The working relationships between ward-based volunteers and paid staff in a hospice setting: A participatory action research study

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere

Abstract

Background - Much of the work carried out in hospice settings by paid staff would be impossible without the support of volunteers. Effective working between paid staff and volunteers is needed to prevent problems in their working relationships. Researchers have called for improvements in communication, clearer roles and boundaries, and increasing team building between paid staff and volunteers in palliative care settings. Despite repeated recommendations, there has often been a lack of proactive research, including participatory approaches, to drive positive change.

Aim - The overarching aim of the thesis was to gain insight into hospice volunteering, identify strengths and challenges to the working relationship between paid staff and volunteers, and improve any identified barriers to effective collaboration in hospice practice as necessary.

Literature review - A meta-ethnographic review of qualitative research exploring the experiences of paid staff and volunteers working together in palliative care was conducted. Following analysis of 14 articles identified from four databases (CINAHL, PsycINFO, Medline, and AMED), five storylines were constructed: 1) "we [paid staff] are the cake and they [volunteers] are the cream": understanding the volunteer role – separate, but part of a whole; 2) "…we [volunteers] don't know what's wrong with people but sometimes we need to know": access to information and importance of trust; 3) "everybody looks out for each other": access to paid staff and their support; 4) "...we [volunteers] don't meddle in the medical": boundaries; 5) "it's the small things that the staff does for me that makes me feel good about my work": sense of value and significance. Ongoing issues in working relationships between paid staff and volunteers were identified, which informed my methodological choice of participatory research.

Methods - Participatory action research, underpinned by critical and solidarity theories, was conducted with paid staff and volunteers in a UK hospice. The study was in three main phases:

- Phase one: An exploration of the hospice's context through semi-structured interviews with paid staff and volunteers, and a review of relevant documentation.
- Phase two: Iterative participatory action research cycles, directed by a participatory action research group. The aim was to plan, act, observe, and reflect on current practice and the impact of suggested changes collaboratively.
- Phase three: A deliberative panel, consisting of members of the wider hospice team to refine the findings of the participatory action research through facilitated discussions.

Data from the three phases were analysed using reflective thematic analysis, involving iterative reflection, action, and collaboration to refine the findings.

Findings - Five semi-structured interviews were conducted with paid staff (n=2) and volunteers (n=3), and documentation was reviewed. The participatory action research group initially included eleven group members (paid staff (n=3) and volunteers(n=8)), with a core group of six group members (paid staff (n=2) and volunteers(n=4)). The deliberative group included two participants (paid staff (n=2)). Five overarching themes were created from the participatory action research: 1) hierarchy and power 'we are not asking for the world' (volunteers do not sit in traditional hierarchical models); 2) belonging 'they must have put a face to the name' (knowing others and being known builds belonging); 3) being together 'let's get mixing' (neutral shared spaces support feelings of being one team); 4) adding value 'what value do we really place on our volunteers?' (different perspectives on ways volunteers add value); 5) information and knowledge sharing 'it's getting the balance' (preventing misunderstanding and being 'on the back foot').

Discussion and Conclusion - Volunteers should be involved and integrated into hospice power and hierarchical structures. Hospices need to create meaningful opportunities for paid staff and volunteers to mix. Silos between teams can negatively impact the working relationships within hospices. Hospices must find new ways of building a sense of mutual belonging for paid staff and volunteers. Volunteers need to be known, involved, and visible within hospice teams to build strong relationships, promote belonging, and clarify their roles in the hospice context.

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Key terms

Palliative care is an approach used to improve the quality of life of patients and their families (or those important to them) who are facing problems associated with life-threatening or life-limiting illnesses. Palliative care providers seek to prevent and relieve suffering through the early identification, appropriate assessment, and treatment of pain and other problems, whether physical, psychosocial, or spiritual. Quality of life is sought to be improved from the point of diagnosis to the post-death phase through bereavement care. Palliative care is life-affirming, in which dying is regarded as a normal human process, looking to neither hasten nor postpone death (World Health Organisation, 2023).

End-of-life care is the term used to describe the comfort, care and support given to patients who are in the last year of their lives (National Institute for Health and Care Research, 2022).

Palliative care services are often provided by those who focus on people with complex needs, related to symptom management, which cannot be easily met by more generalist care and intervention (Finucane et al., 2021). Specialist palliative teams often consist of a range of professional and non-professional providers as part of a Multi-disciplinary Team (MDT) to provide holistic care for patients and those important to them. Teams may be based in a variety of settings, including community, hospital, and hospices (NHS England, 2023).

Hospice and hospice care definitions vary significantly from country to country, for example in America, 'hospice' often refers to a programme of care, whereas in the UK, it is a term commonly used to describe a stand-alone organisation run as an inpatient palliative care unit with specialist teams providing various levels of care for individuals in the community (Howlett, 2018; Thomas et al., 2017). Hospice care in the UK "aims to improve the quality of life and wellbeing of adults, children and young people who have a terminal illness or a long-term condition that cannot be cured, also known as life-limiting. It is free for patients, their carers, and family members. Hospice care can be provided at any stage of a person's condition, not just at the end of their lives. It can include symptom management, social, practical, emotional, and spiritual support. It helps people live as fully and as well as they can to the end of their lives, however long that may be" (Hospice UK, 2024b). UK Hospice in-patient units often have a limited number of beds, with an average length of stay of approximately 10 – 14 days, providing care for those with the most complex and/or unstable symptoms. Patients may be admitted to a hospice inpatient unit during the final stages of life. Hospices often have space for relatives to rest or stay overnight. Care is free to service users and is funded by a combination of charitable donations and National Health Service contributions (Hospice UK, 2024a; Thomas et al., 2017).

Volunteer: within this thesis, volunteering is considered in the context of unpaid individuals who commit their time on a regular basis within the same setting. However, there are different understandings and concepts relating to volunteering that vary from country to country, within different sectors and specialties. Within the thesis, the term 'work' used regarding volunteers refers to the unpaid activity involving mental or physical effort they carry out, whilst acknowledging that 'work' is a complex term and is often associated with paid labour.

Paid staff are people who are employed and/or work for an organisation, receiving financial reward for their work.

Participatory action research directly involves those who are experiencing issues. It is a research approach that involves equal collaboration between researchers and participatory group members to understand social issues and create social change.

Participatory action research group: a collaborative group of people who come together to explore issues of mutual concern and interest. All members of the group take an active part in contributing ideas, activity, sharing power and responsibility for the generation of knowledge and change.

Chapter 1. Introduction

Hospices and palliative care settings face escalating pressure to meet the complex needs of a growing patient population amid constrained resources (including personnel). Simultaneously, palliative care providers strive to maintain the core principles and characteristics of excellence in palliative care in this environment (British Geriatrics Society, 2023; Sjöberg et al., 2021). Palliative care includes a holistic approach to symptom management, timely and responsive care through productive teamwork within care settings (Etkind et al., 2017). Teamwork should incorporate seamless transitions between care providers, effective communication, and collaboration (Seow & Bainbridge, 2018). However, at times, teamwork in various palliative care settings can be inadequate and frustrating for those involved (Cerqueira et al., 2024; Goldsmith et al., 2010; Speck, 2006).

Palliative care teams are often thought of as encouraging inter-professional working, which may or may not include paid non-professionals, such as health care and therapy assistants (O'Donnell et al., 2024; Tolotti et al., 2024). The inclusion of volunteers in interprofessional teamwork is often limited and can lead to tensions and challenges (Kesonen et al., 2022; von Schnurbein et al., 2022). However, much evidence has shown that volunteers are an essential part of hospice and palliative care (Scott, 2018; Söderhamn et al., 2017; Vanderstichelen et al., 2018). Therefore, further exploration of how they work within palliative care teams needs to be considered.

The purpose of this research is to understand, identify strengths and challenges, and change current hospice practices relating to the working relationship between paid staff and volunteers within the United Kingdom (UK). I wanted to create change through the research process itself, through the active engagement of those directly affected by the research, rather than limiting their involvement to being 'research subjects.' I sought to look at challenging over-acceptance of 'things just being the way they are' about the working relationships between paid staff and volunteers. Consequently, these intentions informed the critical theory philosophical perspective and participatory action research methodology, which is discussed in chapter four.

1.1 Background of the researcher

I am a registered nurse and have been qualified for twelve years. I have spent a considerable part of my career working in palliative care across a range of settings. Some of my nursing experience has been as a nurse in adult hospices. During this time, I have seen the importance of volunteers, often leaving me wondering if I was a volunteer in a hospice, what would I want that role to look like? I also considered if my imagined 'wish list' matched what I had seen in practice at different hospice settings in England. At times, I found a disparity between what I would consider a rewarding and fulfilling role and what I witnessed. However, I also considered whether this was the experience of others or just my own thoughts.

Through my employment, I found volunteers to be an essential part of hospice work, often enabling other hospice nurses and myself to carry out essential tasks, that would have been delayed without the volunteer's willingness to help. Sometimes, the requests from nursing staff would have taken the volunteers out of their usual role, such as requesting meal support volunteers to sit with distressed patients. I can recall many situations where volunteers stepped into the gap, providing care and support that would have otherwise been impossible, delayed, or with inferior results. I recognise the crucial role my colleagues had in helping me navigate emotionally challenging situations, from caring for those with life-limiting illnesses to dealing with death. I consider myself extremely fortunate that I worked in hospices where the camaraderie of colleagues made what could be a very hard role rewarding and fulfilling.

I now work in healthcare education, teaching those who are preparing to be healthcare professionals about the value of teamwork, collaboration, and inclusion of patients and those important to them in their care. I aim to empower students through developing knowledge about change and improving current situations and, in turn, look to encourage them to empower others who are often regarded as powerless. From these reflections, I developed a desire to explore the relationships between paid staff and volunteers through participatory action research.

1.2 Thesis structure

Reporting participatory action research is not straightforward, in part due to the complex, fluid, multifaceted processes involved. Furthermore, it does not fit a set pattern that easily corresponds to established reporting conventions (Higginbottom & Liamputtong, 2015; Lloyd-Evans et al., 2023; Smith et al., 2010). Consequently, the following overview of the thesis structure is included to guide readers through the choices in presentation that have been made.

Chapter two includes a discussion on the background and context of this research. It begins with an exploration of the need for both 'evolution and revolution' in hospices in the UK. Some of the issues impacting those working in hospice settings, including the need for support and positive relationships with colleagues, are highlighted. Furthermore, volunteering in palliative care, reflecting on relevant theories of volunteering, and providing a rationale for focusing on solidarity theory due to 'we-thinking' and shared goals are discussed.

Chapter three is a meta-ethnographic review exploring the working relationships between paid staff and volunteers, identifying knowledge gaps to be addressed by this research. The review was published as: Oliver, K., Brown, M., Walshe, C & Salifu, Y. (2023) A Meta-Ethnographic Review of Paid Staff and Volunteers Working together in Palliative Care, *Journal of Pain and Symptom Management*, 66(6) 656-670 https://doi.org/10.1016/j.jpainsymman.2023.08.004 and it was also presented as an e-poster at the 18th World Congress of the European Association for Palliative Care: Oliver, K., Brown, M., Salifu, Y., and Walshe, C. (2023) P 16.003 Paid Staff and Volunteers' Experiences of

Working Together to Provide Palliative Care: A Systematically Constructed Meta-ethnographic Review ("EAPC2023 Abstract Book," 2023, p. 261).

In chapter four, the philosophical perspective of critical theory is explored, and the epistemological and ontological foundations of this research are presented. The methodological choice of participatory research is justified, which was influenced by the overall aims and intent of the study. The specific approach of participatory action research is explained and contextualised.

Chapter five: The methods, findings and analysis of participatory action research progressed through three key phases: firstly, delving into the hospice context, specifically the in-patient unit, to comprehend dynamics in relationships between paid staff and volunteers; secondly, engaging a core participatory action research group, reflecting diverse teams utilising a critical participatory action research approach to guide the research; and thirdly, reflecting on evidence gathered through a deliberative panel.

Chapter six: The analysis from the combined reflexive thematic analysis for all phases of the participatory action research is presented. Five themes were created and discussed in this chapter: hierarchy and power, belonging, being together, adding value and information and knowledge sharing.

Chapter seven includes an in-depth discussion of the results and places them within the wider research context. Discussions encompass consideration of how volunteers are involved and integrated in hospices, in light of hierarchy and power; ways in which meaningful opportunities for paid staff and volunteers to mix; exploring the impact of silos on working relationships in hospices; and ways in which mutual sense of belonging can be built for both paid staff and volunteers.
Chapter eight discusses the implications for practice, policy, and research, followed by a consideration of the strengths and weaknesses of the thesis.

Chapter 2. Background

Volunteers are an essential and well-established part of hospice and palliative care (Coleman & Walshe, 2021). Volunteers have often been regarded as instrumental in shaping the creation and development of the hospice movement (Payne & Morris, 2018). However, despite this rich and interwoven history between volunteers and palliative care settings, there remain tensions and challenges (Claxton-Oldfield, 2016; Claxton-Oldfield & Claxton-Oldfield, 2012; Claxton-Oldfield et al., 2008; Meyer et al., 2018). Ongoing issues and problems faced by volunteers show the need to improve relationships between volunteers and those working in palliative care.

Hospice organisations need to acknowledge that volunteering and those who traditionally volunteer in hospice settings have changed over time (Hogben, 2022; Hospice UK, 2019). The demographic of hospice volunteers in the UK has traditionally been women who are 55 and older and have had free time due to low or no working commitments (due to not working or retirement) (Morris et al., 2013). However, there has been a shift in volunteering and volunteers due to different factors, including financial implications of the cost of living, working longer, and caring for relatives (Scott, 2018). Hospices must adapt to these changes by understanding volunteers' motivations to engage and remain in their volunteering roles. Therefore, the chapter includes an introductory discussion around concepts and definitions of volunteering, highlighting the relevance of volunteering to working with paid staff and emphasising the importance of volunteering within palliative care and hospice settings. The research context is introduced by exploring some of the challenges facing the palliative care workforce, drawing attention to the need for volunteering in palliative and hospice care, and highlighting the need for effective working relationships between paid staff and volunteers. Finally, the chapter concludes with an exploration of some relevant theories of volunteering and the rationale for the choice of underpinning the thesis with solidarity theory relating to volunteering.

The research included in the background section focuses on the UK setting, as this is where the primary research has been conducted, to provide an understanding of the specific context, definitions, challenges, and enablers that are unique to the UK. However, where relevant, the background and other chapters of the thesis also reflect wider evidence to place the study in a broader perspective.

2.1 Volunteers in palliative care

In England, across all volunteering sectors, women are more likely than men to volunteer and older people are more likely to volunteer than younger people, whether this is formally or informally (The National Council for Voluntary Organisations, 2024a; Woodhouse & Zayed, 2024). For formal volunteering, people aged 65 to 74 have the highest levels across all age groups. The lowest levels of formal volunteering in England are found among those aged 25 to 34 (The National Council for Voluntary Organisations, 2024a). There has been a drop in the number of people volunteering in England over recent years (Department for Culture, 2024). The drop in volunteering may have been caused by the COVID-19 pandemic (The National Council for Voluntary Organisations, 2024a). However, economic circumstances may have also impacted those who would have previously volunteered. Financial challenges within the UK in recent decades have created a cost-of-living crisis, requiring some to work more and volunteer less (Mohan, 2024). General findings in the UK about volunteering across all sectors are reflective of hospice and palliative care (Scott, 2018).

Much of the work carried out by palliative and end-of-life care services would be impossible without the support of volunteers (Scott, 2015). Over 125,000 volunteers give their time to support hospices and palliative care services across the UK with significant economic value (Hospice UK, 2020b). There is a long history of volunteers working in palliative and end-of-life care; however, their role is continuously changing and evolving (Morris et al., 2017). Volunteers are involved in a broad range of hospice roles in the UK, including working in most hospice in-patient units. They frequently become involved in providing practical and emotional support to patients and their families, also acting as an important link between them and the various hospice teams (Claxton-Oldfield & Blacklock, 2017; Horey et al., 2015).

Within the context of hospice volunteering in the UK, volunteers are involved in a wide range of roles including direct patient contact (in settings such as in-patient units, day-centre units, and community teams) and non-patient contact roles (including fundraising, administrative support, and publicity) (Morris et al., 2017; Scott, 2018). Due to the wide range of roles, the differences in who they work with, and how they work with others in each of these positions, the thesis focuses on volunteers with direct patient contact, based in hospice in-patient settings (which will be further explored in chapter five). There is a wide variety of volunteer roles within in-patient settings, as volunteers may offer practical, social, emotional, and spiritual support (Burbeck, Low, et al., 2014).

Volunteers may be directly connected to a wide range of different paid staff and teams. For example, roles can be connected to nursing, kitchen, complementary therapy, counselling and bereavement support, reception and admin support, and spiritual care teams. Volunteers most commonly offer prior professional skills in non-healthcare related voluntary roles, such as, complementary therapy, and spiritual care (Burbeck, Low, et al., 2014). However, volunteers with prior nursing or healthcare knowledge have at times been treated with caution by paid staff (Overgaard, 2015).

Due to differences in roles, the specific requirements, including training and induction may also vary. There is considerable variation in volunteer training across different hospice settings, even within the UK. Topics may include an introduction to the organisation and palliative care, responsibilities and role boundaries, and more specific training for each role (Scott, 2018). Training can help to prepare volunteers for the role, for example, through developing communication skills, understanding the context of palliative and end-of-life care, and learning about self-care (Brighton et al., 2017; Worthington, 2008).

Volunteer-professional collaboration should involve mutual information-sharing regarding patient conditions and the coordination of care provision (Vanderstichelen et al., 2019). However, Claxton-Oldfield (2016) found that some volunteers felt ignored or unsupported by paid hospice staff. Some volunteers felt 'in the dark' about patient information for those they are working with, which can make their tasks more difficult than needed (Harland, 2016). Claxton-Oldfield et al. (2008) identified that while nurses felt that volunteers should share the information they gain about patients with paid staff, 47% of nurses thought it was inappropriate for volunteers to be given medical information about patients. Of the remaining respondents, they commented that information given to volunteers should be limited. This may have contributed to other volunteers feeling that their role was 'controlled' by paid staff, and as such, they saw themselves as 'subordinate' (Meyer et al., 2018; Trent & Allen, 2019). Ineffective working relationships between volunteers and paid staff may reduce volunteer capacity to provide high-quality care to patients and families at the hospice. Palliative care settings should encourage greater equity and seek to reduce over dominance of specific groups (Ravel, 2018).

Effective communication, coordination, and teamwork are central components of palliative care (Engel et al., 2023). However, limited information-sharing between paid staff and volunteers has been viewed as a possible barrier (Jünger et al., 2007). Additionally, lack of communication between health and social care professionals remains a substantial area of complaint that is regularly raised in palliative and end-of-life care (Care Quality Commission, 2015). Failures in working relationships between different teams within hospice environments could lead to uncoordinated care, misunderstandings regarding each other's roles and responsibilities, and miscommunication. Failing relationships could further result in dissatisfaction amongst team members (Vanderstichelen et al., 2019).

Volunteer retention is a critical issue for hospices because of the investment that goes into training a volunteer, often drawing on limited resources. The King's Fund (2018) emphasises that acknowledging the needs of volunteers, including the provision of support, suitable opportunities, and an inclusive environment, are essential factors in enhancing volunteer retention. Wilson et al. (2005) found contradictory opinions between staff and volunteers about volunteer roles, responsibilities, and information needs. They suggested that further research, including exploring how to improve communication and cooperation between paid staff and volunteers, may partly resolve these issues.

2.2 Challenges for hospice teams providing palliative care and the need for change

In recent years, the need for palliative and end-of-life care in the UK has been steadily increasing, driven by a range of factors, including demographic shifts, advancement in medical technology, and changes in healthcare policies (NHS England, 2021). In 2023, over 10 million people in the UK were aged 65 and over. The number of people aged 65-79 is predicted to increase by 30% to over 10 million in the next 40 years, while the number of people aged 80 and over is expected to more than double to over 6 million (Centre for Ageing Better, 2023; Kingston et al., 2018). As people live longer, they often face more complicated and demanding health issues as they approach the end of life (Sjöberg et al., 2021). Furthermore, a growing number of younger people now have more complex multi-morbidities than previous generations, often attributed to lifestyle factors and changes in society (Whitty et al., 2020).

The provision of more complex care for patients will require increased specialist care, posing many challenges to often overstretched palliative care services (British Geriatrics Society, 2023; Etkind et al., 2017; NHS, 2023). Despite many challenges faced by hospices within the UK, there is also a real opportunity to drive positive change, such as ensuring that the right people are deployed around the patient and encouraging greater collaborative working (both in and between hospices) (Hospice UK, 2020a).

Bleakley et al. (2019) reflected that hospices in the UK need both ‘evolution and revolution’ in their future development. There has been much ‘evolution’ and considerable change in recent years with changes to hospice teams and practices, within day-care and well-being services, hospice at home, and inpatient units. However, there is also a need for further ‘revolution’ as hospices take bolder steps in development and trailblazing in different areas (Bleakley et al., 2019). Individual hospices seeking culture development may look at and create new models of care through ‘mini revolutions,’ encouraging transformational change for the benefit of paid staff and volunteers (Herczeg, 2023).

COVID-19 had a significant impact on all areas of healthcare, including the hospice sector. In many ways, COVID-19 changed how palliative and end-of-life care is delivered to people, including changes within hospice services as teams, service provision, place of care, and access to resources (Rowe et al., 2021). Those working in hospice settings frequently experienced increased anxiety due to extreme pressures placed on already overwhelmed hospice services in the UK. Whilst hospice staff often tried to maintain the quality of care they provided within their work; they found that it was challenging to maintain the level of palliative care they wished to give (Bailey et al., 2023). In part, this may have been due to the decline in hospice volunteers, which would have had a significant impact on the care provision many palliative care services were then able to offer (Walshe et al., 2022). However, COVID-19 also gave hospices a chance to review old, ineffective systems and make positive changes and adaptions, including ways of effectively engaging volunteers (Academy of Medical Royal Colleges, 2021).

2.3 Experiences of the hospice workforce

Those working in hospice settings are not immune to the suffering of others they care for, and, as such, stress is an inevitable consequence of palliative and end-of-life care work. Whilst this is not unique to those working in palliative care, as stress and burnout are frequently reported for healthcare workers (Maresca et al., 2022; Prasad et al., 2021), some aspects of this care can significantly impact the wellbeing of hospice staff (Ingleton et al., 2008). Those working in palliative care frequently encounter emotional stressors, such as breaking bad news, patient suffering, and frequent exposure to death, which may lead to poor long-term emotional and psychological outcomes. Work-related stress has been reported as a significant problem in healthcare in the UK (Shemtob et al., 2022). Consequently, addressing the underlying causes related to factors such as workplace demand, relationships, and support is necessary for improved staff engagement and enabling recovery from burnout (McFadden et al., 2021; Shemtob et al., 2022).

Burnout is linked to reducing an individual's capacity to care and show compassion, also causing feelings of ineffectiveness (Hofmeyer et al., 2020). Staff and volunteer burnout within a hospice setting may have a negative impact on their ability to care for patients and each other. One approach to managing and preventing negative outcomes includes seeking support from those within the working environment who understand the unique context (Desbiens & Fillion, 2007; Papworth et al., 2023). Maintaining positive relationships with colleagues (both paid and voluntary) can help to show when they are struggling and support them in seeking appropriate support and guidance (Shemtob et al., 2022).

Paid staff members often consider that volunteers have more time to devote to the caring role than they do (Bateman et al., 2016; Ervin & Moore, 2014; The King's Fund, 2018). However, there is potential for tension when staff perceive that volunteers are 'taking the place' of employed staff members in the form of substitution (Charalambous, 2014; Malby et al., 2017; Robinson et al., 2021). This may be linked to a lack of clarity around specific job roles and the purpose of volunteer workers. Paradis and Usui (1989) undertook a study due to perceived conflicts between paid and volunteer staff in an end-of-life care setting. They recommended that there should be a refocus on finding and defining areas where staff and volunteer tasks or responsibilities differ. The King's Fund (2018) adds that volunteers should be regarded as 'complementary' rather than 'supplementary' to employed staff. This may be addressed by including greater joint working, shared training experiences, or communication opportunities between the teams within the hospice setting. Paid staff having a better understanding of the volunteer role and their motivations would help to improve the working experience of both paid staff and volunteers.

2.4 Exploring definitions of volunteering to reduce misunderstandings between paid staff and volunteers

The National Council for Voluntary Organisations (2024b) state that “volunteers give time, carrying out activities that aim to benefit their community or society. Volunteers are unpaid and choose how they wish to give their time.” My understanding of volunteering is considered in the context of unpaid individuals who commit their time regularly within the same setting. However, there are different understandings and concepts relating to volunteering that vary from country to country, within different sectors and specialties. Hustinx et al. (2010, p. 410) add that “volunteering is a complex phenomenon that has permeable boundaries and spans a wide variety of activities, organisations, and sectors…, different disciplines attribute different meanings and functions to volunteering.” Therefore, trying to create a definition of volunteering can be challenging due to its breadth and variety (Aboramadan, 2019; Hustinx et al., 2010). For example, volunteering within some countries may be seen as strictly under the supervision and guidance of paid staff, whilst others may have volunteer-led services, with paid staff ‘under’ volunteers (Georgeou & Haas, 2019). Many have tried to define volunteering by what it is not rather than what it is. Such as, volunteering is *not* paid employment, *not* forced activity, often defined as *not* sporadic or spontaneous (one-off activity), but also *not* unpaid work as an informal carer (Hustinx et al., 2010).

The King's Fund (2013) discussed some of the challenges and tensions due to the constantly changing nature of volunteering. Volunteers are seen as essential team members in some care settings, but this perspective varies, creating uncertainty for both volunteers and providers about their roles. Uncertainty may be in part due to a lack of organisational strategic vision for the role of volunteers. The King's Fund (2013) encouraged care providers to take a more strategic approach towards volunteers as a means of meeting their objectives and goals. Since then, Brook and Hood (2021) conducted a qualitative project report for the

NHS and Health Education England (HEE), concluding that there was a greater need for clarity and consistency around volunteer roles and volunteer management. Within healthcare, there is variation in how volunteers are engaged and deployed between different settings and specialties. For instance, some services may feel that volunteers should be ‘behind the scenes’ or involved with fundraising only, while other care settings may have volunteers engaged in befriending services, thus fully engaged with patients (Vanderstichelen et al., 2018).

