefits of taking part?

There are no direct benefits to you for taking part in this study. By taking part, you will help us to find out more about what is important and effective about social support for people living with a life-limiting illness, and help us find out more detail about the ethos and uniqueness of the service you are involved in providing. A summary of findings will be available to participants if requested.

What if there is a problem or complaint?

If a problem arises please contact Natasha Bradley of 0796 901 5126 and we will try to resolve the problem. If you remain unhappy please contact the University Research Governance Officer on 0151 794 8290, providing the name of the researcher and the name of this study (given at the top of this letter).

Will the information I give be kept confidential?

The information that you give us will be confidential and stored securely. Every person taking part in the study will be allocated a unique number so that no information that might be used to identify you will be stored. Only the research team will have access to the data that is collected. It is likely that this research will be published in journals and presented at conferences, however all participants will remain anonymous. However, there are some legal limits to confidentiality, - if anything you tell us indicates a risk of harm to yourself or others, the researcher will have to escalate this, initially through discussion with the project supervisor.

What will happen if I decide I do not want to continue taking part?

It is not a problem if at any time you decide you do not want to carry on taking part in the study. Your participation is voluntary and you can withdraw without any consequences to you. You will be asked to contact Natasha Bradley to tell her that you no longer wish to take part.

Who do I contact about this study?

If you wish to take part, or would like to discuss anything in further detail, please contact Natasha Bradley on 0796 901 5126 or Natasha.bradley@liverpool.ac.uk.

Appendix I. Consent Form (Provider)

Title of Study: **Social Support in Palliative Care**

Researcher(s): **Natasha Bradley**

Supervisor: Professor Mari Lloyd-Williams

Please initial box

3. I confirm that I have read and have understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

4. I understand that my participation is voluntary and that I am free to withdraw without giving any reason, without my rights being affected. In addition, should I not wish to answer any particular question or questions, I am free to decline. ☐

8. I understand that, under the Data Protection Act, I can at any time ask for access to the information I provide and I can also request the destruction of that information if I wish. ☐

9. I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications. ☐

10. I understand that any concerns about me or someone else being in potential danger will be addressed in line with University of Liverpool Guidelines. ☐

11. I understand and agree that my participation will be audio recorded and I am aware of and consent to transcription of these recordings into a Word document for data analysis. ☐

12. I agree to take part in the above study. ☐

___________________________________ __________ _____________________

Name of Participant Date Signature

___________________________________ __________ _____________________

Name of Person taking consent Date Signature