Volunteering in healthcare is shaped by clinical governance and guidelines, which may require volunteers to sign contracts or give verbal agreement to a set of standards, commit to shifts, and often complete training (Charalambous, 2020). Volunteering is a theme in the NHS (2019, p. 90) Long-Term Plan, which acknowledged that “well-designed and managed volunteering programmes improve satisfaction and wellbeing ratings for staff, as well as volunteers and patients.” In 2021, Health Education England (2023) introduced the National Volunteering Certificate as a way of improving consistency and standardisation in volunteer roles. However, many private and charity-run locations are outside of the NHS, which may not fully engage with NHS volunteer programmes, creating a disparity in care settings for volunteers. Volunteering in healthcare cannot be ‘one-size-fits-all’ in terms of policy and regulation, due to the vast array of settings, roles, and situations volunteers are engaged with. However, some broad guidance appears appropriate to prevent volunteers from being held back from role fulfilment because of organisational fear around volunteers potentially overstepping boundaries.

2.5 Exploring the motivations that underpin volunteer involvement in a hospice context: theories of volunteering

The focus of the work presented in this thesis is the working relationship between volunteers and paid staff. Exploring theories of why individuals volunteer and what sustains their continued involvement enables a deeper understanding of some of the influences on their working relationships with paid staff (Zboja et al., 2020). Different prominent theories of volunteering were potentially relevant in this thesis, including the empathy-altruism hypothesis and functional theory. However, there were aspects of these theories that did not fully align with the aim of this research. Table 2.1 includes a brief overview of three main theories of volunteering, indicating (in blue) how solidarity theory can be compared and contrasted to other theories. A rationale for the influencing choice of solidarity theory in this thesis is given, which informed my decisions about the research methods and design, and how I interpreted the data collected.

Table 2.1 – A brief comparison of three key theories of volunteering (blue indicates the theoretical underpinnings of the thesis)

Descriptive	**Empathy-altruism hypothesis**	**Functional theory**	**Solidarity theory**
Brief general description	Volunteering has often been linked to concepts of altruism, as it can be defined as a specific form of motivation with the sole aim of helping another (Kahana et al., 2013; Post, 2008).	Volunteering is a way for individuals to meet their own needs for social interaction, self-esteem, and purpose. Volunteers may offer their time for very different reasons due to their varying motivations, and these motives may change over time (Clary et al., 1998; Finkelstein et al., 2005; Snyder et al., 1999).	Within solidarity theory, volunteering is seen as a way for individuals to express their commitment to their community and others. This has been regarded as being involved in mutual support or connection to others in large or small groups and connected with ‘we-thinking’ rather than individual ideas and initiatives (Laitinen & Pessi, 2014).

Areas where was congruence with this study	Emotional-based empathy (feeling another person’s emotions) is a greater motivator towards volunteer action than cognitive-based empathy (knowing how other people think and feel) (Persson & Kajonius, 2016). It is relevant for hospices looking to encourage and retain volunteers to understand that feelings and emotions often drive altruism.	Including Volunteer Functional theory would improve volunteer engagement and satisfaction by better-linking volunteer roles with their underlying motivation for volunteering (Finkelstein et al., 2005; Lin & Lou; Planalp & Trost, 2009). Functional theory includes consideration of social reasons for volunteering, which is relevant to this thesis.	Solidarity theory is particularly relevant to examining meaning in social relationships, which explore the interpersonal bonds of sympathy, empathy, and mutual understanding with a particular group (such as those with life-limiting and life-threatening illnesses) (O’Toole & Calvard, 2020).
Areas of challenge and where theory does not fully align	Within this thesis, the intention is to focus on how paid staff and volunteers work together. Therefore, as the empathy-altruism hypothesis appears to focus more on concepts related to the individual, it may miss some of the wider concepts associated with relationships and connections with others.	Volunteer functional theory encompasses a broad spectrum of various motivations for volunteering, which is not adequately specific to enable an explicit linking of theory to this work.	Solidarity theory is relevant for this thesis and applied throughout the following chapters.

Conscious group identity is one of the key motivating factors involved in solidarity theory. When an individual identifies with a group, bonds with it, and feels that they belong, they often commit to it and invest in the group. Bonds of sentiment and shared values, interest in the group’s well-being, shared values and beliefs, and a readiness to show moral support are further important hallmarks of solidarity theory (May, 1996). Since the first writing of Emile Durkheim’s ‘the division of labour in society,’ solidarity has been understood in multiple ways, for example, much of the focus of solidarity theory has been around political concepts, social welfare regimes, and public discussions (Kapeller & Wolkenstein, 2013; Wilde, 2007). However, O’Toole and Calvard (2020) describe solidarity as a ‘dynamic interrelationship,’ in which volunteering practices, shared experiences, and meaningful purpose are found when applied in complex volunteering work with others.

Individualisation in Western society has been seen as one of the most significant challenges to volunteering, by reducing the remaining sense of solidarity among communities (De Beer & Koster, 2009; Eimhjellen et al., 2018). The step towards individualisation of modern society can be positive as a means of liberation from traditional ways of life and communities. However, individualisation may also relate to a greater sense of 'existential uncertainty,' as individuals disconnect from what were previously the 'fixed anchors' in society (Rasborg, 2021). Volunteers may now combine more traditional models and reasons for volunteering with newer, more individualised features, creating a more 'self-reflexive' approach (Hustinx & Lammertyn, 2000). Organisations who look to attract and retain volunteers based on older, traditional views of volunteering, originating "from a bygone institutional context and are not adapted to recent socio-cultural changes" (Hustinx & Lammertyn, 2000, p. 3) may now struggle to meet volunteers' needs.

Solidarity theory is particularly relevant to examining meaning in social relationships, which explore the interpersonal bonds of sympathy, empathy, and mutual understanding with a particular group (such as those with life-limiting and life-threatening illnesses) (O'Toole & Calvard, 2020). The term 'we thinking' relates to groups that intentionally seek to build shared identity, which becomes a basis for mutual concern, shared goals, and identification with a central concept (Laitinen & Pessi, 2014). "Collective intentionality lies at the heart of solidarity and social action. Collective intentions refer to thinking in a 'We-mode' oriented toward the social group, contrary to individual-oriented thinking in 'I-mode'" (Kirgil, 2023, p. 1). Consequently, solidarity theory and 'We thinking' involve a collective commitment to the realisation of the shared goal and, importantly, intentionally looking to achieve the goal with others, rather than individually (Sangiovanni, 2015). Seeking to achieve goals with others corresponds with the overall aim of this thesis - to investigate how paid staff and volunteers work together in a specific setting of a hospice. I considered solidarity theory as a relevant means of underpinning the study, particularly in light of 'we-thinking' and understanding shared goals, interests, and objectives, creating a sense of unity in groups. Solidarity theory and 'we-thinking' are reflected within the context of the following chapters, considering the relationships and bonds between paid staff and volunteers.

2.6 Conclusion

My aim in this chapter was to explore some of the key theories and definitions related to paid staff and volunteers in palliative care and hospice settings in the UK. Some of the challenges facing the palliative care workforce and some of the unique issues relevant to those working in hospices have been discussed. I also reflected on the role of volunteers, both broadly and in palliative care environments. The chapter includes definitions of volunteering that inform later sections of this thesis. For this study, I considered volunteering in the context of unpaid individuals who commit their time regularly within the same setting. Furthermore, I have found solidarity theory to be relevant to this thesis, due to its consideration of 'we-thinking' and having shared goals and focus, which is in-keeping with working relationships between paid staff and volunteers.

Chapter 3. Literature Review: Paid staff and volunteers' experiences of working together to provide palliative care: a meta-ethnographic review

3.1 Introduction

In this literature review, I critically explore the experiences of paid staff and volunteers working together in palliative care settings through a meta-ethnographic approach, highlighting key themes, challenges, and collaborative dynamics that shape their interactions and care delivery. Much of the information within this chapter has already been published in a peer-reviewed journal: Oliver, K., Brown, M., Walshe, C & Salifu, Y. (2023) A Meta-Ethnographic Review of Paid Staff and Volunteers Working together in Palliative Care, Journal of Pain and Symptom Management, 66(6) 656-670 https://doi.org/10.1016/j.jpainsymman.2023.08.004. There is additional content within this chapter focused on providing richer detail and context both in the methods and methodology and the breadth and depth of the results and discussion. The paper is found in Appendix A. Additionally, the meta-ethnographic review was presented as an e-poster at the 18th World Congress of the European Association for Palliative Care: Oliver, K., Brown, M., Salifu, Y., and Walshe, C. (2023) P 16.003 Paid Staff and Volunteers' Experiences of Working Together to Provide Palliative Care: A Systematically Constructed Meta-ethnographic Review ("EAPC2023 Abstract Book," 2023, p. 261). The poster is found in Appendix B.

The involvement of volunteers in settings providing palliative care is regarded as a vital part of the care provided to patients and those important to them (Candy et al., 2015). However, the relationship of volunteers with other team members, including those regarded as 'professionals,' providing palliative care has at times been reported to be challenging (Vanderstichelen et al., 2018). Whilst collaboration between volunteers and paid staff members of the team has been highlighted as an essential element of successful working, failures in coordination and tensions within teams may lead to volunteers not being able to make an effective contribution (Field-Richards & Arthur, 2012; Payne, 2002; Vanderstichelen et al., 2018). Volunteers have reported feeling that they received insufficient information to prepare them for patient contact (Harland, 2016). The information volunteers considered to be helpful to be able to successfully fulfil their role differed from what staff gave or thought necessary for them to know (Meyer et al., 2018). Volunteers and paid staff have both suggested that greater opportunities for contact and integration between teams would be beneficial to improve their working relationship and understanding of each other's needs (Meyer et al., 2018).

Previous reviews exploring volunteer experiences in palliative care settings have touched on their relationships with the wider healthcare team (Bloomer & Walshe, 2020; Claxton-Oldfield, 2015; Wilson et al., 2005). However, to date, no reviews have been conducted to specifically explore the way paid staff and volunteers work together when providing palliative care. This is an important contributing factor to the effectiveness and satisfaction of volunteers (Meyer et al., 2018). Earlier literature review recommendations have been for further research into improving communication and cooperation between paid staff and volunteers (Wilson et al., 2005). A meta-ethnographic review is an appropriate method for exploring this phenomenon as this approach looks to "derive substantive interpretations" that may be seen as a complete and standalone study (Noblit & Hare, 1988, p. 9). Consequently, the purpose of this meta-ethnographic review was to develop a deeper understanding of the views expressed by volunteers and paid staff about their experiences of working together in palliative care settings.

3.2 The review

3.2.1 Phase one: selecting meta-ethnography and getting started

My aim of this study was to explore the views expressed by volunteers and paid staff about their experiences of working together in palliative care settings. There are many approaches commonly used in literature reviews that were considered in light of this study's aim and purpose. One approach to literature reviews is to incorporate quantitative research, such as meta-analysis. This often looks to determine the effectiveness of an intervention or treatment by analysing numerical data from several studies (Aveyard, 2016). Whilst quantitative approaches are regarded as beneficial for more focused and objective research, the intention of conducting this study was to explore why this issue happens rather than how it occurs. Consequently, quantitative approaches to literature reviews were not considered.

Some approaches to mixed methods literature reviews, including both qualitative and quantitative research, can develop theory, such as realist reviews. Critical realist reviews are recognised for their ability engage with multifaceted and complex issues relating to the social world and relationships (Pawson et al., 2005). Despite these positive views, it has been criticised for lacking a structured methodology and guidance on how to apply it (Fletcher, 2016). Whilst research including both qualitative and quantitative elements has grown in popularity, conducting meta-ethnographic literature reviews does not require the inclusion of any quantitative research. Therefore, as the purpose of doing this review was to explore the opinions, thoughts, and feelings of volunteers and paid staff, only literature review approaches looking only at qualitative research were considered.

Within qualitative literature reviews, there are several commonly used approaches, such as those employing meta-aggregation. This approach brings together a summary of the themes identified in the selected review papers. Meta-aggregation is not used to interpret findings or to create new knowledge, which this literature review aims to achieve (Aveyard, 2016). Meta-ethnography was chosen to enable a robust way of exploring these experiences and developing an understanding of these social phenomena. Meta-ethnography also enabled the researcher to retain the context and meaning of the original participant's and author's voices, which I deemed important in developing new understandings of this relationship (Britten et al., 2002). Within meta-ethnography, this is achieved by translating, transferring concepts, metaphors, and understanding across selected studies through a seven-step process (Table 3.1) (Noblit & Hare, 1988).

Meta-ethnography was developed by Noblit and Hare (1988) as a means of bringing together separate parts to form a new whole. Meta-ethnography aims not to simply combine the results of different qualitative data but to use the findings from individual studies to create new interpretations (Aveyard, 2016). Consequently, relevant qualitative research exploring different aspects of the working relationship between paid staff and volunteers was selected that would build a new understanding of the phenomenon. Meta-ethnography is useful in this kind of healthcare-related research, particularly in understanding the experiences of individuals (Atkins et al., 2008). It was intended that through appropriately conducting and reporting meta-ethnography the review could generate new evidence and may develop an understanding of services (France, Uny, et al., 2019). Noblit and Hare (1988) claim that the meanings developed through this approach may identify issues that need to be addressed and be seen as a 'call to action.' Consequently, this was fitting to explore paid staff and volunteers' experiences of working together to provide palliative care, which aims to generate evidence for further research.

This review was completed in line with a meta-ethnographic approach. Although the 7 phases are not meant to be used as a 'step-by-step' approach, it was used as a guide for the study process and considered the Meta-ethnography reporting guidance (eMERGe guidance on improving reporting meta-ethnography, which can be found in appendix C (France, Cunningham, et al., 2019). However, France, Cunningham, et al. (2019) warn that there is no 'one size fits all' approach to employ when conducting a meta-ethnographic review, as each researcher needs to make individual decisions on issues such as the methods, review aim, and the nature and quantity of data to be synthesised. Although meta-ethnography has a seven-step process, it is also iterative, and the phases are not to be held as discrete, but they may often overlap and/or run in parallel (Sattar et al., 2021). Therefore, whilst this has been used as a guide, any changes to this have been reported to aid transparency.

Table 3.1 – An overview of the research process of meta-ethnography

Phase of meta-ethnography (phases may overlap and/or run parallel)	**Purpose and requirements of the phase**
Phase one: 'getting started'	Identifying an area of exploration in which qualitative research can be employed to inform. This aims to find something which is worth studying through meta-ethnography.
Phase two: 'deciding what is relevant to the initial interest'	Determining the studies relevant and of interest to the chosen area of exploration.
Phase three: 'reading the studies'	In-depth reading and re-reading of selected papers to begin identifying interpretive metaphors.
Phase four: 'determining how the studies are related'	Studies must be put together by deciding the key metaphors, concepts by comparing and contrasting them. Initial assumptions can begin to be made.
Phase five: 'translating the studies into one another'	Translating studies whilst also maintaining the main concepts and metaphors of each paper.
Phase six: 'synthesising translations'	The various translations are compared to determine if larger concepts can incorporate and encompass some of these separate translations.
Phase seven: 'expressing the synthesis'	Express the translation and synthesis in an appropriate way to the identified audience.

3.2.2 Phase two: deciding what is relevant to the initial interest

Based on the aim of the study, this review question was constructed: How do volunteers and paid staff working in palliative care settings describe their experiences of working together?

The Literature review question was developed and guided by using PICo (**P**opulation, **I**ntervention, **Co**ntext) (See Table 3.2).

*Table 3.2 – **P**opulation, **I**ntervention, and **Co**ntext of Interest.*

Population	Volunteer and paid staff providing palliative care to patients
Intervention	Collaboration/Working together
Context	Any care settings providing palliative care to patients

Search strategy:

A search strategy was developed with the advice and guidance from a Lancaster University librarian who has specialist subject knowledge of health research. PsycINFO, CINAHL, Medline Complete, and AMED (The Allied and Complementary Medicine Database) databases were searched from the beginning of the databases up to the 5th December 2021 (date of the final search). These databases were selected to give a range of allied health and nursing perspectives, as well as the inclusion of databases that consider palliative and multidisciplinary approaches. Search terms such as 'volunteers' and 'palliative care' were developed with Medical subject headings (MeSH) terms and other synonyms found in relevant initial scoping reviews to capture potentially relevant papers for this review. The use of phrase searching was also used in the searches and words were truncated to ensure that variations of words were not excluded. MeSH were modified according to each database which were used in combination with free-text search terms to build a comprehensive search approach. Database limiters were applied to only include academic journals, written in the English language, and peer reviewed. Boolean operators (AND, OR) were used as they are beneficial in building or limiting searches (Coughlan, 2017). After a discussion with the librarian, the use of 'NOT' was omitted, as this may have unintentionally excluded valuable research. Additional search terms, such as 'paid staff' were found to overly limit the results and omitted potentially relevant results (See Appendix D).

Inclusion and exclusion criteria:

The inclusion and exclusion criteria were applied to the studies located (See Table 3.3).

Table 3.3 – Inclusion and exclusion criteria.

Inclusion	Exclusion
• Research exploring volunteers (considered for this review as a person who works for an organization without being paid) providing direct patient care (inclusive of physical care/verbal support/meal and drinks provision), in collaboration (working directly with or alongside) paid staff in palliative care settings. • Any care settings providing palliative care (may include care provided to any patient (adult or child) with any formal terminal diagnosis (not limited to cancer). • Primary research employing any qualitative approach. • Research published in the English language. • Published, peer-reviewed research.	• All quantitative research, including those with a combination of qualitative and quantitative research methods, as **meta-ethnography** only enables the inclusion of qualitative studies (Sattar et al., 2021). • Literature reviews (however, the reference lists may be used for 'snowballing'). • Grey literature.

The citations were retrieved and organised using Endnote X9. The 'second checker' was liaised with to review a sample of the first 500 titles and abstracts to confirm agreement and the final selection of included papers was confirmed by both the second checker and myself in full agreement. Of the remaining studies, the titles and abstracts were read compared to the inclusion and exclusion criteria. After this process, the full text of the remaining papers was read, considering the paper's suitability for the review.

Quality Appraisal:

Included papers were appraised for quality using the Critical Appraisal Skills Programme (CASP) tool for qualitative research, which aids assessment of the quality of research across 10 relevant domains. This quality appraisal tool is a non-specific tool for the varied range of qualitative research approaches and, as such, may only be used to provide an incomplete assessment of the quality of research (Williams et al., 2020). The value of using ‘checklists’ has been questioned in meta-ethnographic studies due to the risk that insightful studies would be excluded based on quality criteria (Sattar et al., 2021). Consequently, the CASP scores generated were not used as a means of excluding papers, but to aid understanding of the strengths and weaknesses of each paper. A table of the main characteristics of the included papers can be seen in Appendix E, which provides an overview of the research approaches, participants, location of research, and the author’s main findings and CASP scores.

3.2.3 Phase three: reading the studies

Data abstraction and synthesis:

The process of data abstraction followed Noblit and Hare’s (1988) guidelines for synthesising qualitative data. The papers were repeatedly re-read and the main components, comments, and experiences from the different papers were compared aiming to ensure no relevant findings were missed or ignored. Data were extracted and recorded from the papers, initially using mind maps and later a table of first and second-order constructs for each paper was created. This was then amalgamated into a summary of all papers, showing how they relate and providing examples of the overarching concepts identified, using direct quotes to avoid misinterpretation. Data were extracted across the whole paper, including the methods and discussion sections of papers, rather than limited only to the findings, as recommended by France, Uny, et al. (2019) to avoid the loss of relevant conceptual data. The ‘second checker’ was liaised with to discuss and confirm this process. They initially considered the papers independently before comparing emerging metaphors, concepts, and storylines to those created by the first author and then discussed to ensure agreement (See Appendix F).

3.2.4 Phase four: determining how the studies are related

The papers and data extraction forms were repeatedly read and the main components, comments, and experiences from the different papers were compared, aiming to ensure no relevant findings were missed or ignored (example of initial data extraction form in Appendix G, which were then further refined based on repeated reading of papers). The papers were assessed for reciprocal (where the accounts given are directly comparable) and refutational translation (where the accounts given are opposed to each other) across the studies. Furthermore, it was considered if there were lines of argument developing, which has been described as “a “whole” among a set of parts” (Noblit & Hare, 1988, p. 63).

3.2.5 Phase five: translating the studies into one another

The original papers were re-read again to ensure comments had not been taken out of context. This aimed to “protect the particular, respect holism, and enable comparison” (Noblit & Hare, 1988, p. 28). In this way, the study aimed to uphold the main concepts and metaphors from each paper during translation and comparison. Meta-ethnography aims to construct interpretations rather than provide an analysis (Noblit & Hare, 1988). Concept mapping was used to aid this process to help visually represent the relationships between the different concepts (see Appendix H). Again, the ‘second checker’ was liaised with to discuss and confirm this process.

Reflexivity:

Within meta-ethnography reflexivity is an important aspect of the research. This was acknowledged by Noblit and Hare (1988, p. 25), who stated that “the analyst is always translating studies into their own world view.” The findings of the review are based on personal interpretations of the selected studies, and subjectivity and personal understanding of the topic will have impacted on the interpretation of data. The ‘second checker’ and I have backgrounds as adult nurses working in palliative care settings. Furthermore, Consequently, a reflective diary was kept, aiding transparency.

3.3 Findings

3.3.1 Search outcome

A total of 4, 575 papers were identified from four databases (CINAHL: 1,882; PsycINFO: 1,212; Medline: 1,008; AMED: 473). Of these results, 1,140 duplicates were removed. Of the remaining 3,435 studies, the titles and abstracts were read compared to the inclusion and exclusion criteria, leading to the exclusion of 3,178 papers. The full text of the remaining 257 papers was read, considering the paper's suitability for the review. 243 papers were excluded for the following reasons: 4 papers were excluded due to not being in the English language, 79 papers were excluded as they were not focused on the working relationships between paid staff and volunteers. 80 papers used quantitative or Mixed methods, 79 papers were not primary research, and one paper was not locatable by the library team. This led to the inclusion of 14 papers in the final review (Figure 3.1 and appendix E). A systematic approach was used and recorded using an adapted version of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram (see Figure 3.1).

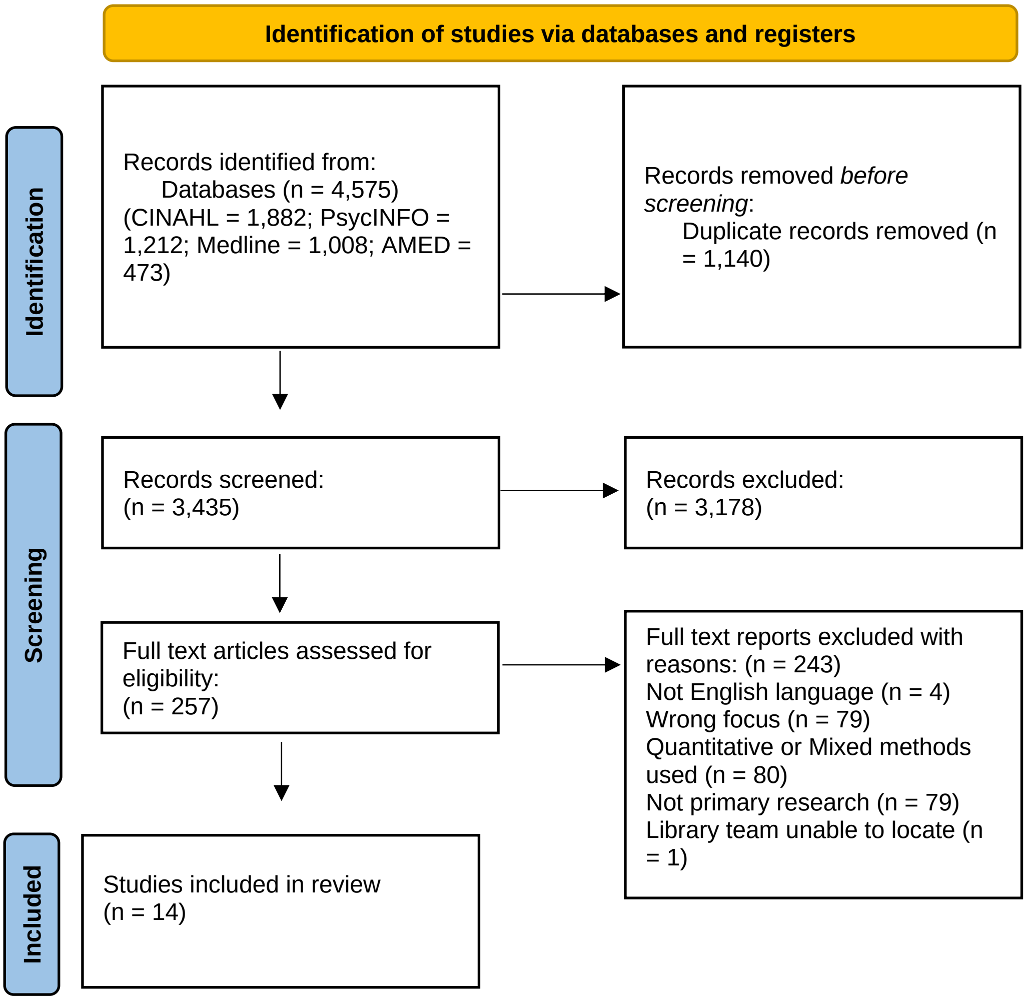


Figure 3.1: The PRISMA 2020 flow diagram indicating how the final 14 papers were found.

3.4 Phase six: synthesising translations & Phase seven: expressing the synthesis

Characteristics of included studies:

All 14 included qualitative studies met the inclusion criteria. Studies were published between 1987 and 2021 and were conducted in the United States of America (n=5), United Kingdom (n=3), Belgium (n=2), Denmark (n=1), Sweden (n=1), Canada (n=1), and one including both findings from Denmark and Australia. Study methods included interviews (described as 'in-depth,' semi-structured,' 'unstructured,' 'loosely-structured,' 'phenomenological hermeneutic approach interviews,' and 'descriptive'), these were often in combination with focus groups, field notes, and observations. Two studies included a combination of volunteers, paid staff, and family members as participants and five studies included volunteers and paid staff. However, seven of the included papers only included volunteer's perspectives. Settings included a nursing home that provided general palliative care, hospice in-patient settings, day hospices, the community setting, a children's hospice, and a prison.

The intention of the review was to go beyond the findings of individual papers to create new overarching interpretations by translating concepts and metaphors into each other. Noblit (2016, p. 4) added that the selected studies need 'to be translated into each other as wholes—that is, create analogies between and amongst set storylines that encompass the whole,' thus providing a fuller interpretation. Final consideration of the storylines was undertaken by the first and second checker (Table 3.4).

Table 3.4 – Storylines identified from the included papers (titles have been created from direct quotes taken from the included papers, illustrating each of the storylines).

Storyline 1	"*We [paid staff] are the cake, and they [volunteers] are the cream*": understanding the volunteer role - separate, but part of a whole.
Storyline 2	"*…we [volunteers] don't know what's wrong with people but sometimes we need to know*": access to information and importance of trust.
Storyline 3	"*Everybody looks out for each other*": access to, and valuing of, paid staff and their support.
Storyline 4	*"...we don't meddle in the medical":* physical and institutional boundaries.
Storyline 5	"*it's the small things that the staff does for me that makes me feel good about my work*": a sense of value and significance.

Storyline one - "we [paid staff] are the cake, and they [volunteers] are the cream": understanding the volunteer role – separate, but part of a whole.

The first storyline illustrates the different ways volunteers and paid staff viewed the volunteer role, seeing it as distinct but also connected to paid staff. Volunteers often considered themselves integral to the team, using words such as '*we*' to indicate being part of the organisation, with examples of this being enabled by senior management (Brown, 2011;

Sadler & Marty, 1998). However, this relationship between volunteers and organisation could also be perceived as 'them' and 'us,' where they '*do not connect'* (Stølen, 2021, p. 5). This could create separation and misunderstandings between the volunteers and other team members.

At times, paid staff considered volunteers as having a supplementary role. The care and support provided by volunteers were seen as extra to the essential contribution made by paid staff (Duggal et al., 2008; Overgaard, 2015). For some, paid staff valued being distinct and different, with separate roles, as much as volunteers did:

> *"We [paid staff] are the cake, and they [volunteers] are the cream. That is extremely important because they are not taking any piece of the cake. That is the difference between volunteers and professionals"* (Overgaard, 2015, p. 384).

Often, when this sense of separation was expressed, paid staff and volunteers worked separately, both in location (sometimes in the same building but different areas) or separate tasks (Stølen, 2021).

Volunteer's distinctiveness was perceived positively, enabling them to overlap the worlds of paid staff and patients in a way described as a '*unique hybrid,'* and where volunteers could be the '*eyes and ears'* of paid staff (Cloyes et al., 2017; Field-Richards & Arthur, 2012; McKee et al., 2010; Vanderstichelen et al., 2020b). Volunteers recognised this different function to paid staff, enabling them to perform different roles because they were not paid, staff:

> *"The nurses, they go into the home, and it's like, 'Okay, I [the nurse] got to get this done and I've got to get that done...' It's very task-oriented... [But] I've seen [volunteers] just being there, that is what they do: they are being there; they sit, they listen"* (McKee et al., 2010, p. 106).

Both volunteers and nurses noted the importance of 'being there' as a role of the volunteer that separates them from paid staff. In this way, they saw the difference between "being," which was linked with volunteers, and "doing," which was associated with nursing staff. However, at times, volunteers also found expressing their unique role challenging with formal care providers, instead referring to the tasks they performed to give credibility to what they did. This may have contributed to the lack of understanding from paid staff about their role (McKee et al., 2010; Vanderstichelen et al., 2020b). If volunteers felt uncertainty about the volunteer role, it was believed to lead to a sense of insecurity (Andersson & Ohlen, 2005; Paradis et al., 1987).

Although there was a generalised wish to be separate and different from each other, there was also a common feeling of mutual appreciation and regard (Duggal et al., 2008; McKee et al., 2010; Vanderstichelen et al., 2018).

Storyline two - "…we [volunteers] don't know what's wrong with people but sometimes we need to know": access to information and importance of trust.

This second storyline shows how paid staff and volunteers discussed information sharing and how, for volunteers, this was also connected to feeling trustworthy. Knowing what information could be shared was challenging for both volunteers and paid staff. Volunteers perceived that paid staff did not always share important information that they required to work effectively (Elliott & Umeh, 2013; Field-Richards & Arthur, 2012; Stølen, 2021).

Long-term volunteers felt they knew patients well, but this changed with heightened demands for privacy and confidentiality. Ambiguity around confidentiality agreements or the perceived level of seriousness that volunteers took about patient confidentiality limited the information paid staff were willing to share. Volunteers found that this strict approach to confidentiality made it difficult to perform their roles safely (Elliott & Umeh, 2013; Overgaard, 2015; Stølen, 2021; Vanderstichelen et al., 2019):

> *"So, I [wasn't] meant to give her digestive biscuits, but I didn't know that…we don't know what's wrong with people but sometimes we need to know"* (Field-Richards & Arthur, 2012, p. 629).

Some volunteers felt that the lack of information sharing was because they were not considered trustworthy, despite signing confidentiality agreements (Elliott & Umeh, 2013):

> *"… obviously the nurses stick to the confidentiality and unfortunately volunteers aren't told and yet we have to take the confidentiality thing very seriously but we're not trusted with that, which is odd really as you're trusted so far with patients"* (Elliott & Umeh, 2013, pp. 381-382).

Some paid staff did not feel it was important for volunteers to be informed about the details of patients' illnesses because this did not affect their ability to work effectively. Paid staff also tried to prevent any 'wrongdoing' by sharing more information than they should (Stølen, 2021). However, this caused disappointment for volunteers, as they were interested in the people they met. The lack of information about patients led to volunteers misunderstanding the paid staff's rationale for their actions towards patients (Andersson & Ohlen, 2005). At times this extended to paid staff not sharing information about an individual's death (Stølen, 2021):

> *"If someone dies, they can't tell you. Then you happen to find out accidentally. When you are in the house a lot, this is strange (...) You know the resident"* (Stølen, 2021, p. 8).

Becoming a volunteer often involves learning to trust not only others, but also to trust themselves and the importance of being trustworthy. A sense of mutual trust was a foundational element of effective teamwork between volunteers and paid staff (Cloyes et al., 2017; McKee et al., 2010).

Storyline three - "everybody looks out for each other": access to paid staff and their support.

The third storyline focuses on the views relating to the value volunteers place on different types of support received from paid staff.

Support offered to volunteers by paid staff was either functional or emotional. Some volunteers sought assistance and advice from a variety of paid hospice workers including social workers, nurses, and clergy. Functional support was perceived as drawing on the experiences of paid staff about challenging situations, compared to emotional support, which focused on processing difficult experiences encountered. Some volunteers preferred to discuss their experiences with fellow volunteers. It was thought that those with similar perspectives were in a better position to empathise and support volunteers emotionally (Brown, 2011; Cloyes et al., 2017; Vanderstichelen et al., 2020b).

Other volunteers felt that they wanted greater social connection with staff, which would increase a sense of belonging to the team:

> *"You have a close relationship with the nurses, a one-on-one interaction, which you may not experience in other healthcare settings…everybody looks out for each other"* (Duggal et al., 2008, p. 1000).

Volunteers desired fellowship with paid staff, which was one of the reasons for volunteering. Volunteering was not only about functional working with patients but also about feeling connected to a wider team consisting of other volunteers and paid staff. When this need for fellowship is not met it could create feelings of rejection (Andersson & Ohlen, 2005). Some paid staff said they were readily available for volunteers to speak to, suggesting volunteers were permitted to engage with paid staff. Despite this offer being made some volunteers felt awkward disturbing nursing staff, implying that further reassurance of the working relationship may have been needed for some volunteers (Dein & Abbas, 2005; Paradis et al., 1987):

> *"Also the day hospice nurses. They are always there and say repeatedly that 'we are here, if there are any problems please come and speak to us'. We have a very good relationship"* (Dein & Abbas, 2005, p. 61).

Volunteers found working with, or in the presence of, paid staff was reassuring. However, some volunteers reported having difficulty contacting paid staff. The infrequency of working together due to shift patterns was seen as a barrier to effective communication which was felt could lead to confusion and misunderstandings. Volunteers expressed concern that this may cause important information about patient care to be lost, putting excessive pressure and responsibility on the volunteers (Field-Richards & Arthur, 2012; Paradis et al., 1987; Vanderstichelen et al., 2019; Vanderstichelen et al., 2020b).

The role of a volunteer coordinator facilitated communication when there was limited contact between paid staff and volunteers. In addition to seeking support from paid staff, volunteers referred to volunteer coordinators for problem-solving and advice. This was often felt to be an important relationship for volunteers (Brown, 2011; Paradis et al., 1987; Vanderstichelen et al., 2019). However, some of the paid staff felt that the role of the co-ordinator could create a 'third person' and become a barrier to cooperation and the development of mutual understanding. Whilst coordinators were seen as an important part of aiding volunteers to solve problems, it was perceived that they should also encourage volunteers to make use of the interdisciplinary team when needed (Brown, 2011; Stølen, 2021).

Storyline four - "...we [volunteers] don't meddle in the medical": boundaries.

This storyline includes the perception that boundaries could be physical, institutional, and at times unspoken.

At times there were feelings of boundaries that kept volunteers outside the 'professional domain,' including multidisciplinary team meetings. This was 'valued' by some volunteers, as they wished to respect the boundaries (Elliott & Umeh, 2013; Field-Richards & Arthur, 2012; Stølen, 2021). Whilst another volunteer referred to it as *"...we don't meddle in the medical"* (Vanderstichelen et al., 2020b, p. 5). Volunteers were aware that they should not 'cross the line,' although these boundaries were never strictly defined and at times exceptions occurred:

> *"… you're busy in the kitchen with who knows what, but you hear the nurse that, er, someone is anxious, er, wishes for someone to be near, wishes – you drop everything..."* (Vanderstichelen et al., 2020b, p. 5).

When requested by paid staff, volunteers appeared to function in a different domain than their volunteer-tasked role. It was thought that when volunteers felt uncertainty about their boundaries, volunteers may be afraid that they would accidentally stray into the 'domain of the nurses' (Andersson & Ohlen, 2005).

Volunteers used the expression *'stepping on toes'* of paid staff regarding invisible and unspoken boundaries:

> *"There are lots of practical things I'd like to talk a little bit more about, like the boundaries between what a volunteer can do and what the professional caregivers do – to have a better understanding of the nature of their professional work (…) I'm afraid of stepping on someone's toes…"* (Stølen, 2021, p. 5).

However, within another context, paid staff were also concerned this could happen with volunteers. This was overcome through supervision, which was used to evaluate volunteers' strengths and weaknesses positively, 'without stepping on toes' (Stølen, 2021; Vanderstichelen et al., 2019).

Shifting boundaries, driven by an increased sense of formality through policy and restrictions, impacted working relationships between paid staff and volunteers. Nevertheless, change was often seen positively by some volunteers, appreciating an increased structure, which was clearly explained and defined (Field-Richards & Arthur, 2012; Overgaard, 2015).

Some volunteers were not permitted to enter patient rooms, creating physical boundaries. Volunteers described feeling they had crossed an 'institutional boundary' although this was unspoken, it represented a physical area specifically for paid staff. Lack of interaction from paid staff caused volunteers uncertainty about being welcomed into the physical space. However, some paid staff believed that if volunteers were not working in the same areas, they missed the opportunity to get to know each other. This suggests that there may have been a misunderstanding between the two groups. Volunteers felt that having a shared physical space would make a ‘big difference’ to working relationships (Overgaard, 2015; Stølen, 2021; Vanderstichelen et al., 2019).

Storyline five - "it's the small things that the staff does for me that makes me feel good about my work": sense of value and significance.

The final storyline illustrates the sense of significance and value felt by volunteers as part of a wider hierarchical structure.

Feeling appreciation from paid staff helped volunteers see their role as significant and worthwhile (Elliott & Umeh, 2013). When appreciation was lacking volunteers felt unimportant and unnoticed. The desire for recognition varied amongst volunteers, some valuing formal recognition through newsletters and special volunteer events (Andersson & Ohlen, 2005; Sadler & Marty, 1998). Others felt that formal recognition in this way was not necessary, preferring more informal recognition:

> *"it's the small things that the staff does for me that makes me feel good about my work"* (Sadler & Marty, 1998, p. 61).

This suggests that whilst volunteer preference on how recognition is received is individual, the desire for it in some form from paid staff was more widely expressed (Field-Richards & Arthur, 2012).

Recognition by paid staff of volunteer’s individual interests, abilities, and skills influenced their experience of volunteering and sense of value. Volunteers saw their role as unique and that their contribution should be guided by their strengths. When this was not recognised by paid staff it led to disappointment, although, there was general acceptance of the tasks assigned to them that were not to their preference (Andersson & Ohlen, 2005; Field-Richards & Arthur, 2012). Volunteers felt that it was important to carry out tasks to the best of their ability, but at times paid staff did not appear to see the value of their contribution, such as baking (Andersson & Ohlen, 2005; Field-Richards & Arthur, 2012). At times volunteers who had a healthcare professional background were regarded with apprehension:

> *"Hang your uniforms outside. You simply cannot bring your old job in here"* (Overgaard, 2015, p. 384).

However, volunteers with non-healthcare backgrounds were encouraged to use their skills within the hospice.

Often there was a deep mutual regard and respect between volunteers and paid staff (Duggal et al., 2008; Field-Richards & Arthur, 2012; McKee et al., 2010). Respect was also given to volunteers by paid staff due to the level of knowledge they had about the patients and how they were feeling. Volunteers saw that being regarded as 'good volunteers' was linked to their continued willingness to learn about patients and from others, suggesting that gaining respect was connected to demonstrations of commitment from volunteers (Cloyes et al., 2017).

Some volunteers felt ambiguity over volunteer status due to 'organisational hierarchy' created uncertainty and 'status conflict' (Paradis et al., 1987). However, some volunteers were aware of a sense of hierarchy:

> *"you've got to make sure that [you] speak to the staff, not do something off your own bat"* (Elliott & Umeh, 2013, p. 379).

This suggests that they were required to seek permission from paid staff before acting. The metaphor of a tandem bike was used to describe the working relationship, suggesting a closeness and connection between paid staff and volunteers for effective working. Within the metaphor, the paid staff member is still the lead in the relationship at the front of the bike with the volunteer at the back (Vanderstichelen et al., 2019).

A high level of satisfaction from volunteers with the wider principles of the hospice movement was attributed to a non-hierarchical approach to multidisciplinary working, valuing individual contributions, rather than status or qualifications (Dein and Abbas, 2005). Not all appeared to agree with this view, as some volunteers and paid staff questioned if volunteers were 'qualified' for certain discussions (Paradis et al., 1987; Sadler & Marty, 1998; Vanderstichelen et al., 2019).

3.5 Discussion

The aim of this meta-ethnographic review was to explore the views expressed by volunteers and paid staff about their experiences of working together in palliative care settings. This review has highlighted challenges for volunteers, paid staff, and settings providing palliative care when looking to work together. The overarching concept throughout all five storylines was of team and team working between volunteers and paid staff, which was evident with the term 'we' being used. Teamwork can be seen threaded through three key issues identified, which relate to redefining what palliative care teams are and who they should include, considering the impact of power and hierarchy on teams, and the importance of intentionally building relationships between volunteers and paid staff.

The desire of volunteers to work as part of a team with paid staff was clear within several of the storylines and seen by volunteers wanting to be connected in a meaningful and purposeful way. The importance of teamwork is often seen as a key element of effective palliative care (Fernando & Hughes, 2019), although this is often limited to those regarded as 'healthcare professionals' or paid staff. Within healthcare the term 'interprofessional team working' is often used, advocated and included as a core element of pre-registration teaching (Carney et al., 2019; Harper et al., 2019; McGinness et al., 2019). This concept encourages healthcare professionals to view other professionals as having an equally valid contribution to make to patient care and to work collaboratively. It has been further suggested that trans-professional working, which seeks to transcend individual disciplines to form more integrated and cohesive teams would enable team members to develop greater knowledge and understanding of each other's roles and responsibilities (Chiocchio & Richer, 2015; Haruta et al., 2017). This positive model still does not necessarily seem to remove barriers to fully include relationships between paid staff and volunteers. Consequently, many volunteers may still be seen as outside of the core team within a palliative care setting. This separation links with the metaphor used in storyline one of "we [paid staff] are the cake, and they [volunteers] are the cream," seeing healthcare professionals and paid staff as essential and volunteers as non-essential.

The findings of this review are that the boundaries of interprofessional teams within palliative care should be challenged, in order to consider the unique and valid contribution volunteers make when included as integral members of the team. However, how to make this meaningful and prevent their inclusion from being only a token or goodwill gesture would need consideration within each palliative care setting. Teams meet and work for different purposes, for example, to discuss patient care, to discuss staffing issues, or to discuss the running of the setting. Therefore, consideration needs to be given to which meetings and teams would be appropriate for different groups of volunteers to be involved in, so that their contribution can be meaningful and mutually beneficial. This would need to include transparency in communication verbally and written, such as during initial induction training and written job descriptions for both volunteers and paid staff to prevent misunderstandings. Furthermore, this would reduce the concern expressed in storyline four about the fear of 'stepping on toes' due to unspoken boundaries.

Recognition of a hierarchical and power imbalance between paid staff and volunteers was noted within storyline five. Within healthcare, there have been historical imbalances of hierarchy and subsequent power, notably between doctors and nurses. There is a long-standing perspective that nursing was an oppressed role, and nurses were subservient to doctors (Bloomer et al., 2013). Successful changes have been made to this relationship, seeking to eradicate the need for the ‘nurse-doctor game’ within healthcare practice (Stein et al., 1990). Whilst improvements are evident in relationships between healthcare professionals, throughout the storylines it was seen that volunteers perceived they had a lower status in the organisation than paid staff. Meyer et al. (2018) also found that volunteers could feel subordinate and controlled by paid staff. This links to the metaphor in storyline five of the tandem bike, with the paid staff up-front, directing, and leading, with the volunteer behind following, implying they had less control. Volunteer empowerment is a key aspect in encouraging volunteer engagement, building an increased sense of control over their contribution within the setting. Highlighting that paid staff, of all levels, play an essential role in volunteers feeling empowered and an important part of the team. This may be achieved by volunteers and paid staff building shared goals and including volunteers in decision-making processes. Traeger and Alfes (2019) suggest that volunteer empowerment can be aided by having the skills, knowledge, and ability to carry out tasks effectively through training and development. Joint training for volunteers and paid staff during induction on relevant topics, such as the values and structure of the organisation, moving and handling, and core principles of palliative care may help to reduce the sense of power imbalance.

Throughout the storylines, it was important for volunteers and paid staff to intentionally build positive and meaningful relationships. Increasing social interaction between paid staff and volunteers was seen in storyline three to be a constructive way of improving working relationships and further building a sense of fellowship that was deemed to be important to some volunteers. Over the last few years, COVID-19 restricted many volunteers' ability to have face-to-face contact in palliative care settings, leading to reduced social interaction and changing the way communication with patients, paid staff, and other volunteers occurred (Dickerson, 2021). Palliative care settings should ensure volunteers maintain a sense of community and camaraderie, as highlighted in this review. Settings going through times of change or growth can reduce the sense of intimacy within these settings, which may negatively impact the experience of volunteers (Wilson et al., 2005). Therefore, as demands for palliative care services increase and settings expand, there should be consideration for how a sense of fellowship and belonging can still be fostered.

The storylines show that a sense of recognition was important for volunteers to feel valued by paid staff, which is also echoed in other studies (Claxton-Oldfield & Claxton-Oldfield, 2012; Low et al., 2005; Wilson et al., 2005). The findings of this review highlight the importance of acknowledging volunteers' contributions, which were linked to their sense of personal worth. Maslow's theory of human motivation views that for individuals to reach their potential, they first need to feel they belong and find their place in a group, followed by meeting their esteem needs. This includes feeling a sense of esteem, attention, and recognition from others (Maslow & Lewis, 1987; Maslow, 1958). A qualitative study also found that volunteering can build self-growth and well-being by building their sense of individual purpose (Turk et al., 2022). Therefore, for volunteers to reach their potential in their work as part of a palliative care team, they need to feel acknowledged and appreciated by the wider team. Effective communication, successful utilisation of volunteers, and having joint social events between paid staff and volunteers may be effective ways of improving volunteer retention and satisfaction (Claxton-Oldfield & Claxton-Oldfield, 2012).

3.6 Recommendations

- Recommendations for practice

There is potential that joint education, including the ethos of palliative care and the organisational values, would develop a mutual sense of belonging to one team with a clear vision and intent. The inclusion of volunteers in team meetings should be considered to improve information sharing, enable volunteers to make a unique and valid contribution, also foster a sense of empowerment. Encouraging volunteers and paid staff to be in each other's presence more, both during work and socially, may encourage improved relationships. This may include simple initiatives, such as a shared room for breaks. Successful working between paid staff and volunteers should not be taken for granted to prevent potential problems and breakdowns in their relationships.

- Recommendations for policy

UK guidelines, such as National Institute for Health and Care Excellence, Care of Dying Adults in the Last Days of Life (2015), and End of Life Care for Adults: Service Delivery (2019), are often aimed specifically at health and social care professionals. The recommendations include the benefit of multi-professional working. However, as previously discussed, this may exclude the contribution of volunteers. Consequently, including volunteers in relevant aspects of policy on how they can contribute to effective palliative care through working with paid staff may be useful. Volunteer inclusion in UK-wide guidelines may also support individual palliative care settings in navigating some of the challenges discussed throughout the storylines, enabling them to filter this into their local guidelines.

- Recommendations for future research

The findings of this review are that there were still problems with the working relationships between paid staff and volunteers. Therefore, primary research seeking to build further understanding of issues surrounding relationships and make improvements where needed is recommended. Empowerment for both paid staff and volunteers was raised as an area for consideration, which links with the aims of participatory action research. Action research can be used to encourage groups to feel empowered by enabling the participants to control and take ownership of the direction and focus of the research (Dudgeon et al., 2017). Therefore, participatory action research, exploring the relationships between paid staff and volunteers in a palliative care setting is recommended.

3.7 Strengths and Limitations

The findings of this meta-ethnographic review offer a new insight into the working relationships between paid staff and volunteers in palliative care settings. This has shown some of the strengths and weaknesses, which may then be used to support and guide future improvements to these working relationships.

The research approach used and decisions made to only include qualitative research in the review may have led to some studies of quantitative or mixed methods with findings relating to this issue not being considered. However, it was believed that this methodical approach was appropriate and justified due to the nature of the phenomena being explored. Meta-ethnography is an iterative and interpretive approach; therefore, my worldview would have influenced the findings of this review. Although, by following the eMERGe reporting guidance (Appendix C), I have looked to provide transparent reporting to improve the robustness of the review (France, Cunningham, et al., 2019).

The research included in the final review is all Western-centric cultural backgrounds, and whilst variations due to country of origin have been found, the inclusion of other cultures may have included a different insight and valuable perspective. Future research considering a wider cultural context may be beneficial.

3.8 Conclusion

The findings of this meta-ethnographic review show that whilst recognising individual roles and purposes within a palliative care setting, being part of one collective team is important for both volunteers and paid staff to work together effectively. This encourages a sense of belonging, camaraderie, and common purpose. It was also highlighted that paid staff are key in empowering volunteers through building shared goals and including volunteers in decision-making. Finally, for successful working relationships between paid staff and volunteers, proactive engagement and interaction between both groups is needed. The recommendation made in the meta-ethnographic review to actively engage with paid staff and volunteers through participatory action research can be seen throughout the remainder of this thesis.

Chapter 4. Methodology

4.1 Introduction

The research question for this study is: 'how can ward-based volunteers and paid hospice staff develop and improve their working relationships with each other'? The findings from chapter three showed me that effective relationships between paid staff and volunteers hinge on proactive engagement, role recognition, mutual information sharing, and intentional interaction. Chapter three also contained discussions around the need for greater inclusion, hierarchy and power imbalances, and pushing beyond traditional concepts of teamwork, to include volunteers. Consequently, I believed that exploring the phenomenon of the working relationships between paid staff and volunteers by actively involving them in the research could create change directly affecting them in a timely way. It was found in the review that none of the included studies used a participatory action research approach, which would encourage, empower, and support equal participation of those involved (Oliver et al., 2023).

The objectives of this study were:

1. To explore areas (or current practices) that act as enablers or barriers to productive communication and team functioning between ward-based volunteers and paid hospice staff.
2. To look for practical changes ward-based volunteers and paid hospice staff could implement related to the working practice and communication, aimed at improving team working.
3. To evaluate the impact of any changes introduced, which will seek to inform further changes, if needed, in the working practices of paid staff and volunteers.

I chose participatory action research, underpinned by critical theory, for this research to explore the working relationships between hospice ward-based volunteers and paid staff. I recognised that it was important for the group to be able to make positive changes to current practice where needed. In this chapter, I discuss my philosophical assumptions underpinning this study, including ontology, epistemology, leading to my choices of methodology and methods.

4.2 Philosophical assumptions - Critical Theory

The choice of my methodology was influenced by my paradigm (how I view the world and reality), my ontology (the study of being), and epistemology (concerned with the nature and scope of knowledge) (Scotland, 2012). Therefore, the justifications for the choices I made during the research process are presented. My values, beliefs, and personal standards influenced how I perceived reality and what occurs, and how I believed knowledge could be created during the research process (Jackson, 2013; Levers, 2013). Consequently, some of the challenges of the research process are addressed, and the impact this has had on the research process is outlined.

It was vital to position my work and consider where the research ‘fitted’ to make sense to myself and others. Considerations included my positionality, which was influenced by, and influenced, the research goals, the goals of the research, the design, and questions considered relevant. Table 4.1 includes a brief overview of three main paradigms, indicating (in blue) how critical theory was compared and contrasted to other paradigms. This helped me position my choice of critical theory, whilst also recognising that this table is a limited and superficial overview of deeper thinking. When compared to positivism and interpretivism, I believed critical theory was the most relevant philosophical perspective when I considered how participants and myself could engage with well-defined organisations, including hospice palliative care providers.

Table 4.1 – A brief comparison of three key philosophical perspectives (blue indicates the theoretical underpinnings of the thesis).

Descriptive	Positivism	Interpretivism	Critical theory
Ontology (the study of being)	Reality is considered to be based on empirical facts, independent of the individual and their consciousness (Scotland, 2012).	Reality is multiple and relative, depending on other systems of meanings (Guba & Lincoln, 1994).	Reality is approached from historical realism. Knowledge and reality are shaped by socio-economic, political, cultural, class, ethnicity, and gender. Reality is socially constructed, based on the recognition and participation of those with lived experience (Call-Cummings et al., 2023).
Epistemology (the nature and scope of knowledge)	Knowledge is perceived as objective. Those seeking to acquire 'legitimate knowledge' may do so by looking to show the observable, or 'factual realities', creating a copy or true likeness of what is seen (Morrow & Brown, 1994, p. 53).	Knowledge is subjective, as 'the meaning, voice, standpoint, experience, thoughts, and feelings expressed by the individual' (Junjie & Yingxin, 2022, p. 11). Interpretivist perspectives seek to include fullness and depth to the insights gathered rather than attempting to provide a definite answer to be generalised (Alharahsheh & Pius, 2020).	Linked to subjectivism, which is an epistemology based on real-world phenomena and is connected to societal meaning and understanding of what is seen (Scotland, 2012, p. 13). Researchers cannot separate themselves from what they know, and this influences their study. Knowledge is often co-constructed (Call-Cummings et al., 2023).
Methodology	Often experimental, seeking verification of a hypothesis, mainly quantitative.	Focus on developing understanding and interpretation. Often qualitative.	Critical theoretical approaches tend to rely on dialogic methods. Aim to 'transform ignorance and misapprehensions... into more informed consciousness' (Guba & Lincoln, 1994, p. 110).
Concluding comments	The positivist paradigm has been widely considered relevant in health research. In part because positivist	Enables consideration of the thoughts and feelings of paid staff and volunteers, to discover what they think the issues are and	Recognising that inequalities in power dynamics exist and can (and should) be challenged. The transformative nature of critical theory is in keeping

	approaches enable a generalisable perspective. Positivist views do not necessarily allow for the voice of the individual to be considered in great depth.	to explore these opinions with them. Does not take the additional step of creating action, pushing beyond the research methods commonly associated with interpretivism.	with seeking to make changes (with those directly impacted by the issue) and change where needed.

I was influenced by the literature synthesised (Chapter 3), where the importance of volunteer empowerment and control was highlighted. Critical theorists question knowledge and consider how power is used in the situations they are exploring (Paradis et al., 2020). Critical theory can enable researchers to 'poke holes' in the issues that challenge individuals, which may limit their potential. This approach enables deeper questioning of reality that has previously been regarded as absolute and unalterable (Popkewitz, 2009). Critical theory is "a form of thinking that is designed not only to comprehend, but also to *transform*: its purpose is to change not only our knowledge of the objective world—of society, of institutions, of culture, and so on—but simultaneously the nature of the subject in a *practical sense"* (Thompson, 2017, p. 2).

Many different philosophies are positioned under the 'umbrella' of critical theory, including feminism, some forms of postcolonialism, and critical race theory. However, the origins of critical theory principally emerged out of the philosophies of Karl Marx, which were later developed to create what is commonly understood as critical theory (Thompson, 2017). Marx was interested in societal problems, predominantly caused by class and power struggles, seeking change through empowerment and transformation. Contrary to traditional research and philosophy of the time, Marx stated that "… philosophers have only interpreted the world, in various ways; the point is to change it" (Marx, 1845; cited in Sandoval et al., 2014). Marx's words have personally resonated with the rationale for this study, which intended to create change if it was felt this would be beneficial for those involved.

Marx's original theory was further developed, creating a more subjective view, considering cultural and institutional issues that could be restrictive. Social change needed to start from the individuals whom the change would impact, rather than a positivist approach, which would operate externally and be imposed on them (Martin, 2002). A group of researchers, known as the 'Frankfurt school' in the early 1920s, further developed critical theory, which helped it to change into a framework for social research (Thompson, 2017). The Frankfurt school researchers considered that societal norms had created a culture that was 'intellectually inactive and politically passive,' and generalised ideologies that were accepted without questioning by individuals (Cole, 2019). I have felt at times through personal experience that those 'on the ground' in healthcare, such as nurses, volunteers, and healthcare assistants, can become passive and accepting of changes without questioning or understanding the rationale behind the change. This may be due to many factors, including lack of time, lack of explanation from those implementing change, and hierarchical factors. Bartunek et al. (2006, p. 2) state that "little attention has been paid to how change recipients understand a change, even less is given to how they feel about it". Research grounded in critical theory must highlight societal issues, identify key change agents, and propose practical solutions for transformation (Bohman, 2021).

In the 1960s, Jürgen Habermas became a prominent and influential member of the Frankfurt School and his work has been considered the most significant contribution to the 'new phase' of critical theory, which sought to reflect social and economic changes (Wellmer, 2014). Critical social science advances critical thinking by emphasising diverse perspectives and recognising historical and cultural influences (Alvesson & Deetz, 2020). However, as well as developing understanding, those applying critical social science also explore alternative ways of doing things, which may disrupt traditional and established social orders. The intent of this research, which is influenced by critical theory, was aimed at challenge and change, rather than simply representing, and explaining what is already happening. Previous research has shown that both volunteers and paid staff have said that greater opportunities for contact and integration between teams would be beneficial to improve their working relationship and understanding of each other's needs (Burbeck, Candy, et al., 2014; Guirguis-Younger & Grafanaki, 2008). However, whilst this has been suggested, during the literature review process in chapter three, research was not found that attempted to introduce these recommendations (Oliver et al., 2023).

Critical theorists are concerned with empowering individuals and groups to push through barriers and constraints put on them due to issues about their position in life (Savin-Baden & Howell-Major, 2013). Research at times has viewed volunteers as an undervalued group, who may lack equal power compared to paid staff (López-Cabrera et al., 2020). However, there are circumstances when it is felt that the power balance is swung the other way towards volunteers in some non-profit organisations, who place a high value on volunteering in the organisational vision and priorities (López-Cabrera et al., 2020). Through the perspective of critical theory, researchers may look to raise the awareness of those who are disempowered, bringing to light issues in society so that it then becomes a means for social change (Strunk & Betties, 2019). In this sense, both volunteers and paid staff may equally feel the need for their voice to be heard and acted on due to feelings of different hierarchical and institutional constraints. Hence, an approach that enabled both perspectives to be considered and have equality in input, without pre-existing assumptions about possible power imbalances, was an important consideration in this research.

Critical theory and solidarity theory enable consideration of how power operates within society, identifying dominant groups that perpetuate inequalities, and how marginalised groups can be empowered by recognising these dynamics. One description of solidarity is that it may be used to discuss "revolutionary critical social movements criticising the normal order and the prevailing injustices" (Laitinen & Pessi, 2014, p. 2). Through conducting this research, I sought to challenge the status quo and over-acceptance of problems, instead showing an alternative to the current situation and how it (and they) could be. For research based on critical theory to be successful, people need to be willing to act and change (Fay, 1993). Therefore, ensuring that participants had an opportunity to ask questions and decide independently if they wished to participate in the research was important. Research based on a foundation of solidarity and critical theory can support a transformative perspective. This perspective shaped the types of questions asked of participants, and how data was collected and analysed.

4.3 Methodological choices

Critical researchers may utilise many different research methodologies, including, critical ethnography, critical discourse analysis, and action research, and they are often receptive to different approaches to develop better understandings of the lived experiences of individuals and groups (Framer & Chevrette, 2017; Scotland, 2012). Foley and Valenzuela (2005) comment that critical ethnographers seek to speak on behalf of their participants as a means of empowering them, furthermore, they attempt to make a call for action through their research. Critical ethnographers seek to push further than conventional ethnographers, by making further connections of meaning to issues, such as social power and control. Another approach commonly employed by critical researchers is critical discourse analysis. In this approach analysts want “to understand, expose, and ultimately challenge social inequality” through different methods and approaches that support the critical study of text and talk (Van Dijk, 2015, p. 466). Critical discourse analysis has been advocated as a multi-disciplinary research approach, in which researchers seek to explain issues rather than simply describe them (Van Dijk, 2015). These attributes would fit with the research question for this study; however, I felt that the research should also support practical ways to achieve transformation (Bohman, 2021). Therefore, the aim of the research was not just an attempt to call for action, but to take action through the research process.

The term ‘participation’ has grown in popularity in research and other fields such as business; however, what is meant by ‘doing participation’ is not always clear (Cornwall, 2008, p. 269). Arnstein’s (1969) ladder of participation (see Figure 4.1) was designed to be provocative and includes eight levels of participation, with ‘manipulation’ at the lowest level and increasing to ‘citizen control’ at the highest level. Within the middle rungs of the ladder are what Arnstein (1969) describes as ‘degrees of tokenism,’ where individuals may have a voice during consultation, but those with power may not action this. Therefore, tokenism may be viewed as equally disheartening as non-participation for participants if their views are not listened to. Research approaches utilising an active, practical participatory approach were considered, which reflect partnership, delegation, and ultimately, intending for ‘citizen control.’ The higher rungs of the ladder intend to encourage the ‘usually powerless’ to have enough influence and control to “make the target institutions responsive to their views, aspirations, and needs” (Arnstein, 1969, p. 217). Participatory research approaches have gained increasing importance, particularly in English-speaking countries (Thomas, 2012). Participatory approaches include cooperative inquiry, participatory learning and action, and participatory action research. The common aspect of these approaches is to change social reality through collaboration with researchers, service users, and practitioners (Bergold & Thomas, 2012).

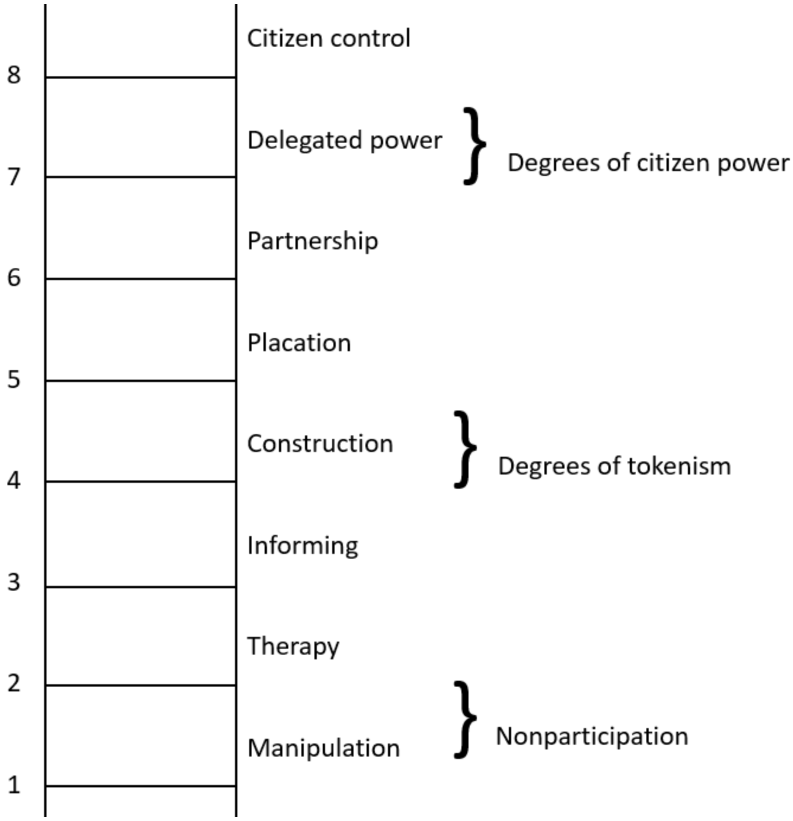


Figure 4.1: The eight rungs of the ladder of citizen partnership

Research has at times been considered too academic to be of significance within practice settings (Smith & Wilkins, 2018). Therefore, action research is a positive way of drawing theory and practice together (Savin-Baden & Howell-Major, 2013). Researchers employing an action research approach encourage an active rather than passive role for participants. Active involvement looks to create a partnership between researchers and participants, empowering all involved. The aim of participatory-based researchers is “to change social practices, including research itself, to make them more rational and reasonable, more productive, and sustainable and more just and inclusive” (Kemmis et al., 2014a, p. 2). My aims of this study included looking for practical changes, implementing changes, improving teamwork, and evaluating the working practices of paid staff and volunteers. Action research (which has also been linked to critical theory (Scotland, 2012)) was relevant to the study objectives of looking for practical changes that ward-based volunteers and paid hospice staff could implement, related to the working practice and communication.

4.4 Critical participatory action research

Kurt Lewin is often credited as the author of action research, as he was interested in how social sciences could help address issues of exploitation for minority groups and assist in resolving social conflicts. His view of action research included key elements of democracy and active involvement. The influence of Lewin’s work and theory is still evident and referred to within modern action research discussions (Savin-Baden & Howell-Major, 2013). Within action research, researchers may act independently or facilitate a team. There are variants to research involving action, including participatory action research, in which researchers do not act as facilitators of the process (as seen in action research) but as co-producers of learning (Bell et al., 2004). Critical participatory action research adds reflection, addressing any untoward consequences of wider social practices, also requiring those involved in research to consider relevant concepts and theories (Kemmis et al., 2014b). Whilst there are many practical similarities between action research, participatory action research, and critical participatory action research, there are differences in philosophy and underpinning theory that distinguish them (McIntyre, 2007).

Various forms of action research emphasise social aspects of the research and often link to the perspectives of the critical theorist Habermas and his analysis of social life (Kemmis, 2008; Morrow & Brown, 1994; Waterman et al., 2001). Much of Habermas's latter writing has explored “contemporary problems and crises to re-think the world as a basis for doing things differently — transforming things” (Kemmis, 2008, p. 19). Many researchers involved in action research also attempt to transform through practical and social intervention. Waterman et al. (2001, p. 14) add that “advocates of this approach seek to criticise dominant conceptualisations of society that, in their opinion, may serve to disadvantage certain sections of society”. Consequently, various forms of action research, including participatory action research and critical participatory action research may be seen as ways to bridge the gap between critical theory and its practical outworking (Hockley et al., 2012).

Critical participatory action research is appropriate for use with critical theory due to the links to the ontology and epistemology of critical theory (see Table 4.1), which encourages active and constructive change to take place. The position of the critical paradigm is that individuals may gain an understanding of different perceptions, challenges, and changes needed regarding failing areas of society, seeking to educate, enable, and emancipate those involved in the research process (Fay, 1993). I saw this as relevant for volunteers, who may at times feel disempowered, unprepared, and undervalued (Harland, 2016). Participatory action research has developed as a research approach that connects studying social groups and addressing social problems (Kindon et al., 2007). The purpose of research using a critical participatory action research approach is typically to gain knowledge, whilst simultaneously seeking to change or improve a situation.

Within this study, the objectives were to evaluate the impact of any changes made by the group relating to the working relationships between paid staff and volunteers. Critical participatory action research, underpinned by critical theory can be beneficial in healthcare settings to improve practice and care. The benefit may in part be due to critical participatory action research’s association with a ‘hands-on’ approach, engaging those who are directly impacted by the study process and outcomes (Swantz et al., 2006). Researchers who employ critical participatory action research may engage in a wide range of projects, and each will take different approaches and areas of interest. However, there will be some commonalities between them, including having a collective commitment to explore and reflect upon an identified issue (McIntyre, 2007).

The meta-ethnographic review in chapter three helped me to clarify the current state of practice, revealing that while previous research has explored the relationship between paid staff and volunteers and offered improvement suggestions, it did not create any change at the time of the study (Oliver et al., 2023). Critical participatory action research was selected to collaboratively challenge the hospice's and individuals' assumptions through observation, conversation, and reflection.

The critical participatory researchers seek collaboration with group members to avoid further marginalising participants that may already be considered as lacking power or suppressed. Those taking part are encouraged to have a voice throughout the study, by supporting the group to make decisions about the research process (Baum et al., 2006). Critical participatory action research has been criticised for being too idealistic and utopian (Hockley et al., 2012; Waterman et al., 2001). Others have argued that participatory action research can be overly biased, as researchers lack separation due to being involved in research (Danley & Ellison, 1999; White et al., 2004). However, blurring the lines between the researcher and participants links with the concepts of challenging traditional power imbalances, seeking greater ‘citizen control’ and ‘we-thinking.’

There has been debate over whether critical participatory action research is a qualitative methodology or not, caused by confusion about its philosophical origins. Some researchers employing participatory action research approaches may choose to follow quantitative or pragmatic methods to capture data. However, critical participatory action research often values multiple subjective perspectives of the participants, which is more intricately linked to the theoretical underpinnings of qualitative research traditions than those of quantitative worldviews (Baum et al., 2006; Savin-Baden & Howell-Major, 2013). Whilst my preference would be to focus on qualitative research approaches, the participatory action research group may have wished to collect quantitative data. McIntyre (2007) also reflected on the challenges of power balance within participatory action research and that the group made choices that would not be theirs. Consequently, I needed to accept flexibility in how data might be collected, recognising the shared ownership of the participatory action research with others.

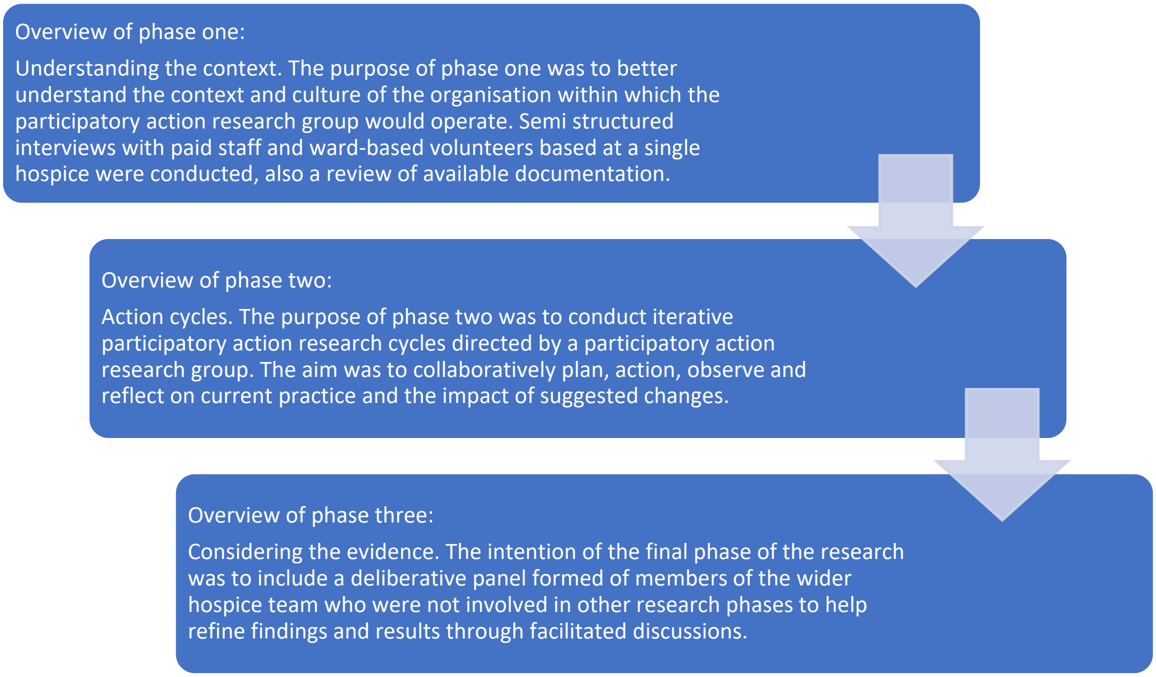
The significance of the direct involvement of paid staff and volunteers in research, enabling them to make choices that affect them, shaped my philosophical perspectives and assumptions. This chapter has included consideration of my ontological and epistemological positions linked to critical theory, which has guided the decision to focus on critical participatory action research as the approach for this thesis. The driving force of this research, which was explored in chapter three, has been encouraging paid staff and volunteers to be part of a collective team, influenced by building a sense of belonging, common purpose, shared decision-making, and common goals. These influencing factors, the practical considerations, and the outworking of the methodological choices are further presented in the following chapter.

Chapter 5. Methods, Findings, and Analysis from the participatory action research

5.1 Introduction

Reporting the methods, findings and analysis of critical participatory action research (in future simplified to participatory action research) can be challenging, partly due to the complex, fluid, multifaceted processes involved. Furthermore, it does not fit a set pattern that easily corresponds to established reporting conventions (Higginbottom & Liamputtong, 2015; Lloyd-Evans et al., 2023; Smith et al., 2010). However, reporting participatory action research is highly effective in reflecting on, and showing the journey and learning through the process. It has been described as enabling researchers to be 'flexible, emergent and creative,' which I have sought to present in this chapter (Koshy et al., 2010, p. 125). Braun and Clarke (2024, p. supplemental material) prefer the heading analysis over findings or results when reflexive thematic analysis is in use. Stating that using the word 'findings' would imply "that the researcher 'found', 'discovered' or 'identified' pre-existing themes", whilst "results is strongly associated with the outputs of statistical analysis". Consequently, the term 'analysis' is specifically used when discussing the reflexive thematic analysis.

The participatory action research was conducted in three main phases (see Figure 5.1). The methods, findings and analysis had a significant overlap, and they intersect due to the iterative nature of the study. Therefore, the methods and findings from each phase are presented in turn, followed by a final combined cross-phase reflexive thematic analysis based on all three phases in chapter six. Issues of reflexivity and ethical considerations impacted all phases equally and, as such, are discussed at the end of the three phases, before the presentation of the reflexive thematic analysis.



Overview of phase one:

Understanding the context. The purpose of phase one was to better understand the context and culture of the organisation within which the participatory action research group would operate. Semi structured interviews with paid staff and ward-based volunteers based at a single hospice were conducted, also a review of available documentation.

Overview of phase two:

Action cycles. The purpose of phase two was to conduct iterative participatory action research cycles directed by a participatory action research group. The aim was to collaboratively plan, action, observe and reflect on current practice and the impact of suggested changes.

Overview of phase three:

Considering the evidence. The intention of the final phase of the research was to include a deliberative panel formed of members of the wider hospice team who were not involved in other research phases to help refine findings and results through facilitated discussions.

Figure 5.1: A brief overview of the three research phases of the participatory action research.

5.2 Phase One: Understanding the context - Participatory situational analysis

5.2.1 Aim

Participatory action research does not follow “a highly proceduralised or linear set of steps”, instead researchers consider suitable action, observation, and information-gathering approaches based on the most effective way to learn, understand, and inform the next iteration of the research process (Cornish et al., 2023, p. 3). My aim of the participatory situational analysis was to explore the current connections between the working relationships between paid staff and volunteers at the hospice. Also, consider any identified possible strengths and weaknesses, as well as any potential opportunities and threats to building mutually beneficial relationships. My intention in this phase of the research was to inform the later stage of the participatory action research cycles. Participatory situational analysis helps to provide the context, broad goals and the important relationships to be aware of. This flexible approach is helpful in problem solving and supporting groups in developing strategies that will address the requests and requirements of those involved (Gosling & Edwards, 1995; International Waters Programme & Secretariat of the Pacific Regional Environment Programme, 2004; Intrac for Civil Society, 2017; Velenturf et al., 2018). The specific objectives (adapted from International Waters Programme & Secretariat of the Pacific Regional Environment Programme, 2004) of the participatory situational analysis were to:

1. Consider the primary groups and individuals connected to the working relationships between paid staff and volunteers and begin to consider their interests and needs.

2. Compile basic hospice data that would assist both problem analysis and project planning.

3. Identify and consider paid staff and volunteer perceptions of the causes of problems related to the working relationships between paid staff and volunteers (within phase one and two).

4. Begin to identify and explore possible solutions and activities with the hospice that address some of the initial concerns raised (by the participatory research group in phase two).

5. Assist to identify possible projects for the participatory action research group to explore (by the participatory research group in phase two).

5.2.2 Design

Phase one consisted of two elements. The first was a simply conducted documentary analysis, which was used to explore data, gaining insights and uncovering meaning (Gross, 2018). The documentary analysis was conducted whilst fully adhering to data-protection guidelines, examining relevant information regarding the relationships between paid staff and volunteers, which the hospice volunteer coordinator provided. Some of the information used was also available online in the public domain. The second element of phase one was qualitative semi-structured interviews with paid staff and volunteers.

5.2.3 Setting

The setting was the same for all three phases and was a single 15-bed English hospice in-patient unit. This charity-run hospice provides specialist palliative and end-of-life care and bereavement support within the community, incorporating a day hospice, onsite appointments for a variety of services, and an in-patient unit. The hospice is a stand-alone building in a semi-rural location on the edge of residential areas of a market town. The wider area that the hospice provides care for is a diverse county with a population of more than three-quarters of a million, with contrasting industrial and rural areas of differing health profiles and needs. The wider county has an estimated 180,000 people who have at least one long-term health condition. The hospice provides palliative and end-of-life care to people aged 18 and over. They provide care to people living with life-limiting illnesses, including cancer, neurological diseases, and end-stage heart, kidney, and lung diseases.

5.2.4 Population

I felt that the relationship between paid staff and volunteers on the in-patient unit was of significant interest and would result in insightful learning for both group members and myself, as well as informing the research findings. I believed that while all hospice staff and volunteers could contribute to discussions on their working relationships, the diverse data collected might have resulted in specific and nuanced points being overlooked. Consequently, phase one only focused on paid staff and volunteers directly working in the in-patient unit. Please see Table 5.1 for the inclusion and exclusion criteria.

Table 5.1 - Inclusion and exclusion criteria for phase one.

	Phase one
Inclusion criteria	Participants were required to be 18 or above. Any paid staff or volunteers, whose work-base was at the hospice in-patient unit.

	No time limit was required for participants to have been at the hospice, as including those who had been there many years compared to those who were new may have added an interesting insight to the results. Gender and ethnic backgrounds were not restricted.
Exclusion criteria	Paid staff or volunteers who were not directly connected with the in-patient unit.

5.2.5 Sample

Due to the small size of the total population and the intention of the interviews, a non-probability, voluntary response sample was appropriate for the semi-structured interviews as my aim was not to create generalisable findings. A potential negative of this sampling approach is that the individuals who voluntarily respond may have stronger opinions than the rest of the population, making them an unrepresentative sample of the wider setting (Cheung et al., 2017). However, as the intention of the interviews was to inform the later phase of the participatory action research, a voluntary response sample enabled me to conduct interviews in a simple way as a starting point in exploring this phenomenon.

It was planned that the interviews would be conducted with the same number of paid staff and volunteers, based on the hospice in-patient unit. This was to present a balanced representation of both groups in the findings. If the balance had not been a reasonably even representation of paid staff and volunteers, then further requests for participants would have been made.

5.2.6 Recruitment

The recruitment strategy for hospice-employed staff and voluntary team members was through posters (see Appendix I) in the hospice staff room and the in-patient reception area, which is a space shared by paid and volunteer team members. The posters included information that enabled potential participants to understand the purpose and intentions of the research (Koshy et al., 2010). The poster invited expressions of interest and those wanting further information about the study were able to take a copy of the participation sheet, and/or have an informal conversation with me, aimed at reducing barriers for potential participants (Given, 2008). A contact number was on the poster for individuals to gain further information without coercion to participate.

5.2.7 Data collection

The participatory situational analysis began by reviewing the published hospice annual reports and quality accounts from 2019-2020, and 2021-2022, highlighting any reference or influencing factors relating to the working relationships between paid staff and volunteers. Furthermore, the hospice volunteer policy, recruitment and selection policy, and job/role descriptions for the in-patient team leader and volunteers connected to the in-patient unit that were current at the time of review were also included in the documentary analysis. These documents were systematically read line by line and any information identified which directly related to volunteers, or any data related to paid staff working with volunteers was highlighted on the original document and then copied to a main Excel spreadsheet (Bowen, 2009). All extracted data were then used to inform the interview question guide, along with the knowledge gained through the meta-ethnographic review (Oliver et al., 2023). This was then combined with the interview data, and mind maps were created to provide an overview of the main concepts to be further explored by the participatory research group in phase two (Fearnley, 2022).

I conducted interviews with members of the volunteer team and paid staff, based on the hospice in-patient unit. The participants were given the choice of being interviewed face-to-face or online via Microsoft Teams. The interviews were guided by the topic guide (see Appendix J), which included some possible points that could be asked, focused on the area of interest. These topics were created based on the meta-ethnographic literature review found in chapter three and reading the local hospice documents shared during the initial stage of the documentary and participatory situational analysis. The guide was intended to help me explore participants' experiences as paid staff, or volunteers, of their current collaboration at the hospice in-patient unit. The last topic was focused on any suggestions they may have of how volunteer-professional collaboration could be improved. The aim was to enable the participants to shape the interviews, and I could then direct the conversation so that rich data could be gained.

5.2.8 Data Analysis

Participatory action research often includes a range of different methods to create a bigger project so that researchers and the group can develop an understanding of the phenomena of interest (Kindon et al., 2007). My aim of the participatory situational analysis was to inform the next phases of the study. Consequently, I felt reflexive thematic analysis was appropriate, as I hoped that the participatory action research group would further add their own interpretation to this as they explored the findings I presented. Reflexive thematic analysis was applied to data from the documents and the semi-structured interview data in the participatory situational analysis. Reflexive thematic analysis was subsequently applied to all three phases of the study for congruence across the participatory action research. Reflexive thematic analysis was developed by Braun and Clarke from their initial writing about thematic analysis in 2006 as they sought to further encourage researchers to consider their own subjectivity and reflexivity (Braun & Clarke, 2019). Initial reflexive thematic analysis was conducted to form broad 'first thoughts' themes from phase one that were presented at the first participatory action research meeting to inform the group and create a starting point.

Reflexive thematic analysis helped develop overarching themes guided by Braun and Clarke's (2024) Reflexive Thematic Analysis Reporting Guidelines (RTARG) and Byrne's (2022) worked example of reflexive thematic analysis (see Table 5.2 for further description of how reflexive thematic analysis was applied in phase two). Whilst this guidance presents a structured approach to analysis, a recursive approach was used, which at times moved between and back and forth through different stages, in light of new codes, understanding, and recognising the creativity of reflexive thematic analysis. Braun and Clarke (2019) warn that reflexive thematic analysis should not be used as a formula or recipe to follow and intend their guide to be used in creative ways to generate analysis. I transcribed all the interview recordings verbatim which helped me to become familiar with the data.

I sought to identify and report the patterns found across the interview data set, to search for the core meaning relating to the research question (Naeem et al., 2023). Consequently, the transcripts were read and re-read to look for relevant statements, quotes, keywords, codes, and common themes. Transcripts were anonymised so that individuals could not be identified.

Initial coding was made on paper with comments made in the margin of transcripts and colour coding. This was further developed using NVivo to organise transcripts. However, I found that this was not the most creative way of enabling me to immerse myself in data. Therefore, I employed an iterative approach, where I created initial codes and potential themes, then repeatedly re-read the original transcribed text to check and look for further codes that would either confirm or change my initial thoughts. A codebook was created to manage codes and to look for connections between codes. Braun and Clarke (2019) assert that codes and themes do not simply 'emerge' during the analysis process as reflexive thematic analysis requires data immersion, thoughtful consideration of data, and reflection. My thoughts and code creation were influenced and guided by my understanding of critical and solidarity theories. Therefore, a diary was used to capture the process, as I was aware that the process would change and develop over time as I engaged in deeper ways with data, consequently, my reflections about the process would be used as a memory aid (and become part of the analysis where relevant). Themes are creative, interpretive stories that reflect data, the researcher's analytical journey, and codes. These initial themes were later used to inform the participatory action research group in the next phase of the research process.

5.2.9 Findings and Analysis

5 interviews were carried out between 8th December 2021 and 20th May 2022. The interviews were with 2 paid staff members and 3 volunteers. All interviewees were white, female, and

aged between 50 – 66. They were all based at or had frequent contact with the inpatient unit at the hospice.

The intention was that any online interviews were conducted via Microsoft Teams as this was a Lancaster University-approved application. This was dependent on current UK government COVID-19 regulations, as the study was conducted between December 2021 and May 2022. Consequently, 4 interviews took place face-to-face at the hospice in a private room and 1 interview took place via Microsoft Teams at the participant's request. The mean interview time was 29.5 minutes.

All interviews were audio recorded via an encrypted Dictaphone. Audio recording only was also made for any interviews conducted online, as ethical approval did not include visual recordings. The participants were asked to commit up to an hour and a half for the interview and they would be asked questions about their experiences and thoughts related to the working relationships between hospice ward-based volunteers and paid staff.

The initial analysis, created from the situational analysis consisted of six early candidate themes: A unified team (including support, joint training), Appreciation (including vital/necessary/useful, trust and responsibility), Communication and collaboration (including handover sheets and role of the volunteer coordinator), Recognition of volunteer roles (including new roles, backgrounds), Impact of COVID-19. Below is an example of the presentation during the first participatory action research meeting:

1. A unified team (including support, and joint training)

This was almost the umbrella theme that threaded through the interviews, reports, and policies. It often reflected how people saw the working relationship between paid staff and volunteers. There was a desire to be a unified, whole team rather than two separate teams.

Working together with trust and respect was discussed within a hospice annual report to create conditions to support this.

> *"While there are a number of things only the clinical staff are allowed to do, there's no 'us and them'..." (Document 1 Page 39)*

One way it was thought that being a united team could be supported was through joint training days where both paid staff and volunteers needed to do the same training, such as moving and handling, as a way of mixing more between the two groups.

2. Appreciation (including vital/necessary/useful, trust, and responsibility)

Words including *"amazing"* and *"fantastic"* were used by paid staff to describe volunteers at the hospice. Their contribution was said to be immeasurable within a hospice annual report, as it was noted that without them the hospice would struggle without their *"time, skills and commitment",* which was appreciated, along with the contribution of the paid staff.

Overall, there was a common experience among those who had and were volunteering that they felt valued by paid staff. This was often expressed verbally, with paid staff saying *"thank you so much,"* which often made volunteers feel useful and that they were doing something worthwhile.

At times volunteers noted that whilst they were appreciated by staff, they were unsure how to verbalise the significance of their role. Also, finding difficulty to describe it:

> *"... we have proven that it's – necessary... is necessary too strong a word? Coz it's not necessary, it's not a vital part coz other people can do what we do... but I think it's a very, we are a very useful part of the team... So, it's, yeah, we're not vital, are we? I don't think anybody is vital coz you would have someone else on the ward to do it... vitals' not the right word, I think we're useful…" (Interview Volunteer 2)*

Paid staff felt that it would be beneficial to show appreciation more through different ways including *"throwing a party for volunteers"*. It was discussed that a ball and a summer fair had previously happened for volunteers before COVID-19.

3. Communication and collaboration (including handover sheets and the role of the volunteer coordinator)

Some collaboration between paid staff and volunteers was thought to be direct, whereas at times it was also described as indirect, or incidental collaboration.

It was recognised that the various roles (paid and voluntary) were all about communication with each other. One paid staff member expressed it as:

> *"I think also that for them it's going to be a social thing, it's getting people out, because you come into an environment like this and it's all about talking – even if you don't want to – you will be talking all day and I think the volunteers do the same as well, you know they probably don't realise that they are communicating with us all day." (Interview Paid Staff 2)*

Paid staff valued volunteers sharing helpful patient information with them, such as inappropriate meal orders due to the patient's dietary requirements. Which was balanced with both paid staff and volunteers recognising that at times they did not need to know everything about patients.

Some volunteer groups had access to a handover sheet, which included information about meals and which rooms not to enter. This could tell them to speak to nursing staff before going to see a patient. Some ward-based volunteers did not have a handover sheet but thought the information on it should relate to dietary requirements and moving and handling.

Volunteers shared information with paid staff:

> *"... [Volunteers] also escalate any concerns, including any perceived changes in the condition of the patient, to nursing staff." (Document 1 Page 38)*

At times there were thought to be communication issues, as information about volunteer roles did not seem to be effectively passed on to paid staff.

4. **Recognition of volunteer roles (including new roles, and backgrounds)**

Life experience was recognised as a way of helping volunteers relate to issues at the hospice.

> *"I think a lot of our volunteers come from nursing backgrounds anyway so, I think that they know don't they, they know what nursing is about so, I think yeah, I think that's the biggest strength, I think." (Interview Paid Staff 1)*

This helped some to feel comfortable in the in-patient setting and with the kind of tasks they were doing. Also, having previous experience with people and communication, which helped to make them feel useful.

5. **Recognition of each other (including names and sharing news)**

Whiteboards with volunteer names on them were discussed by both paid staff and volunteers:

> *"We have sort of tried to look at different ways of involving the volunteers, but we, which was sort of like – I would like to see their names on the whiteboard alongside us." (Interview Paid staff 1)*

Another area that was mentioned for knowing each other's names was the use of name badges that were easier to see and were seen as a positive:

> *"...those are really good! I mean my eyesight is not brilliant, but it is very easy. You know 'cause if you're trying to read the name and see is that (name of nurse)? You know in the past, you've got to peer right at their chest, but these [new] ones you can see, so I, I think that's really good." (Interview Volunteer 1)*

6. Impact of COVID-19 on the relationships between paid staff and volunteers

COVID-19 had an impact on many aspects of the working relationship and how people worked together. Many of the points and themes discussed were influenced or overshadowed by COVID-19 and what people had experienced.

COVID-19 had an impact on how volunteers and paid staff were able to communicate with each other. This included reduced ability to interact because of having to wear face masks at the hospice:

> *"So, I mean even just wearing masks doesn't make it easy for me to, you know, 'cause you go down the ward in the past you have had done a big smile and said 'hello', but it doesn't work the same with the mask on." (Interview Volunteer 1)*

It was noted that the two teams had become more separate during COVID-19 and this had made working at the hospice more challenging work. There was a desire to get together again post-COVID-19 and to get mixing again.

These initial findings informed the next phase of the study (phase two), which was focused on action cycles exploring the working relationships between paid staff and volunteers.

5.3 Phase two: Action cycles

5.3.1 Aim

As outlined at the start of the chapter, this research was conducted in three phases. The purpose of phase two was to conduct iterative participatory action research cycles, which were directed by a participatory action research group. The focus of the group was to explore the working relationships between paid staff and volunteers in, or connected to, the hospice in-patient unit.

5.3.2 Design

Within participatory action research, ‘action’ is achieved through core action groups, where participants are encouraged to conduct reflective cycles, through planning, acting, observing, and reflecting, before then considering what further action(s) should be taken (Baum et al., 2006) (see Figure 5.2 for visual depiction of participatory action research cycles).

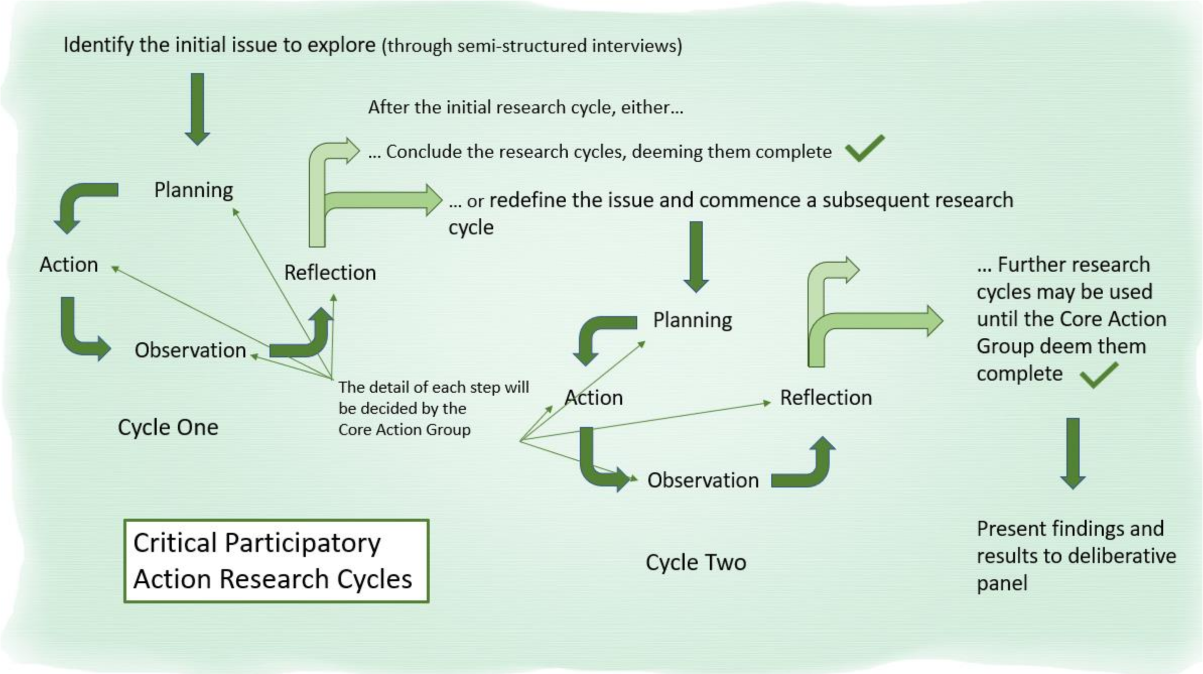


Figure 5.2: An image created to visually develop my understanding of participatory action research cycles and shared with the core action research group.

5.3.3 Setting

The setting was the same as in phase one, specifically focusing on the 15-bed in-patient unit, which provides 24-hour care for patients.

5.3.4 Population

The second phase of the study was designed to further explore the working relationships between paid staff and volunteers, using the initial findings of phase one as a catalyst for potential action. A core action group was required for phase two of the research, which would be actively involved in creating action cycles. One of the positive aspects that drew me to participatory action research was that it directly affects and aims to be beneficial to those who take part in the research (Fine & Torre, 2021). Consequently, I decided that the participatory action research group should be members of the paid staff or volunteer team, who either directly worked on or had regular working contact with the inpatient unit at the hospice. See Table 5.2 for the inclusion and exclusion criteria.

Table 5.2 - Inclusion and exclusion criteria for phase two.

	Phase two
Inclusion criteria	Participants were required to be 18 or above. Any paid staff or volunteers, whose work-base was, or had regular working contact with the hospice in-patient unit. No time limit was required for participants to have been at the hospice, as including those who had been there many years compared to those who were new may have added an interesting insight to the results. Gender and ethnic backgrounds were not restricted.
Exclusion criteria	Paid staff or volunteers who were not directly connected with the in-patient unit.

5.3.5 Sample

I aimed to recruit an equal mix of ward-based paid staff and members of the voluntary team for the participatory action research group. Schmuck (2008) suggests that 8 to 10 participants create the optimal group size for conducting effective action research. I aimed that the group would consist of 6-10 individuals as this study was set in a small location of a local hospice, reflecting a relatively small total population size. Fine and Torre (2021) describe critical action research groups as diverse research collectives including a range of core researchers. I intended that group participants would be from a range of teams, such as nursing and medical teams, allied healthcare teams, and catering and hospitality teams. There was potential for this to be challenging due to different views, areas of focus, and opinions amongst the different teams. However, I thought it was important to reflect on the different perspectives of the working relationships between paid staff and volunteers.

Using critical participatory action research requires participants to be involved and to take on some responsibility in the group. Consequently, participants needed to have an initial interest in the study to sustain their engagement. Due to the need for commitment from participants, a non-probability, voluntary response sampling was used for the participatory action research group. In this phase of the research, recruiting individuals with potentially stronger views than the total hospice population was a potential benefit, as this may have created greater engagement and group participation.

5.3.6 Recruitment

The only variation to the recruitment process from the first phase was that during phase two the core action research group wanted to further encourage others to take part as part of their action research cycles. The group particularly wanted more paid staff to be involved as they felt this would offer a broader perspective to the group. This was done through a general email to staff and a discussion about what the group was at a staff and volunteer meeting.

5.3.7 Data collection

There is no one set approach to data collection in critical participatory action research, therefore, there was potential that the group may have chosen to use both qualitative and quantitative elements, including interviews, questionnaires, and surveys (Koshy et al., 2010). I maintained data ownership and storage, which was regularly reviewed during the process.

However, in action research the principal researcher is not solely responsible for the collection of data, so discussion regularly took place with the core action group on the ‘who,’ ‘how,’ and the ‘purpose’ of data collection and analysis (Moule et al., 2017).

There was potential that due to the COVID-19 pandemic, social distancing restrictions may have been in place during the core action group cycles, which were planned to be face-to-face. Therefore, a contingency plan for online meetings was in place, although this was not required, as restrictions were lifted by this stage of the research. Data included face-to-face meetings, emails, meeting notes and diary entries, questionnaire responses, and any other information collated during core action group meetings.

During the first participatory action research meeting, the group discussed their ground rules, a planned format, and intended frequency and length for future meetings. I aimed to set from the outset of the meetings that *“my voice becomes a bit less and the group becomes a bit more”* adding that *“I’m a participant in the group along with you”* (Main researcher PAR meeting 1) to encourage the collaborative group ownership, empowerment and seeking to level out the group hierarchy.

The structure and aims of the participatory action research were discussed and an image was shown and explained (Figure 5.3). The group felt that an email of the meeting minutes would be helpful so they could check if it was a true reflection of what had happened and been discussed.

Additional data was collected through a personal journal consisting of pre-during-post meeting notes. The journal enabled reflection on key points, ideas, personal reflections, emerging concepts, and links to theory. Reflections were also made on challenges in the group and how we responded to these problems, as well as what had gone well (see Appendix K).

5.3.8 Data analysis

Qualitative data were organised and analysed to find and identify key themes based on Braun and Clarke's (2019) approach to reflexive thematic analysis (see Table 5.3 for a worked example of reflexive thematic analysis from phase two). Descriptive analysis was used for any quantitative data collected by the group, as this can be helpful when research is restricted to a low sample and the aim is not to generalise the findings to a wider population (Kaliyadan & Kulkarni, 2019).

Throughout the participatory action research cycles, a comprehensive reflective research journal was kept, recording the progress throughout the research process. It has been shown that this form of journal-keeping can be used to increase the dependability of research, by presenting a transparent account for observers who are external to the research group (Cho & Trent, 2006). I kept the diary and ensured all names were anonymised. The journal recorded my thoughts, reflections, and feelings before and after meetings. These reflections later helped to inform the analysis to help show my 'insider' position in the research process (see Appendix K for excerpts from my journal).

Table 5.3 – Based on Byrne's (2022) worked example of reflexive thematic analysis.

Stage	**Example of what took place in each step**	**Link to worked example from phase two**
Stage 1: familiarisation with data	Initially 'actively listening' to recordings without taking notes to become familiar with the content. Transcribing data, reading and re-reading transcripts (also referring back to original recordings for clarification where needed). Noting down initial thoughts in diary entries.	Extract of diary entry (Appendix K)
Stage 2: Generating initial codes	Noting interesting features in-text. Creating initial codes across the whole data set in a systematic way.	Preliminary codes (see Appendix L)
Stage 3: Searching for themes	Collating codes into potential themes, testing and gathering information that is relevant to each theme.	Preliminary codes, comments, and first thoughts (see Appendix L)

Stage 4: Reviewing themes	Checking the themes by going back to the original transcribed text. Checking this in relation to codes and extracted quotes across the data set.	-preliminary codes, comments first and 2nd iteration (see Appendix L) -final themes concept maps (see Appendix M & N)
Stage 5: Defining themes	Creation of clear titles for each theme.	-Codebook and links to themes (see Appendix O) -Preliminary codes, comments and first thoughts, second iteration (see Appendix L)
Stage 6: Writing up the report	Discussion of analysis related back to the research question to produce the written report.	-Data source from different phases of the participatory action research (see Appendix P) -Chapters 6 and 7

5.3.9 Findings and Analysis

The participatory action research group met 14 times between 6th March 2023 and 4th March 2024, with a final celebration meeting on 25th March 2024. The participatory action research group initially included paid staff (n=3) and volunteers (n=8), with a core group of paid staff (n=2) and volunteers (n=4). The core group were white, male (n=1), female (n=5), and had a mean age of 58.

As I was also a member of the participatory action research group (in addition to the above group demographic data) terms including 'us', 'we' and 'our' are often used within the findings and analysis when discussing the group. The terms intend to reflect the research aims, which were to include and encourage group ownership of the participatory action research. Furthermore, these terms reflected solidarity theory, showing the group's commitment to shared identity and goals through 'we-thinking'.

A summary of the initial analysis from the interviews that formed phase one of the research was used to formulate and agree on some of the initial issues the group could explore, using a SWOT (Strengths, Weaknesses, Opportunities, and Threats) analysis (Table 5.4). This informed the development of the first cycle of critical participatory action research, which sought to follow the process of assessment, planning, implementation, and evaluation (Land & Harvey, 2016).

Table 5.4 - The initial SWOT analysis created during the first participatory action research meeting.

Strengths: -Mutual aims and concerns, which is the well-being of patients -ability to recognise the strengths & weaknesses of people, and then give support -able to adapt to each other's needs -self-confidence to speak up (allowed freedom to speak) -recognition of 'off days' -being able to volunteer/work at the hospice -attracts people with certain personalities -sense of trust between paid staff & volunteers -sense of appreciation & welcome -hand over from kitchen staff	**Weakness:** -not always being aware of what you are walking into (patient rooms) -shift patterns -communication can be both a strength & weakness -not knowing 'who is who' -not knowing each other's roles
Opportunities: -lots of volunteers come wanting to gain experience -different students that come wanting to build confidence -able to free up paid staff to care for patients -diversity of paid staff & volunteers (gender, age, personalities etc) -teamwork -commitment from the hospice that they want this study to go ahead -volunteer meetings	**Threats:** - 'them upstairs,' higher up -if the group decides they want to change things they may need to 'go through hoops' -time scales -worry of potential coercion into doing things at hospice don't want to do -other commitments & how to manage these -wider cultural issues

Over the course of the year, the participatory action research group changed, particularly after the first meeting, when some of the group left as they felt it was more commitment than they could give, or it was not what they were expecting. The change in dynamics was also reflected on by the remaining group members at different stages of the year.

The participatory action research process was highly iterative. There was one main cycle that was discussed, planned, actioned, explored, and altered throughout the whole year, while smaller cycles coincided with this and often created an overlap between the cycles which were often interlinked. Various points and concepts relating to different cycles were often discussed at the same time, creating more integrated conversations, where knowledge development could not be separated due to how it evolved in meetings. Figure 5.3 reflects this change from what was anticipated at the start of the project of neat cycles (shown in Figure 5.2), one following on from the last, to what took place.

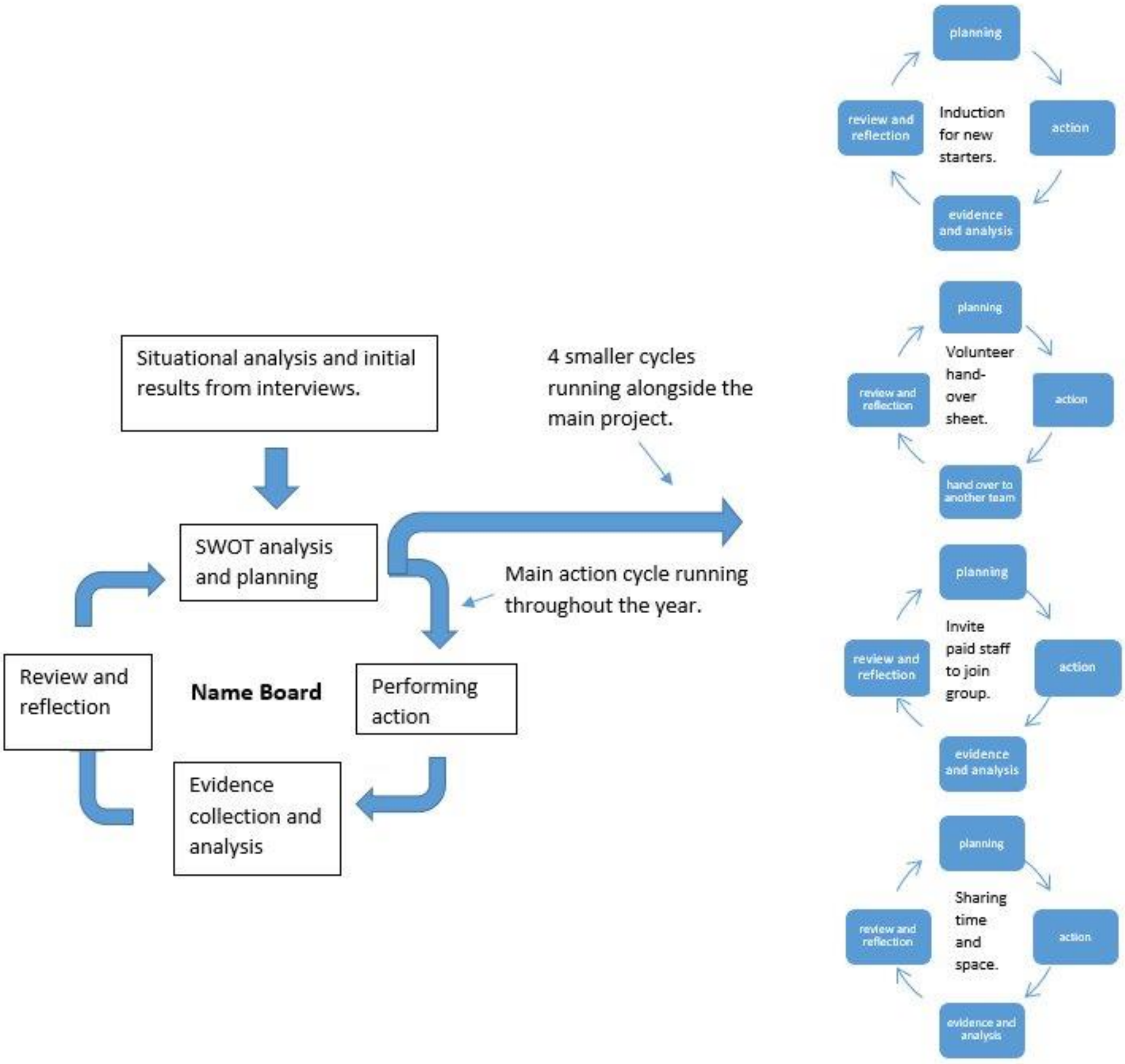


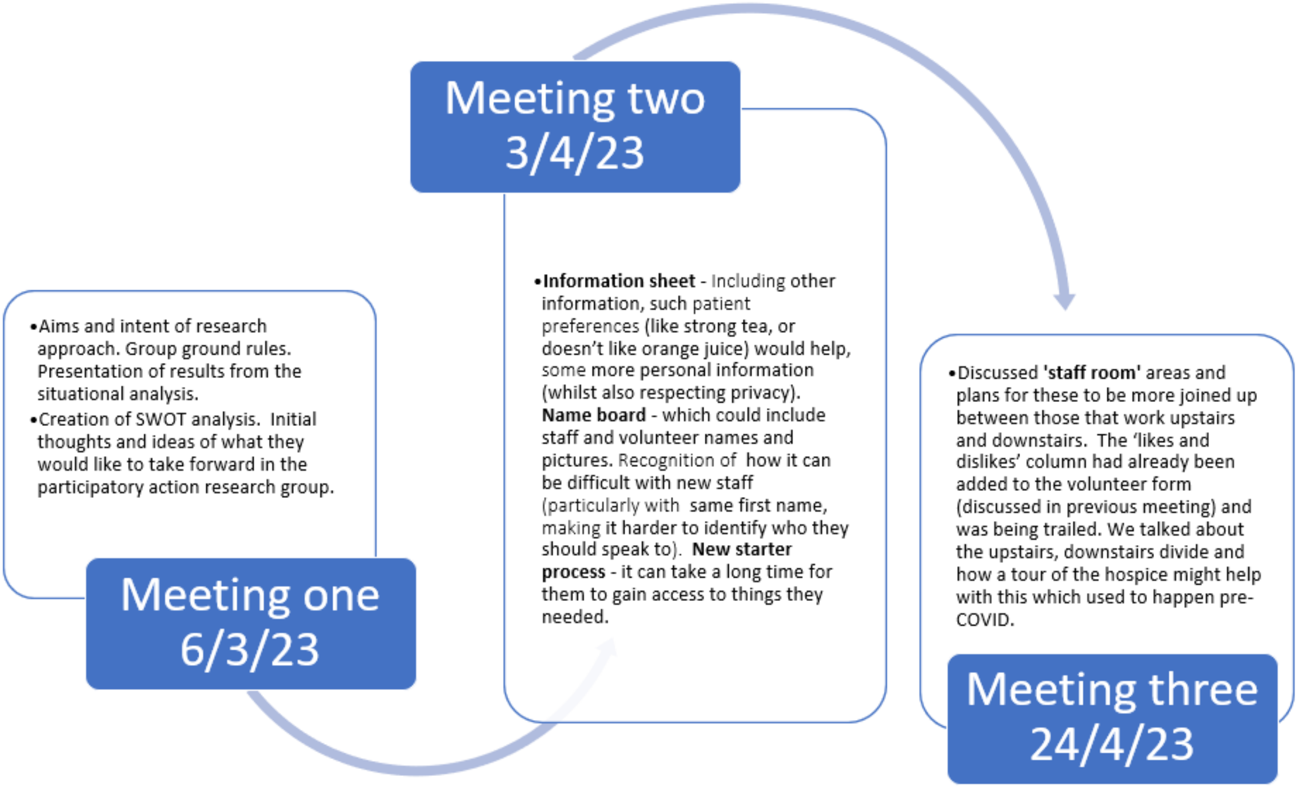
Figure 5.3: Image showing the participatory action research cycles.

The group had one main cycle, focusing on the creation of a new name board for the in-patient unit and four smaller, sub-cycles. Some of the smaller cycles were fully completed, whilst others were not due to feeding back to others in the hospice, not being involved in the next steps, or some becoming part of ongoing changes.

The group members attended as many meetings as possible over the year; we had agreed that occasional non-attendance was acceptable and that we would send the group minutes to "*keep them in the loop.*" I attended all but one meeting and the group sent me an overview of the meeting via email.

We noted points we felt were most important from the initial SWOT to take forward and explore further within the group meetings (Figure 5.4 – includes a summary of the group meetings):

- The name board on the in-patient unit to include both paid staff and volunteers.
- Exploring the induction process for new volunteers at the hospice
- The volunteer hand-over sheet for volunteers located on the in-patient unit
- Seeking to involve paid staff in the group
- Finding more ways for paid staff and volunteers to share space and time together



Meeting one 6/3/23

- Aims and intent of research approach. Group ground rules. Presentation of results from the situational analysis.
- Creation of SWOT analysis. Initial thoughts and ideas of what they would like to take forward in the participatory action research group.

Meeting two 3/4/23

- **Information sheet** - Including other information, such patient preferences (like strong tea, or doesn't like orange juice) would help, some more personal information (whilst also respecting privacy). **Name board** - which could include staff and volunteer names and pictures. Recognition of how it can be difficult with new staff (particularly with same first name, making it harder to identify who they should speak to). **New starter process** - it can take a long time for them to gain access to things they needed.

Meeting three 24/4/23

- Discussed **'staff room'** areas and plans for these to be more joined up between those that work upstairs and downstairs. The 'likes and dislikes' column had already been added to the volunteer form (discussed in previous meeting) and was being trailed. We talked about the upstairs, downstairs divide and how a tour of the hospice might help with this which used to happen pre-COVID.

Meeting four 22/5/23

- The group had previously thought it would be good for volunteers to have more information about palliative care issues related to disease at the volunteer meetings. The group looked at the volunteer induction forms and started adding comments to them. Discussed if there would be chance for feedback on the breakroom and that maybe this is something the group could do when the room is in use (how does it benefit relationships between paid staff and volunteers), bridge gap between upstairs and downstairs staff.

Meeting five 12/6/23

- Email sent out to volunteers about the volunteer induction process. The group looked at the volunteer handbook, which it was commented was possibly made without the input of volunteers, which would have been helpful. We discussed that the ward manager had said it would be OK for volunteer names to be added to the board. We discussed that emails had gone out asking if any volunteers would like a tour of the building, which was mentioned was a positive outcome of the group's recommendations.

Meeting six 10/7/23

- Meeting considered the feedback received from the email sent out to volunteers. Discussed that this would be good if doctors could speak at volunteer meetings, which came up at the last volunteer meeting and the ward manager was going to look into this. We also discussed if this would be something that could be part of the volunteer induction, enough information not to frighten, but to prepare.

Meeting seven 31/7/23

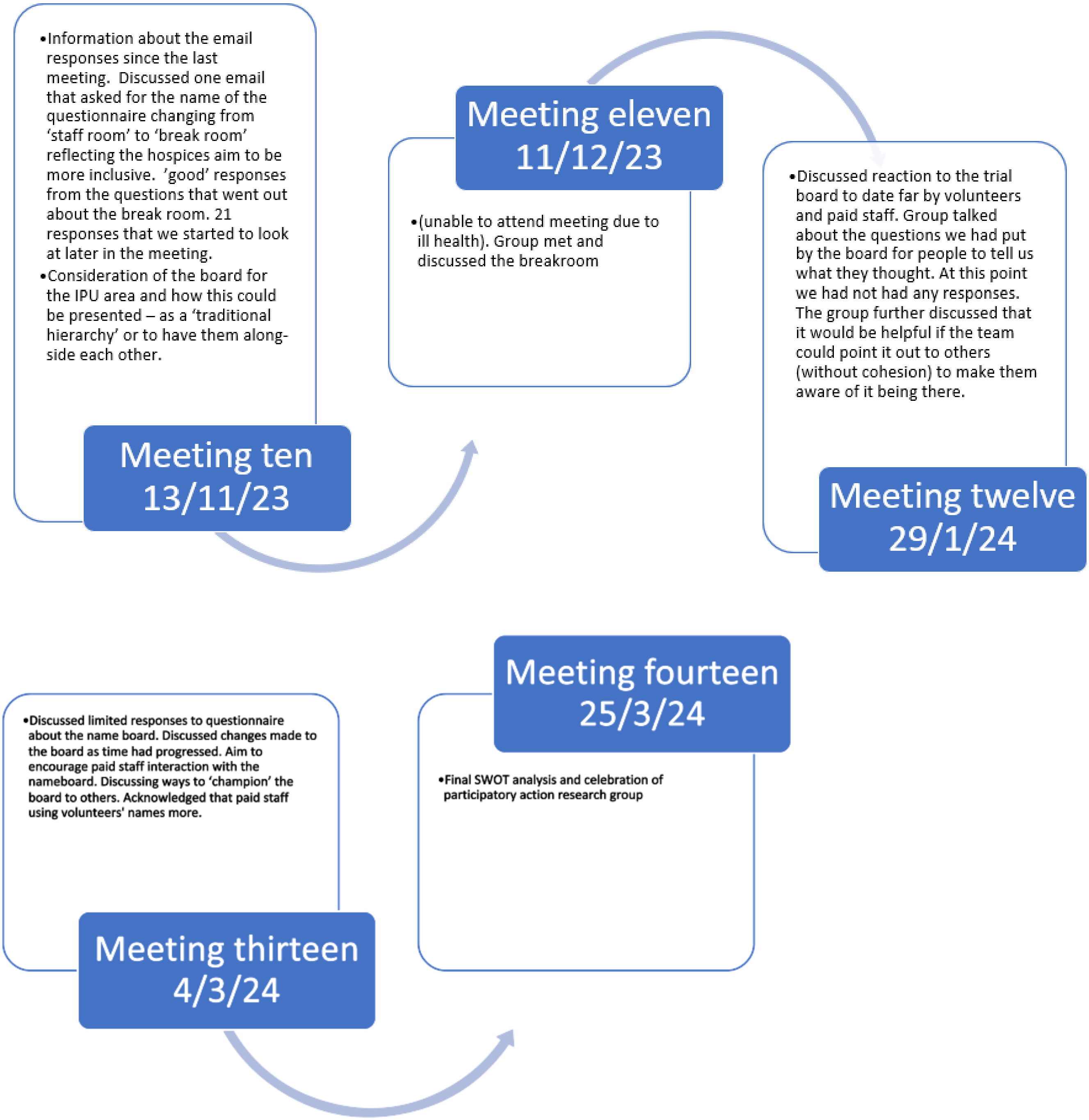
- Discussed feedback given previously from the questions. Discussion about photo board and taking photos. Group went on to the ward to look at possible locations of the name board.

Meeting eight 11/9/23

- Group attended by guest. Discussed progress of the name board. Staff wearing badges was important for patient safety as it is not always known who is asking to come into the building. Hospice board showing the trusties, which was like a 'who is who', which was thought to be helpful to know some of the bigger team. Breakroom to build relationships between paid staff and volunteers. Improving a way of changing the feeling of 'upstairs and downstairs' Concern that the room had been used as a meeting room for certain groups of staff and patient issues were being discussed in there.

Meeting nine 16/10/23

- The name board with photos and names on it would help to build a bridge also help to break down hierarchies. The group discussed the plan to mock-up the board to inform the creation of a final board. We discussed the proposed questions about the break room that had been emailed out.



Meeting ten 13/11/23

- Information about the email responses since the last meeting. Discussed one email that asked for the name of the questionnaire changing from 'staff room' to 'break room' reflecting the hospices aim to be more inclusive. 'good' responses from the questions that went out about the break room. 21 responses that we started to look at later in the meeting.
- Consideration of the board for the IPU area and how this could be presented – as a 'traditional hierarchy' or to have them along-side each other.

Meeting eleven 11/12/23

- (unable to attend meeting due to ill health). Group met and discussed the breakroom

Meeting twelve 29/1/24

- Discussed reaction to the trial board to date far by volunteers and paid staff. Group talked about the questions we had put by the board for people to tell us what they thought. At this point we had not had any responses. The group further discussed that it would be helpful if the team could point it out to others (without cohesion) to make them aware of it being there.

Meeting thirteen 4/3/24

- Discussed limited responses to questionnaire about the name board. Discussed changes made to the board as time had progressed. Aim to encourage paid staff interaction with the nameboard. Discussing ways to 'champion' the board to others. Acknowledged that paid staff using volunteers' names more.

Meeting fourteen 25/3/24

- Final SWOT analysis and celebration of participatory action research group

Figure 5.4: including a brief outline of the fourteen participatory action research meetings.

To conclude the participatory group, we completed a final SWOT analysis (Table 5.5), and the group had the opportunity to submit an anonymous personal reflection on the research process.

Table 5.5 - Final SWOT analysis created by the participatory action research group during the final meeting.

Strengths:	**Weakness:**
-The new uniforms have helped with a sense of unity. -They know each other more due to the new name badges (all now have the yellow name badges, which are more visible) and due to the board with photos of volunteers and paid staff. -A greater sense of confidence - some of which was due to having longer in the role, which means they are more established, so 'settled in volunteer roles'. -The trial name board is working well, and people are using it. -Having a 'proactive' and 'dynamic' volunteer coordinator -The group felt that volunteers were able to pick up on how staff felt on the ward through the 'vibe on the ward'. -Some strong characters have been good at putting their photo on the board, they lead the way for others.	-Different volunteer roles appear to not always be explained to new starters at inductions, but group members felt confident to feedback that this should be improved. -At present, there is still not an effective method of handover for some of the volunteers, in part thought to be due to different start times. -Volunteer forum was started but stopped 'due to lack of interest' from volunteers. -Working from home has meant less chance to meet and talk to other people 'before you could just nip into their office'.
Opportunities:	**Threats:**
-Regular volunteer meetings for those on the inpatient unit.	-At times personalities can clash (sometimes this can be volunteers with other volunteers, at times paid staff to step in and mediate).

	-Things take a long time to change, change never happens quickly. -Some people do not always like change. -At the moment there are not many senior paid staff putting their photo on the board.

5.4 Phase three: Considering the evidence

5.4.1 Aim

A deliberative panel was established as a means of further seeking to increase the trustworthiness of the research (Moule, Aveyard & Goodman, 2017). The aim was to create a group from within the hospice to present the initial analysis and overview of the participatory action research project. The intention was not only to ‘test’ the findings but also to give others who were not able to commit to the core participatory action research group an opportunity to share their knowledge, experience, and further develop ideas. It was felt that it was important to share what the group had been doing more widely to hopefully encourage and inspire others about the working relationships between paid staff and volunteers.

5.4.2 Design

The intention of the final phase of the research was to include a deliberative panel formed of members of the wider hospice team who were not involved in other research phases to help refine findings and results through facilitated discussions. Deliberative panels can enable wider groups to inform research, often involving complex or multi-faceted issues. This can be particularly useful to bring diverse perspectives into research conversations to further enrich studies (National Centre for Social Research, 2025).

5.4.3 Setting

The setting for this phase included the whole hospice discussed in 5.2.3, without limitations to specific sections or teams.

5.4.4 Population

The third phase of the study was designed to discuss phase one and two of the research and to set it within the wider hospice context. The deliberative panel meeting included all paid staff and volunteers working in the hospice (see Table 5.2 for the inclusion and exclusion criteria).

Table 5.6 - Inclusion and exclusion criteria for phase three.

	Phase three
Inclusion criteria	Participants were required to be 18 or above. Any paid staff or volunteers, including those who were not directly connected with the in-patient unit. No time limit was required for participants to have been at the hospice, as including those who had been there many years compared to those who were new may have added an interesting insight to the results. Gender and ethnic backgrounds were not restricted.
Exclusion criteria	None was felt necessary for the deliberative panel as paid staff and volunteers based in hospice charity shops or other areas of the hospice would also have insights that may give a different perspective to the research.

5.4.5 Sample

A non-probability, voluntary response sampling was used for the deliberative panel. It was hoped that the sample would include a range of views and perspectives of those with an interest in what the participatory action research had been doing and the working relationships between paid staff and volunteers.

5.4.6 Recruitment

The only variation to the recruitment process from the first phase was that the poster requested expressions of interest. Later, after two responses and a date was agreed upon, the information including the time and date of the meeting was added to the poster.

5.4.7 Data collection

The deliberative panel meeting included a PowerPoint presentation of the initial findings, and an overview of the research process up to that point (see Appendix Q). The deliberative panel included the discussion, feedback, drawings, and comments made during the meeting in response to the presentation given. The deliberative panel meeting was audio recorded with consent and transcribed verbatim, images drawn were then copied to create a digitally created image of the original sketch.

5.4.8 Data analysis

The transcript of the deliberative panel was added to the initial analysis presented in the meeting. All transcripts from the situational analysis, participatory action research, responses to questionnaires gained, and the deliberative panel were then re-reviewed, and further coding and analysis were carried out in light of new insights gained.

5.4.9 Findings and Analysis

A deliberative panel meeting was held on 30th August 2024 at the hospice. The meeting lasted 1 hour and 7 minutes. It was attended by two members of the hospice-paid staff who both held management positions. The meeting included a presentation of the initial findings and analysis from the participatory action research in phase one and two, followed by a discussion.

5.5 Cross-phase research ethics committee and governance approvals

Research ethics committee approval was sought and granted by the Faculty of Health and Medicine Research Ethics Committee (FHMREC) at Lancaster University (FHMREC20151, 13/8/21) (see Appendix R). After in-depth discussions with the Health Research Authority, they deemed that full HRA approval was not required for this research. Ethical approval was granted by the hospice after full discussions with the chief executive, senior management and key stakeholders.

Ethical approval for action research can be challenging if researchers attempt to overly formalise an approach that is often seen as an organic process (Yanar et al., 2016). One potential solution may have been to request separate ethics approval for each cycle of the research process (Khanlou & Peter, 2005). However, this was not practical, as the delay this would cause could have jeopardised the overall research due to time constraints. The compromise involved detailing as many elements as possible and outlining the research components while recognising that the core participatory action group might pursue different directions. Consequently, the ethics application sought to indicate the questions the research might ask and the directions it may take, also explaining the rationale for the uncertainty shown. Due to the changing nature of the process, I later approached the ethics review board with questions to clarify some aspects of the study, ensuring I was working within the ethical approval (Klocker, 2012). Subsequently, one amendment was submitted and approved by the ethics board to extend the completion date that was initially stated.

5.6 Cross-phase ethical issues

Consent was gained via consent forms from participants in the semi-structured interviews, participatory action research group, and deliberative panel after they had been given and had the opportunity to read the information sheet without coercion (see Appendix S). The information presented to the deliberative panel was summarised and anonymised, although due to the size of the core participatory action research group, there was potential that information was identifiable to individuals. This was made clear on the initial consent forms that full anonymity may not be possible. However, the presentation was sent to the core participatory action research group before the deliberative panel meeting to give them the opportunity to give feedback and ensure they were satisfied with the included information. The deliberative panel group was asked, as part of the consent process to not discuss the content of the sessions with others.

Participants were able to withdraw from the process and did not incur any negative repercussions from their choice. However, they were aware that they were only able to withdraw data and inclusion in the final report up to the point of commencing the participatory action research groups, as it would have been challenging to separate their comments, their responses to them, and their contribution to the group study.

The research explored a challenging area of study, as it sought to collaborate with those providing palliative care, some of whom may have joined the hospice voluntary team after their own bereavement experience. It was also recognised that employed staff participating may have equally found aspects emotionally challenging. Therefore, a screening interview and distress protocol were carried out with potential participants before they took part in the interviews (see Appendix T). Furthermore, psychological support was available for all participants from members of the counselling team who were not connected to the research project. If participants did not wish to discuss issues within the hospice, then signposting was made on the information sheet to external support.

5.7 Reflexivity

Personal reflection was seen as both a potential positive and negative, as I would have some awareness and ‘insider knowledge;’ however, this may have caused me to make assumptions that I needed to be aware of. I considered that my position and views would change as I became more involved in the research and knew more about the participants through the regular meetings. I was mindful that the group and I were learning more about critical participatory action research during the research process, which altered how we viewed the meetings and their purpose. I was also aware that my language changed during the process, initially referring to actions as ‘you’, which over time altered to ‘we’ and ‘us’, reflecting the nature of critical participatory action research. Solidarity theory has influenced my understanding of collective action and ways to consider when the values and beliefs of others are shared and different.

I was also aware that critical theory has been influential in my professional life for several years prior to commencing this study. Consequently, I felt that I had a different starting point to others taking part in the study. I knew that I needed to be mindful not to make assumptions. As previously stated, for critical theory to be successfully applied, people need to want change and desire action (Fay, 1993). I needed to make sure that the group felt able to make their own choices and not just agree with my thoughts to ensure I encouraged citizen control, rather than token participation (Arnstein, 1969).

Whilst having some insider knowledge I was also mindful during the process that I was also now an outsider due to the length of time that had passed since working at the hospice. At times this inside, outside perspective was helpful, as it enabled me to reflect from a unique outlook on the hospice.

Hart and Bond (1995) encourage researchers employing action research to consider their relationships with different stakeholders and how different groups may influence the research and the researcher (Figure 5.5). Consequently, I used this mapping exercise to consider how I related to others and the way that I put weight on certain opinions, often automatically, which was helpful to be aware of. However, whilst I was at times mindful of this, I could not always avoid personal bias and persuasions.

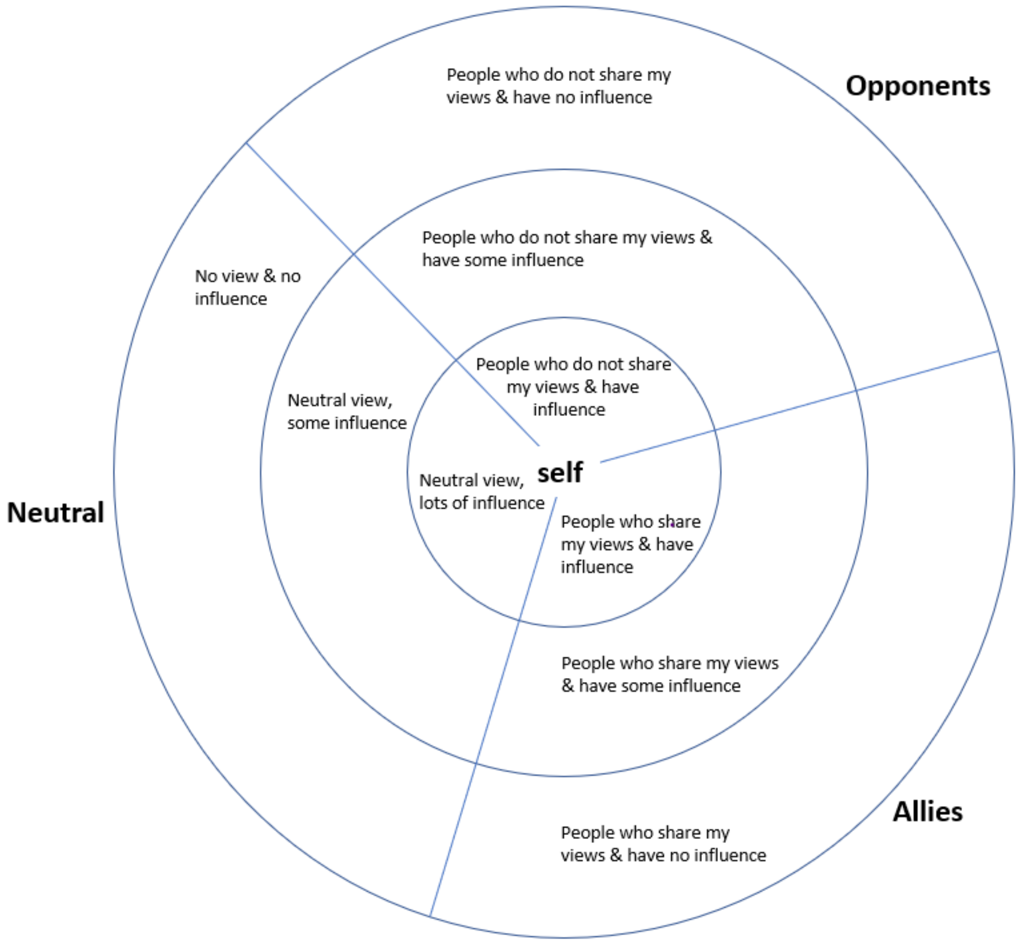


Figure 5.5: Reflexive mapping exercise: spheres of influence of allies, opponents, and neutrals. Found in Hart and Bond (1995, p. 188).

The following chapter is a cross-phase reflexive thematic analysis based on the results of the situational analysis, participatory action research group, and the deliberative panel.

Chapter 6. Cross-phase reflexive thematic analysis

The reflexive thematic analysis results from the three main phases of the participatory action research used for this study, which are presented in this chapter. A description of how the reflexive thematic analysis was developed is found in chapter five. The first phase, situational analysis (a review of hospice annual reports, quality accounts, and interviews) provided insight for phase two, participatory action research group. The final phase consisted of a deliberative panel, where key initial findings and analysis were presented and discussed for clarity, confirmation, and expansion of concepts. Five main themes were developed from these three phases of the analysis (see Figure 6.1, Table 6.1, and Appendix N). The main, overarching theme is hierarchy and power which influenced and impacted how volunteers and paid staff see themselves and others at the hospice. Therefore, the theme of power and hierarchy is presented first to help set the scene for subsequent themes:

(a) Hierarchy and power ‘we are not asking for the world’ (volunteers should not sit in traditional hierarchical models);

(b) Belonging ‘they must have put a face to the name’ (paid staff and volunteers knowing each other and being known by name builds belonging in hospice settings);

(c) Being together ‘let’s get mixing’ (having a neutral shared space and spending time together supports feelings of being one cohesive team);

(d) Adding value ‘What value do we really place on our volunteers?’ (different perspectives on ways volunteers add value);

(e) Information and knowledge sharing ‘it’s getting the balance’ (paid staff sharing information and knowledge with volunteers prevents misunderstanding and being ‘on the back foot’).

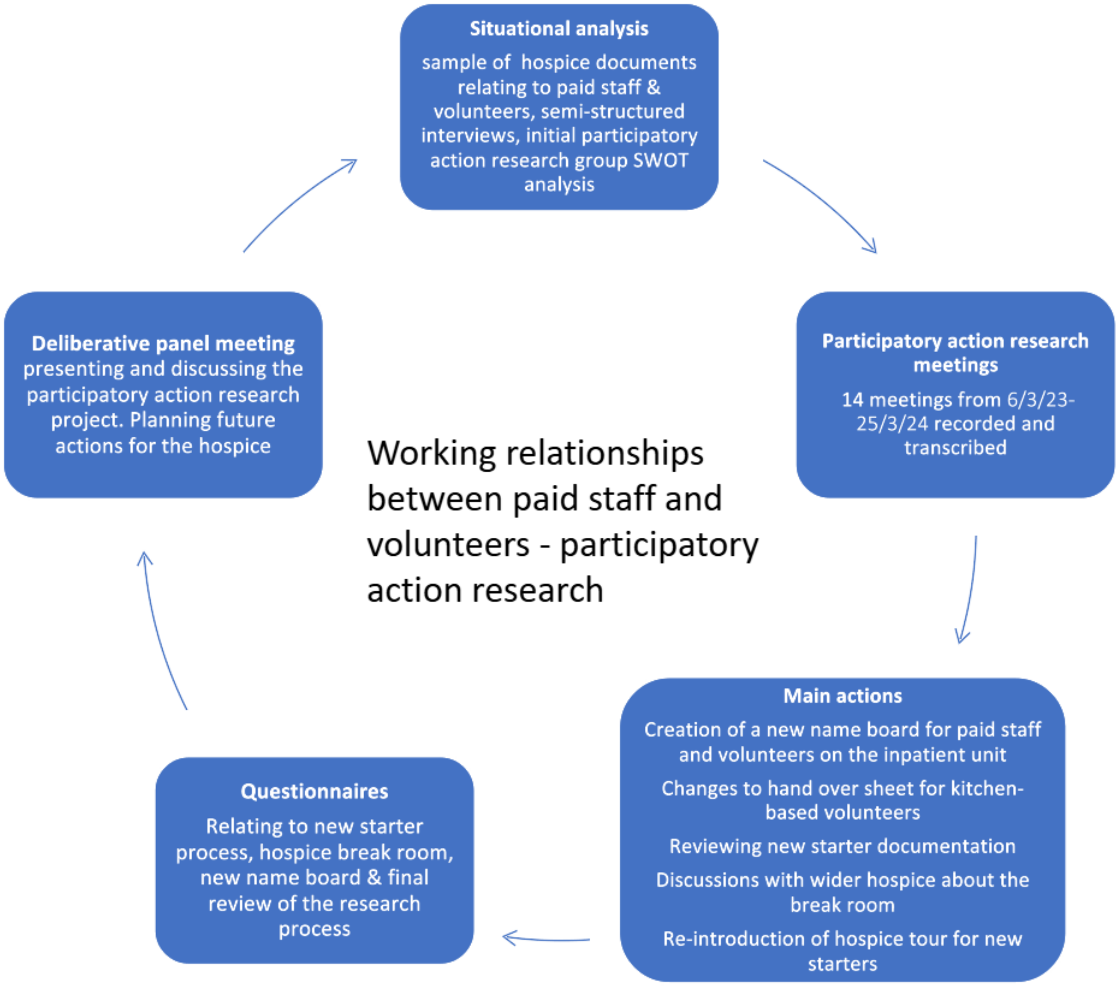


Figure 6.1: Indicates where the main themes of the reflexive thematic analysis are located in the different phases of the participatory action research.

Table 6.1 – Includes where the main themes are situated in the research process.

Theme:	Where main themes are situated in the research process:
Hierarchy and power	Interviews, SWOT analysis, throughout the participatory action research group meetings with phrases including 'them upstairs' being used, main actions related to the theme were the creation of a new name board (where do volunteers fit in the hierarchy) & re-introducing hospice tour for new starters, discussion in the deliberative panel, including application to whole hospice structure.
Belonging	Interviews, SWOT analysis, were discussed throughout the participatory action research group meetings with phrases such as 'becoming part of the furniture' & 'putting a face to the name' being used, the main actions related to the theme was

	the creation of the name board & reviewing new starter documentation, questionnaires connected to the new starter process, discussion at the deliberative panel meeting, including how the hospice relates to the wider hospice movement.
Being together	Interview, SWOT analysis, were discussed throughout the participatory action research group meetings with phrases including 'them and us' and 'everybody has an off day' being used, main actions connected with the theme were discussed with the hospice team around the new break room, the questionnaire regarding the hospice break room, and the lead researcher presented information around the theme to the deliberative panel.
Adding Value	Hospice documents relating to paid staff & volunteers, interviews, and SWOT analysis, were discussed throughout the participatory action research group meetings with phrases such as volunteering has to be 'win-win,' there were no main actions related to this theme, the deliberative panel discussions considered how value is shown to volunteers.
Information sharing	Interviews, SWOT analysis, discussed throughout the participatory action research group meetings with phrases including 'getting that balance between what we need, isn't it, and what's extra' & 'being on the back foot', main actions related to changes to hand over sheet for kitchen-based volunteers, questionnaire connected to the hospice break room had relevance, the deliberative panel discussed paid staff sharing information with volunteers.

6.1 Theme 1 - Hierarchy and power 'we are not asking for the world'

This overarching theme of hierarchy and power at the hospice includes consideration of the following subthemes: Hierarchy at the hospice and leading by example, Permission from hierarchy - *"We are not asking for the world,"* upstairs-downstairs, and where do volunteers fit? Hierarchy and power were identified as major influencing factors in all aspects of the collected data and created the main thread, which is woven into all the themes.

6.1.1 Hierarchy at the hospice and leading by example

The role of the hospice Chief Executive was important in setting the tone and encouraging working relationships between paid staff and volunteers from the top down (as well as having bottom-up initiatives). It was found during interviews that people paid particular attention when information was sent out from the Chief Executive. One volunteer felt *"astounded"* when they received a letter of recognition and appreciation from the Chief Executive for a role they had been involved in at the hospice. Whilst recognition was not expected, the Chief Executive's correspondence, showing appreciation for volunteers was seen as an acknowledgement of volunteers going *"above and beyond,"* which some volunteers appeared to *"thrive on."* Therefore, positive input from those in senior positions at the hospice, including the Chief Executive, could be seen as a driving factor in volunteer satisfaction in their role at the hospice.

The participatory action research group felt that it was *"exciting"* and *"good"* that the Chief Executive made both paid staff and volunteers feel included in what was happening at the hospice. However, they may need to try and *"please all the people"* which could be challenging to manage. The group positively discussed initiatives at the hospice for senior team leaders, including the Chief Executive, spending time shadowing other teams:

> *"... well, [name of the Chief Executive] has done it a few times, yeah... [name of the volunteer coordinator] is doing it... so there's quite a few of them doing it from higher up, down..." [speaker 5 – paid staff]*
> *"Well, good. So that's like a back to the floor" [speaker 6 - volunteer] (PAR meeting 7).*

When members of the participatory action research group considered ways of encouraging paid staff to become more involved in the project, we felt that more senior members of the paid staff team needed to *"lead by example"* as a way of getting others on board with the initiatives we were introducing. However, it was discussed that several healthcare assistants on the ward acted as unofficial volunteer champions. Some healthcare assistants were instrumental in helping build relationships, advocating, and leading by example in the changes the participatory action research group introduced. Some of the volunteers in the group felt that having members of the paid staff team as advocates was helpful, as at times they felt they were not seen and were *"anonymous."* Consequently, although having senior members of paid staff *"on their side"* was seen as important, we commented that positive influencers for volunteers and volunteering on the ward were not always those in senior paid positions.

Volunteers being invited to and included in meetings by paid staff was a way of getting the right people around the table and empowering volunteers. It was discussed in the participatory action group meetings that separate volunteer groups had been set up by the hospice management to seek the volunteer voice in what was happening. It was also suggested in the deliberative meeting that creating a working group, including both paid staff and volunteers, would be a good way of seeing if further ongoing improvements could be made. The encouragement from paid staff to include volunteers often reminded me of the term 'no decision about me without me,' which is regularly used in healthcare in the UK to describe the importance of patient input in their care (O'Brien, 2022). This echoed throughout my reflective journal, as I considered that nothing should happen to volunteers without their input:

> *"... the phrase 'nothing about me without me' is used for patients. It seems that here paid staff and/or volunteers may have felt the same way about the break room. Leading to the thought that others were asked about it but not them (whether this is correct or not is unclear at the moment). This could have caused misunderstanding or resentment between teams." (Extract from the personal reflexive journal after PAR meeting 8)*

6.1.2 Permission from hierarchy - "We are not asking for the world"

Commitment from the hospice that they wanted this participatory action research study to go ahead was seen as an opportunity during the initial SWOT analysis discussions. A potential threat was considered that if the group decided they wanted to change things they may have needed to *"go through hoops"* and the influence of those *"higher up"* on the project:

> *"...it's alright us as a group deciding something and thinking well, we might actually want to implement that, but as we all know when any change is*

> *afoot, it has to go through all the hoops and all the hierarchy" [speaker 7 – paid staff] (PAR meeting 1)*

The participatory action research group was concerned that some of the initiatives we wanted to introduce to improve the working relationships between paid staff and volunteers, such as the new name board, might get *"swept under the carpet"* and as such we wanted to keep bringing our ideas to the forefront of those the group saw as decision-makers:

> *"The thing about this is that I think that they always think it's somebody's bright idea that we'll forget about it after a bit, but the only way to ever get things done is to achieve it. And so, once you've achieved it once, then they do listen to you. They will know that we're not gonna give up. We're not asking for the world." [speaker 5 – paid staff] (PAR meeting 6)*

The participatory action research group wanted to make sure that we included those involved or who would be affected by changes in what was happening. Communication was found to be an essential element of making changes, not only related to the group but also changes introduced within the wider hospice to prevent misunderstandings between teams. We were concerned at times that not including others in the loop would disempower them and potentially *"step on toes"* without meaning to. Within the questionnaires about the new break room, some other teams felt that their opinion was not considered about changes made:

> *"... We weren't asked if we needed this room pre its refurb, as I would have said not needed... [I] think the only people involved in the decision were IPU [in-patient unit] nurses" (Questionnaire 2 - Participant 5)*

Some of the participatory action research group felt that the in-patient unit nurses were not asked about the refurbishment beforehand. Consequently, it was felt by the group that there were misunderstandings caused by individuals or teams not having the full picture. There was potential that false impressions create barriers between teams of feeling that one team is more important to others.

When volunteers received positive feedback about their recommendations from paid staff, they saw this as highly positive and empowering. Furthermore, when paid staff in senior positions permitted bottom-up initiatives it was felt to encourage their voice to be heard:

> *"Yeah. I feel as though it's like giving them and us, everybody a voice. So instead of our chiefs or our people above us telling us or making us ... they're giving us choice now that they are including us, the inclusivity of it is amazing. I love that aspect of it" [speaker 5 – paid staff] (PAR meeting 8).*

One issue that was considered might have prevented volunteer involvement and greater responsibility at the hospice was it being *"all policies and procedures"* (Interview – paid staff 2). The deliberative panel discussed enhancing volunteer roles in the hospice, noting that some opinions may be swayed by the regulated healthcare environment, which is heavily guided by governance and regulations. One panel member who did not have a background in healthcare did not seem to see as many obstacles to volunteers leading teams as those with nursing backgrounds, due to traditional healthcare culture. The deliberative group considered if rethinking and exploring different models of volunteering would be possible. Thus, commencing initiatives involving volunteers by looking at possibilities rather than starting with potential obstacles to their involvement would be helpful in *"pushing [changes] forward"* (Deliberative panel meeting – participant 2).

6.1.3 Upstairs downstairs

During the participatory action research meetings, it was evident that before COVID-19, new paid staff and volunteers starting at the hospice would be given a tour of the whole hospice building. The tour included visiting the upstairs office spaces, as part of their induction. The tour aimed to familiarise them with the building and to make introductions to others. During COVID-19 this was stopped and at the start of the participatory action research had not recommenced after the pandemic. This increased the sense of disconnect between those based in the in-patient unit and kitchens (downstairs) and those based in the offices (upstairs):

> *“... you only see them walking down the stairs and you don't know who they are do you?” [speaker 3 - volunteer] (PAR meeting 2)*

I reflected that , at times that there was a sense of mystery about what happened *“upstairs”* and who they were as a slightly unknown collective. There was a feeling that *“those upstairs”* were the managers and senior hospice staff who were in charge and making decisions about *“them downstairs.”* Those volunteers who had been upstairs previously described it as an event, rather than day-to-day activity, again, extending the sense of separation:

> *“... we went upstairs... and I was amazed 'cause I'd never been upstairs. There were hushed tones outside some people’s offices and they said ‘oh no, we won't go in there’, so you went on to somewhere else and you thought goodness gracious, why wouldn't you go in there?” [speaker 4 – volunteer] (PAR meeting 2)*

It was explained that one of the reasons the tours had not been seen as important was because many of the office staff now worked from home and so many of the offices were not in use.

Further practical issues were discussed at the deliberative meeting, due to the layout of the hospice building, which naturally meant that office staff needed to be located upstairs. However, greater opportunities for finding time and spaces for integration might have been helpful. Creating opportunities to spend time together was also suggested during the participatory action research group meetings:

> *“Would it be quite useful to sit in a room where some of the upstairs staff are to be able to say... that's what she looks like!” [speaker 4 – volunteer] (PAR meeting 3)*

As the participatory action research progressed, the hospice tour was re-introduced by the new ward volunteer coordinator, which one of the deliberative panel members commented was *"brilliant".* Additionally, finding neutral spaces that are hierarchy-free and time to meet may have been a potential way of reducing a sense of disconnect and separation between teams.

6.1.4 Where do volunteers fit?

When the participatory action research group was first discussing where to put volunteers' names on the main inpatient unit board, some decided they would be on the bottom, where there seemed to be a natural gap. As the project progressed, the new trial name board was being used on the inpatient unit with their photographs. We discussed how the board should be set out, as both paid staff and volunteers would be on it:

> *"... I think [name] wanted it to be in like a hierarchy type... I don't like the word and I'm desperate to find a new word for it... But, you know, basically at the very top of is gonna be, you know, the ward manager, the ward sister..." [speaker 5 – paid staff] (PAR meeting 8)*

It was felt that paid staff wanted to be in a *"hierarchy,"* in order of seniority and role. Volunteers were unsure where they should be placed as they did not see themselves in the same structure. Volunteers felt it would be better for them to be at the side of paid staff, rather than at the bottom, which would potentially "*reinforce*" negative ideas of where volunteers are in the hospice hierarchy:

> *"I think the side because putting us underneath everybody else suggests that that is where we are" [speaker 4 – volunteer] (PAR meeting 8)*

At other times some volunteers described that they had a unique *"niche"* role at the hospice that fitted in between different paid staff roles. As the project progressed, volunteers often found that others had put their names on the board before they arrived for a shift. It was described as "*fun*" to see where the volunteer names would be positioned on the board for the day. The group jokingly said that they could guess who had put their names on the board depending on where they were. Those who championed volunteer roles would often put volunteers at the top.

It was realised during the deliberative meeting that volunteers were not represented on other photo boards located around the hospice that showed wider hospice hierarchical structures. When asked about where volunteers fitted within the hospice hierarchy at that time, the response was:

> *"Well, they don't do they? If you look at it…, like you just said [name of other person at meeting], that organizational chart, they're not on there are they..."? (Deliberative panel meeting – participant 1)*

It was felt that this may have an impact on where volunteers saw themselves and their significance at the hospice. A discussion then started about where volunteers would be on the main hospice board and structure, initially considering if they would be under their paid staff line managers. Hospice trustees were identified as being right at the top, who are volunteers, and as such the Chief Executive would need approval from them for any big decisions. One participant felt that volunteers *"surrounded"* the in-patient team and were involved as core parts of the team. However, as the discussion developed, a further layer to this was added, as it was felt that *"the whole organization should be surrounded by volunteers,"* which was an exciting moment of recognition in the meeting. The group then created an image of how they saw the hospice structure, seeing it as a *"massive statement"* to make about the hospice hierarchy and where volunteers fit (see Figure 6.2).

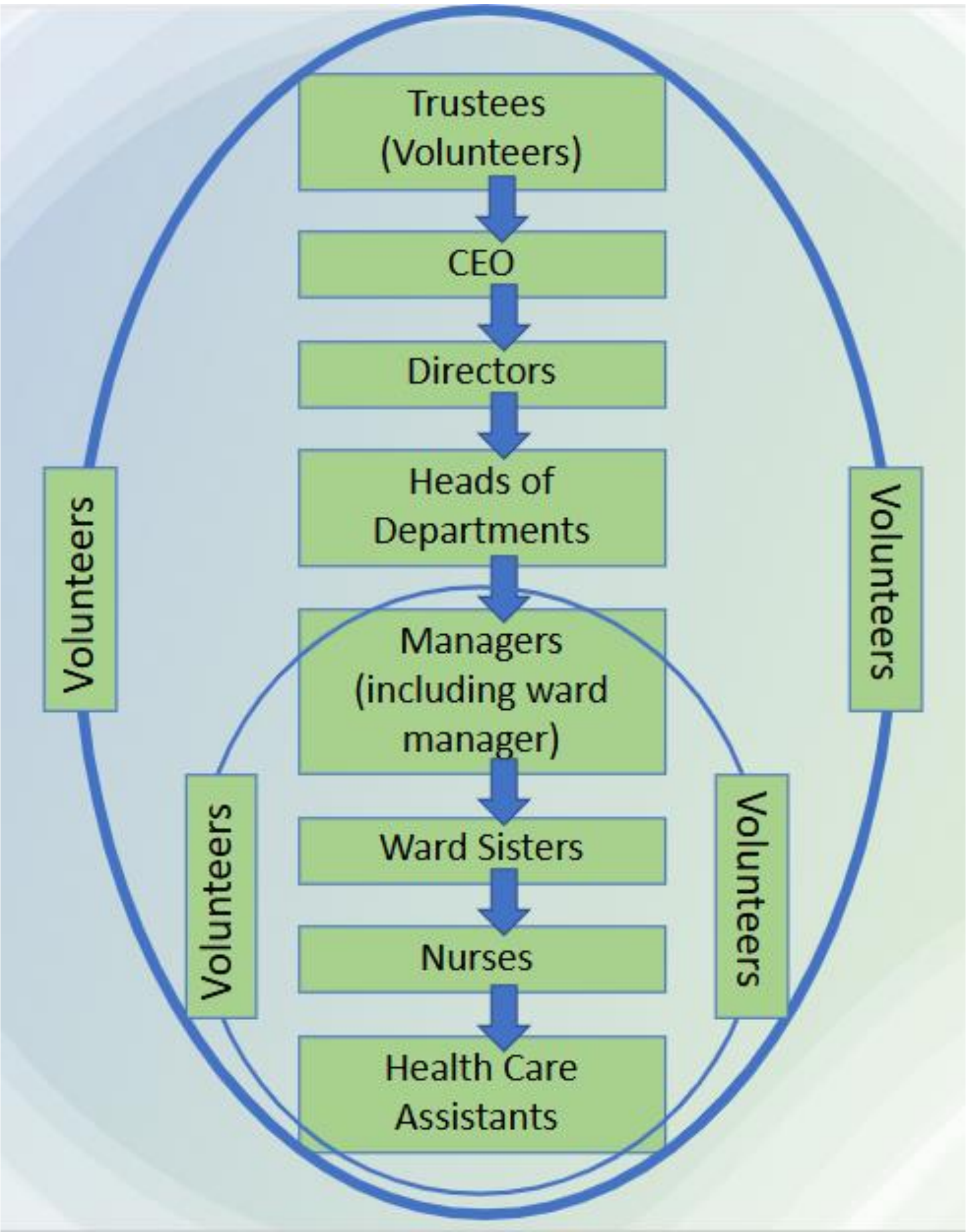


Figure 6.2: Image created during the deliberative panel meeting to show how they saw volunteer involvement within the hospice.

The theme of hierarchy and power has highlighted the value of those in senior positions, at the top of the hospice hierarchy, leading by example within the setting, actively encouraging and engaging with volunteers to inspire and motivate. Nothing should happen to the volunteers without their involvement or consideration, which should not be limited or restricted by what had happened before. Creating greater opportunities for volunteers and paid staff to meet in non-hierarchical ways may help to create deeper connections and integration. Volunteers should be able to see themselves as an integral part of the wider hospice structure to encourage a sense of recognition.

6.2 Theme 2 - Belonging - ‘they must have put the face to the name’

The theme of belonging follows from the theme of hierarchy and power, as volunteers being able to see themselves within the wider hospice structure would also develop a greater sense of belonging. The theme of belonging includes sub-themes of knowing others and being known, the new-starter process for volunteers, and feeling established in roles and being part of something bigger.

6.2.1 Knowing others and being known

The importance of knowing other people's names was a recurrent topic throughout the whole project. Whilst name badges helped with knowing who paid staff were, at times they were challenging, as they could be easily obscured by aprons. It was commented that volunteers needed to then *“peer right at their chest,”* which was particularly awkward for male volunteers and paid staff members. Previously, introductions were made when volunteers and paid staff started at the hospice, as part of the *“hospice tour,”* which was suspended during COVID-19. Not knowing the names of others could put them *“on the back foot”* as they would feel uncomfortable not being able to address people appropriately and make them feel valued. It was difficult for some to challenge those seen as more senior to them without offending if they did not know their name:

> *“Some of the doctors don't even wear badges. I've walked past people and thought I have no idea who you are, but I do know you are a doctor.” [speaker 6 – volunteer] (PAR meeting 4)*

From the interviews, volunteers mentioned the name board in the in-patient unit, which although this included the names of paid staff members on shift that day, volunteers often did not know who they were. Initially, adding photos of paid staff members to the board was considered in the interviews as a possible solution to help build relationships between paid staff and volunteers, seeing it as simple as being able to put a *"face to the name"* (Interview Volunteer 3).

Volunteers saw the benefit of having their names and photos on the board as well as those of paid staff to improve relationships. Volunteers found that whilst paid staff made them feel welcomed and appreciated at the hospice, they may not remember who they were. This was also acknowledged by a paid staff member in interviews who commented that they did not know all the volunteers by name. Consequently, they wanted to include volunteer names along with theirs as a positive way of further involving volunteers in the day-to-day working of the ward and improving communication (Interview Paid staff 2).

It was appreciated when paid staff, including senior members of the hospice paid staff, acknowledged volunteers by name as a way of including them as part of the team:

> *"… a lot of them and like with [name of consultant] she comes past and says 'morning [their name] are you alright?' every time she sees me, you know, 'how are you doing?' And I'm like 'how are you doing?' coz she's got one hell of a job, but she's amazing as well." (Interview Volunteer 1)*

The participatory action research group recognised the cyclical nature of the importance of knowing names throughout the project, that whilst other topics and issues were raised, the name board as a tool for getting to know each other was the most significant:

> *"Well, going back to where we all started... Isn't this all about the interaction between volunteers and paid staff? So, it is just another tool to encourage and support that interaction..." [speaker 6 – volunteer] (PAR meeting 6)*

One volunteer fondly reflected on nursing staff using their name and offering them chocolates that a relative had brought in. The volunteer wondered if paid staff were more aware of them and their name because of the name board. This was also felt by others in the Participatory Action Research Group:

> *"It might be in my imagination, but I feel that a few more people have addressed me as [name] when I've gone down the ward. And the only difference is that that picture is there. So, they must have put the face to the name" [speaker 4 – volunteer] (PAR meeting 9)*

Often it was felt that volunteers would have a sense of pride in adding their names and photos to the board, as this was a way of building rapport between paid staff and volunteers. At the end of the participatory action research meetings, we reflected that we had a greater awareness of others due to the name board that we had *"pushed forward."* I also found as an *"outsider"* that I was able to recognise and know more paid staff and volunteers' names because of the name board, which helped me to increase my sense of belonging in the hospice.

6.2.2 New starter process for volunteers and feeling established in roles

How volunteers started at the hospice as a new volunteer was crucial for fostering a sense of belonging and helping them establish their roles. The initial SWOT analysis acknowledged a strength of the hospice was that volunteers felt a sense of welcome.

For some, the initial process from application to starting appeared to be easy, whereas others experienced delays which they reflected might negatively impact the new starter process:

> *"... other people might be put off, and the amount of time... If somebody like is really keen to get going and you know, and it takes months. They might move on to another organisation." [speaker 8 – volunteer] (PAR meeting 2)*

The participatory action group was interested in improving the new starter process, as helping volunteers feel a greater sense of belonging would benefit the working relationships between paid staff and volunteers.

As the group reviewed some of the documentation at the hospice related to new volunteers, we questioned if this was reflective of the wider volunteer experience. Whilst one questionnaire response suggested greater use of buddy systems, another felt that there were already good structures in place for new starters, suggesting there may have been variation in individual experiences.

Some volunteers linked the length of time volunteering as a means of feeling fully integrated and part of the team. Further reflecting that they saw a difference between newer volunteers and the *"old guard"* at the hospice. The *"old guard"* were well-established volunteers in their role and had been volunteering for a long time:

> *"... gradually, we have just become part of the furniture..." (Interview Volunteer 2)*

However, some volunteers acknowledged that they did not find it easy to feel a sense of belonging in the hospice team and struggled to fit in:

> *"I felt welcome, but I don't think this happens until you've been in role for a while. It takes some effort to feel part of the team" (Questionnaire 1 - Participant 3)*

Others considered how more established volunteer roles were often *"seamless"* between paid staff and volunteers. At times they felt that the roles were so well embedded in hospice culture that it was difficult to distinguish between paid staff and volunteers. However, this level of integration was not necessarily across all teams. Some volunteers questioned if paid staff were always aware of volunteers or expecting them within certain teams. Volunteers explained that at times, paid staff seemed surprised to see them when they arrived for their shift, particularly on bank holidays, adding that they were not expecting them. This seemed to create a sense of disappointment:

> *"half the time they … don't even know that you were coming anyway" [speaker 6 – volunteer] (PAR meeting 7)*

It was explained that despite copies of volunteer rotas being available, paid staff did not seem to look at them, which was thought to be due to the busyness of paid staff. The group thought that adding volunteer names that were on the ward for that day would be a simple way of helping paid staff know who would be there.

Whilst generally there was a sense of welcome from paid staff, initially, some volunteers felt like they were *"walking into someone else's house"* when they went to the inpatient unit. As the participatory action research group meetings progressed, this sense of the inpatient unit belonging to paid staff appeared to lessen. Whilst at times the inpatient unit still felt to be the main working environment of paid staff, volunteers recognised a change because of knowing each other and experiencing greater unity between paid staff and volunteers.

6.2.3 Being part of something bigger

Feeling connected to the wider hospice was discussed at various stages of the research process. Having common aims and common concerns at the hospice was a strength. Volunteers were regarded as an *"important part of the jigsaw"* by paid staff, which was felt by volunteers when they were included in hospice information, such as emails and newsletters:

> *"It makes you feel part of the organisation, you know everybody tells you how vital you are as a volunteer. But to be included in the sort of email trail, yes, obviously ours is a separate one being volunteers, it does make you feel that you are part of, or in the fold if you like – part of it." (Interview Volunteer 2)*

Paid staff and volunteer stories in the hospice newsletters helped volunteers feel a greater sense of connection to those working in other departments of the hospice. However, whilst volunteers added that it was good to know the bigger hospice plans, it was also being included in the smaller day-to-day things that made a difference.

Some teams and hospice departments appeared to work in silos and were not aware of what others were doing or how to share information effectively. Silos impacted on both paid staff and volunteers not being aware of each other. The name board was found to have helped to make paid staff on the ward aware of the number of volunteers connected to the inpatient unit:

> *"And some of the [Health Care Assistants] have said they had a look at the board, … they went through all the photos, and I heard them say wow, we did not realise we've got these many volunteers. And he said, oh, it's really good to see all the photos, we never realised it" [speaker 2 – volunteer] (PAR meeting 8)*

The importance of being part of something bigger was also considered within the deliberative panel meeting. The group felt that whilst it was relevant to individuals within the hospice, the connections of the hospice to the wider hospice community were also felt to be important. Furthermore, the group discussed how the local hospice engages with wider research and conferences; therefore, recognising that they needed to engage with other hospices, and belonging to the hospice community.

The theme of belonging includes the importance of knowing people's names and being recognised by others in building meaningful relationships between paid staff and volunteers. This is significant in preventing volunteers and paid staff from feeling awkward or on the back foot. One way this was found to be improved was by including volunteer names alongside paid staff on the main name board, encouraging a greater sense of belonging. The timeliness of the new starter process can help both paid staff and volunteers feel wanted by the hospice.

Having a sense of connection to others helps feelings of being part of a wider hospice. Both paid staff and volunteers sharing their stories helps create a greater sense of belonging.

6.3 Theme 3 - Being together - 'let's get mixing'

The main theme of being together was highlighted in one of the participant's quotes of "let's get mixing" as a way of describing a need to spend more time together and have more opportunities to share neutral spaces. The theme includes subthemes of: sharing physical space together, and "everybody has an off day."

6.3.1 Sharing physical space together

Being able to share the same physical space at the hospice was seen throughout the different stages of the participatory action research project as an essential part of improving the working relationships between paid staff and volunteers. One paid staff member reflected with apparent sadness on the impact of COVID-19 on the way it changed the ability of the two groups to mix. They referred to a line that could not be crossed that separated the kitchen and ward team (made up of both paid staff and volunteers). The separation made them feel *"dirty"* and it was a *"horrible"* time. They said they *"got through"* although recognising it was a *"tough time"* (interview paid staff 1).

COVID-19 also altered the working habits of many of the non-ward-based staff at the hospice, including hybrid working, which was reflected in the questionnaire responses. The participatory research group thought that many of the offices were not in use as people were working from home. Some of the sessions they had attended for training, hospice meetings, or Schwartz Rounds (which are structured forums for healthcare staff and volunteers to discuss the emotional and social aspects of their practice) were now online. Often being online was a barrier to effectively supporting others and getting to know other hospice team members:

> *"When you sat with somebody saying that, you know, they've had a problem with a patient or even you know something to do with themselves. You want them to be in the room... rather than the other side of the screen" [speaker 5] (PAR meeting 7)*

The participatory action research group acknowledged that some of the hospice team would find home working more convenient, whilst others in the group stated that it hindered effective working. Although, we did recognise that *"you're never going to please everybody all of the time"*:

> *"I find with you know, working from home. You don't get to see certain staff members like they used to do before the pandemic. So, you still find things quite difficult when you need to go to that person. So, it's either you have to remember to ring them or email." [speaker 2 – volunteer] (PAR meeting 10)*

Being in the same hospice location also enabled more opportunities for *"incidental collaboration"* as well as *"intentional"* working together. Therefore, being together and *"muddling along"* with each other was part of being part of the wider hospice team.

The impact of shift patterns was considered as an important influence on paid staff and volunteers being able to know each other:

> *"That's the only drawback of only doing two mornings you can go weeks without seeing a member of staff, so you don't know if they are still here, or if that's a new member, or what..." (Interview volunteer 2)*

It was discussed that it was easier to get to know those in their own teams who shared the same shift patterns as them. Some volunteers reflected that if they came in on another day they would not know as many people. A volunteer mistakenly believed a staff member had left the hospice, but it was simply due to different shift patterns. Initially, the participatory action research group considered if accepting *"that's the reality that's not going to change"* and as such should just be something to be aware of would be sufficient. However, we continued to consider whether finding further opportunities for paid staff and volunteers to spend time together would help relationship building. We felt that asking others based at the hospice would be helpful to know if others also felt the same as we did. One questionnaire respondent agreed, adding:

> *"I only work at the hospice 1 day a week, but to say I have been there over 10 years I hardly know anyone, I like the Schwartz meetings [group-based meetings discussing the emotional impact of a situation that the group members have experienced] as these give an insight to other colleagues and volunteers" (Questionnaire 2 - Participant 3)*

There was agreement in the participatory action research group that having greater shared chances to be together, such as Schwartz meetings and shared training opportunities where possible would help to reduce any sense of *"them and us."* Some training was felt to be more appropriate to be joint than others. But where paid staff and volunteers were learning the same information, it would be good to be able to do this together. Within the hospice documents, there were numerous statements reflecting a significant intention for there to be a joint and inclusive team. Within the interviews, it was discussed by one of the paid members of staff that training would be a good occasion for intentional relationship building:

> *"yeah, or even our training days, I mean the volunteers do have to do … like moving, like especially the ward assistants... have to do moving and handling etc, get them in on our training days – let's get mixing you know – I know it's a bit difficult because of covid, I think it's more separated because of that but yeah, we need to get back to one team they keep saying '[united] (name of hospice)' - so let's be '[united] (name of hospice)'..." (Interview paid staff 1)*

The hospice's intention to be a united team was discussed throughout the group meetings, as the term was used within much of the hospice documentation, including the volunteer handbook. The group thought that the term should only be included if it was explained in full and whether the hospice thought the term was how they saw themselves now or if it was a future aim of the hospice should be clarified:

> *"It's almost as though when you have to put something like that in, it's because it's not happening, you know, because it's making it like a reverse psychology isn't it? Maybe it's an aspiration rather than a, you know, a current thing." [speaker 8 – volunteer] (PAR Meeting 3)*

The group felt that the hospice management should make it clearer what is meant by the terminology used in vision statements. This was addressed by a guest member of the participatory action research group meetings who gave feedback that there was going to be a discussion at a volunteer forum, as it had become apparent that others had not fully understood the intent of the hospice terminology. It was considered that re-introducing the whole hospice induction as a face-to-face session that discussed the hospice values and aims, would be a positive step in building understanding and encouraging paid staff and volunteers to be more unified as a team from the start of their time at the hospice.

A further way that the participatory action research group considered paid staff and volunteers could share space and time together informally was in a shared break room. Initially, we referred to this as the *"staff room"* as this was the traditional term we were accustomed to. When we asked for input from outside the group, feedback was given that the hospice management would prefer to refer to this as the *"break room"* as a way of better reflecting that it was equally open to paid staff and volunteers. The use of language was considered within the group and thought to be a positive small change to be more inclusive and reflect a more neutral tone.

The group wanted to see if there were ways of encouraging more people to use the break room and to explore any possible barriers. We expressed that it could be challenging to go into the room for the first time as it felt like they were walking into someone else's space. This feeling was echoed in another's feedback:

> *"... feel a bit nervous about using it for the first time as may be staff in there I don't know..." (Questionnaire 2 – Participant 15)*

The participatory action research group felt that knowing the names of others and being known was a way of breaking down barriers to using the break room. Therefore, the name board would also help to prevent them from feeling 'uncomfortable' or 'on the back foot' when accessing the break room.

Several different spaces were used within the hospice building for breaks. It was thought that volunteers should not have their own separate break room:

> *"But then, if volunteers can go in a separate bit, we might not feel like we valued all parts of the staff..." [speaker 8 – volunteer] (PAR meeting)*

For some, having a separate quiet space was thought could be helpful, as sometimes they needed to have time on their own.

6.3.2 'Everybody has an off day'

The participatory action research group recognised that whilst it was often helpful to provide spaces for paid staff and volunteers to be together, space also needed to be given for those who do not want to mix. Some people needed to have a *"brain switch off"* and not have to make polite conversation with others. One group member described a challenging time at the hospice, where there seemed to be an overwhelming sense of grief, and they needed to find a *"safe space"* to enable them to cope with it. This experience was echoed by others due to the challenging environment they were in. Some participants seemed concerned that their need for space could be misunderstood by their colleagues:

> *"When I have a break, I don't want to talk about work-related things as everyone else does. That is not a reflection on any team and sharing is not an issue but with it being small with so many teams using it you have no choice but to engage in conversation or be that rude co-worker who doesn't*

> *talk to people when in actual fact I really like the people I work with" (Questionnaire 2 Participant 6)*

Misunderstandings could be caused by people being distracted and misinterpreted by others as ignoring them. Most volunteers recognised that paid staff may be distracted as they could be thinking about the complex care they needed to give, such as medications, or how they would break bad news to a family. Others considered that the *"nature of people"* should be recognised and that some people have off days:

> *"But we deal with human beings and especially I think, particularly with the staff. Everybody has an off day, everybody's got garbage going on, you know, and nobody's a Saint. I mean, I heard a volunteer said to me a few years ago 'oh, that person really snapped at me' and I thought, well, to be honest, that person doesn't normally do that, but maybe they've got, you know, a bad time and in fact, the person they went up to that volunteer later and said, I'm really sorry for what I said earlier. But we are human." [speaker 9 - volunteer] (PAR meeting 1)*

Participants discussed that people have their own understandings and interpretations of what happened at the hospice. This included how some saw the relationship between paid staff and volunteers in different ways. Whilst this could be challenging, it was acknowledged that *"everybody's viewpoint is completely valid."*

The participatory action research group regularly discussed their desire for more paid staff to be part of the group. They wished for members of the nursing team to be able to give their input. At times, the group jokingly considered ways of encouraging paid staff to be involved, such as *"enticing them with cake."* Whilst there was disappointment and thought that it may further show a sense of *"them and us"* it was also recognised that there may have been other reasons paid staff were not engaging:

> *"But I suppose they could say, you know, if you did talk to them, they could say look [name], we just do not have the spare time to give to anything - be*

> *it that group or that group or anything else group. You know, unless you walk in someone else's shoes, you don't know, do you?" [speaker 5 – paid staff] (PAR meeting 9)*

The participatory action research group's thoughts about paid staff not being involved were discussed at the deliberative panel meeting. It was stated that the paid staff's lack of involvement may have given the impression that they were putting up a barrier of not being interested, which was not the case. Highlighting again the importance of open and honest discussions.

The theme of belonging includes ways in which creating intentional shared spaces for paid staff and volunteers to mix. Overall, online working had a negative impact on the ability of paid staff and volunteers to have meaningful formal or informal interactions. Shared time in meetings and joint training where possible could help reduce separation. Furthermore, whole hospice inductions, and small changes, such as the use of inclusive language further reinforce hospice intent for paid staff and volunteers to be a unified team.

6.4 Theme 4 - Adding Value – 'What value do we really place on our volunteers'?

The theme of adding value encompasses perspectives from paid staff, volunteers, and the wider hospice on how volunteers add value, also how they can and should be valued by others. The theme includes four sub-themes of volunteers shown appreciation by paid staff, volunteering has to be win-win, volunteers have expert knowledge and experience, and volunteers are voluntary.

6.4.1 Volunteers shown appreciation by paid staff

Appreciation from paid staff to volunteers was expressed in various ways, such as in-formal words of thanks to individual volunteers, written recognition in emails and newsletters, and acts of recognition, such as thank you parties. Nevertheless, at times, volunteers felt that although appreciation may have been expressed by someone in words, it was not always shown in actions:

> *"… we all had an e-mail, didn't we? From [name of Chief Executive] about the Survey. And she says, you know, huge thanks to you all, all these volunteers, we couldn't do what we do without you. But a lot of the time, it doesn't feel like that, does it? I don't think." [speaker 6 – volunteer] (PAR meeting 4)*

There was also a discussion at one of the participatory action research meetings about the available budget for flowers for volunteers at the hospice, for example, who become ill or bereaved. Many group members preferred not to spend money on rewards like badges for years of service but were surprised and *"a little disappointed"* by the limited overall budget for flowers, cards, and volunteer rewards. It was explained that volunteering in the hospice was classed as a *"deficit budget,"* as it did not generate any income of its own. The question was then raised about what an appropriate amount to budget for volunteers who became seriously ill or if someone died and the hospice wished to send flowers, also where should the finance come from?

> *"How much? I mean, it's an interesting question... what value do we really place on our volunteers?" [speaker 10 – paid staff] (PAR meeting 5)*

It was felt that it would not be possible to please everyone, as some volunteers may wish to receive flowers if they were unwell, while others would rather any money spent go towards patient care. Words like *"tricky"* were used and the phrase *"you could tie yourself in knots"* was used when discussing the issue. It was challenging to conclude the discussions around what financial value should be placed on volunteers as there were different opinions within the group and interviews. We concluded that the motive was important and the *"kind of message"* that was conveyed by the hospice about how they saw volunteers.

6.4.2 Volunteering has to be win-win

Volunteers viewed that one of their key functions at the hospice was as a *"support role"* for paid staff so that they could focus on patient care. Volunteers often talked about *"taking some of the load off paid staff"* as a way of describing what they did well. Volunteers wanted to be helpful to paid staff to enable them to focus on patient care, which was their ultimate goal. There was a significant sense of appreciation from paid staff for the support volunteers gave them, referring to them as a *"godsend."* Paid staff often confirmed that the volunteer intention of supporting them was normally successful.

Volunteers appreciated collaboration with paid staff and valued opportunities to adapt their roles when requested to help:

> *"I don't think I'd say, 'well I'm a volunteer, so you should do that,' you know, I will quite happily do whatever they want me to do" (Interview Volunteer 3)*

At times, some volunteers felt that picking up each other's tasks when they were busy should be more two-way. For example, when volunteers were very busy and behind with their tasks, paid staff were observed sitting and drinking water. Although this was only regarded as *"a silly little niggle,"* rather than a significant issue. A success of the group's activities was that paid staff were now asking volunteers how they could support them. The willingness of paid staff to practically offer support to volunteers made them feel valued and included.

Volunteers recognised that being a valued volunteer was not a passive role, but that they also had an active role in ensuring they were fully integrated and that their role would be beneficial to the wider hospice team:

> *"… at the end of the day it was up to us to go and find somebody to say 'right we are here, what do you want, you know, this is what we will be doing – what else do you want us to do?', coz it's a two-way thing as well..." (Interview Volunteer 2)*

Having a positive culture at the hospice and fostering an appreciation for volunteers was seen through terminology, showing a top-down approach to volunteer appreciation. The active involvement of both paid staff and volunteers in developing valuable relationships was also seen to be needed at an individual level, rather than limited to an organisational level:

> *"The hospice is doing all it can, staff & volunteers have to reflect on their own involvement in relationship building" (Questionnaire 2 - Participant 3)*

Volunteers and paid staff both recognised that the act of volunteering had to be mutually beneficial and that the tasks should be carried out correctly and well, otherwise in some ways it would be better if they did not do them. Therefore, it appeared that to be valued volunteers should add value:

> *"... whether you are paid or unpaid you need to do it right." (Interview Paid staff 1)*

Throughout the interviews and the participatory action research group meetings, it was evident that volunteers needed to have an active role in ensuring they were valued members of the wider hospice team. It was clear that volunteering was a doing word, rather than a passive activity.

6.4.3 Volunteers have expert knowledge and experience

Some volunteers had expert knowledge and experience from previous work such as being business owners, nurses (including senior nursing staff), having financial knowledge, and carer experience, that they were able to draw on in their volunteering role. Within the hospice volunteer policy, it was positively stated that volunteers *"have a special mix of skills and experience."* Paid staff often valued volunteers having expert knowledge and experience that they could bring to their roles at the hospice:

> *"I think a lot of our volunteers come from nursing backgrounds anyway so, I think that they know don't they, they know what nursing is about so, I think yeah, I think that's the biggest strength" (Interview Paid staff 1)*

However, some paid staff felt that volunteer experience was not always fully utilized, and they felt that volunteers could be more involved in patient engagement than they currently were. This was at times echoed by volunteers who felt that life experience was not always recognised by paid staff:

> *"Some don't always think that you've had a life before, when you might have a bit of a brain, and you can be quite useful..." [speaker 9 – volunteer] (PAR meeting 1)*

The importance of paid staff recognising and acknowledging volunteers' previous experience appeared to link with paid staff seeing volunteers as individuals and getting to know them rather than only seeing them as volunteers.

6.4.4 Volunteers are voluntary

Paid staff felt that many of the volunteers went *"above and beyond"* in their support of the hospice, particularly how they supported paid staff. However, volunteers appeared to want to put some limits on the expectations the hospice may have of them. When reviewing some hospice documents about volunteers, the group was unsure of the terminology used at one point to describe volunteers as *"being ready at a moment's notice"* and preferred to change the wording to say *"volunteers are reliable"*:

> *"What does that mean to me? I feel like somebody sitting by a telephone and somebody rings and said can you come in right now? That would put people off." [speaker 6 – volunteer] (PAR meeting 3)*

Feelings that too much reliance was put on volunteers were expressed by one paid staff member, who questioned if some of the roles given to volunteers should instead be paid:

> *"I think volunteers are great – yeh, but I do think we put too much on our volunteers, definitely, as much as they love it and they love what they are doing... so they are amazing, but it does make you think that actually should that not be a paid role? If we need somebody to do that then that should be a role shouldn't it? A position." (Interview Paid staff 1)*

The distinction between paid staff and volunteer roles was also picked up within the volunteer recruitment and selection policy, which encouraged managers to *"be clear that volunteers are not paid staff and as such do not have the same responsibilities as paid staff."* Throughout the policy, the overall aim was to support and protect those who volunteer at the hospice from being unintentionally overburdened. Although, there may be potential that it may restrict those who wish to 'go above and beyond' their volunteer role.

Not all volunteers would wish to extend their roles and some also stressed that they were in-fact voluntary and had limits to what they could offer the hospice:

> *"we're volunteers and you give up your day, give up your days don't you … and you are here on two days and if they say they want to do it on a Wednesday, you think, well hang on a minute I've been here two days, so it's not easy... but if you was paid staff, it would be we are having a meeting today and you would come in wouldn't you... it's different." (Interview Volunteer 3)*

The difference between paid staff and volunteers was recognised and reflected on in the deliberative meeting, confirming that they were aware that volunteers have other commitments and pressures on their time. Therefore, there is potential that whilst volunteers should be protected from being taken for granted, there could also be scope for individual negotiation between the hospice and volunteers who wish to extend their role.

The theme of adding value includes discussions around the perspectives of hospice staff and volunteers on the value of volunteer contributions and how to acknowledge them. Challenges within the hospice as they aimed to recognise volunteers and their service but also how to do this appropriately were seen. Money may not be as essential to volunteers as demonstrating worth through positive interaction between paid staff and volunteers, spending time together, and active support. Volunteers often felt valued when practical support was offered, which was more than words. Volunteers should have an active role in ensuring they are valued in teams; therefore, volunteering is not a passive activity. Paid staff should recognise volunteers' previous and current life experiences and volunteers should have opportunities to share their stories to help paid staff see beyond the volunteer uniform. The hospice sought to protect volunteers from being overworked; however, some volunteers may wish to be given room to expand their roles.

6.5 Theme 5 - Information sharing ‘it's getting that balance...’

In the theme of information sharing how paid staff sharing information and knowledge with volunteers prevents misunderstanding and being *“on the back foot”* is explored. This theme is explored through the following subthemes: somethings volunteers need to know, and some things are not for volunteers’ ears.

6.5.1 Somethings volunteers need to know

At times participants reflected that they did not need to be told something was happening in the inpatient unit as they could sense it. The ability to *“pick up the vibes”* came with experience, knowing the team and the environment:

> *“Like a couple of months ago - We were just... It wasn't manic, but it just felt like everybody was buzzing around, in a nice way, you know, it wasn't anything nasty going on, but it was just like, wow, what have we walked into?” [speaker 3 – volunteer] (PAR meeting 10)*

Whilst at times no explanation was needed, at other times volunteers felt that they needed more information to be better prepared for what they would encounter. *“Not always being aware of what you are walking into (patient rooms)”* was included as an area of weakness in the initial SWOT analysis. One volunteer described a particular situation they encountered:

> *“... And I came out and I actually mentioned to a senior member of staff at the time of it ‘that was a shock, I wish I'd been aware of this’ and they said ‘Well, we're all professionals and we're all medics’ I went well I'm a volunteer, I'm not a medic ... and then they said ‘oh, yeah, that's probably a point’.” [speaker 9 – volunteer] (PAR meeting 1)*

It was also discussed in the participatory action research group that on other occasions paid staff had pre-warned volunteers of potential issues. Also, some of the volunteers had handover sheets that would at times say *"please see nursing staff"* as a way of informing volunteers of information that would help them go into patient rooms prepared for what they would see. It was found that there was a disparity amongst the different volunteer teams in how much information was shared with them. Some teams that had been established longer received printed handover sheets each shift, including information pertinent to their role at the hospice. For example, the kitchen-based volunteers who helped with meals were given information such as the dietary requirements of the patients. Other teams needed to seek verbal handover at the start of their shift, which could be challenging due to the busyness of paid staff. Volunteers did not want to interrupt paid staff or waste time accessing support, delaying patient care:

> *"Yeah, it was last Tuesday, I was up and down the ward looking for somebody... whether room 5 needed water but there was no one there to ask" [speaker 4 – volunteer] (PAR meeting 2)*

The participatory action research group discussed different ways that information sharing could be improved for all teams. We felt that all volunteer teams working on the inpatient unit should have access to a relevant handover sheet, but it was recognised that asking paid staff to produce another sheet would be difficult as they were busy. Handover sheets were something that they thought would be an ongoing issue to seek a solution.

6.5.2 Some things are not for volunteer ears

Whilst volunteers felt that some information about patients was important for them to know, there was other information that they thought was inappropriate for them to know. This included patient medical and personal information. One participant reflected:

> *"... it's getting that balance between what we need, isn't it, and what's extra." (Interview Volunteer 1).*

One paid staff member thought that, at times, volunteers wanted too much information about patients which they thought was not appropriate for their role, although, they also acknowledged that this did not happen often. The deliberative panel felt it was important to know the opinions of both paid staff and volunteers to help improve the relationships between paid staff and volunteers:

> *"It's worth listening to. Yeah, that knowledge and as well because that staff member might not understand why volunteers need the information that they need" (Deliberative panel meeting – participant 2)*

Some volunteers expressed concern that at times paid staff discussed patient information in the break rooms where volunteers were sitting. Volunteers felt that it was inappropriate for them to be listening to this information and were unsure what to do about it. It was discussed at the participatory action research meeting if guidance should be given to all who used the break room on what would and would not be suitable to discuss in that space. Both paid staff and volunteers felt they had a responsibility to maintain patient confidentiality. The final deliberative panel confirmed that action had been taken regarding conversations about private patient information in the break room:

> *"... I think that there was an e-mail went round about that, just to remind people not to have meetings in there because it was uncomfortable at the end of the day" (Deliberative panel meeting – participant 2)*

Specific patient information was felt to be inappropriate for volunteers to know, however, there was a desire for them to develop a general understanding and knowledge of some of the reasons patients came into the hospice. General information on processes at the hospice was also found to prevent misunderstandings. One volunteer described a situation they thought was concerning when new patients came into the hospice. However, when the admission process was fully explained to them it was apparent that this was a misunderstanding due to lack of knowledge. It was thought that general information would help them to be better prepared for what they encounter and to provide better support for patients and paid staff. Volunteers asked if paid staff, including doctors, could attend some of the volunteer meetings to discuss some frequently encountered issues, as this would help them not to feel *“on the back foot.”*

In the final theme, the importance of paid staff sharing relevant information with volunteers to ensure they feel supported and confident in their roles has been explored. This could involve being prepared for what they might see, hear, or smell whilst in patient rooms. Volunteers recognised that they did not need or want specific information about patients, but that general information would help them to feel more prepared for what they might encounter at the hospice, and at times prevent misunderstandings.

Chapter 7. Discussion

7.1 Introduction

My aim of the study was to explore ways of improving the working relationships between paid staff and volunteers in a hospice inpatient unit. I sought to support paid staff and volunteers as they increased their level of knowledge and involvement with each other in their respective roles. The purpose was to empower both groups in their ability to directly change and influence issues of their choice in the hospice environment through participatory action research. Conducting a meta-ethnographic literature review (Chapter three), a situational analysis, a participatory action research group, a deliberative panel (Chapter 5), and qualitative inquiry with reflexive thematic analysis (Chapter 6) enabled the development of an understanding of the working relationships of paid staff and volunteers.

I found that including others through participatory action research supported those interviewed, group members, the deliberative panel, and myself to learn about the working relationships between paid staff and volunteers, and the research process itself. The research approach became integral to the process and its use enabled the formation of stronger relationships between group members (including both paid staff and volunteers and the wider hospice). Participatory action research was utilised as a means of pushing beyond asking about the working relationships between paid staff and volunteers in hospice settings, which had been previously done (Claxton-Oldfield et al., 2006; Claxton-Oldfield & Marrison-Shaw, 2014; Vanderstichelen et al., 2020a), to actively exploring ways of improving any issues identified by those directly affected by it. Participatory action research enabled research to be actively carried out with paid staff and volunteers, rather than passively to them. I also sought to encourage the group to have an equal voice in bringing issues to light and challenging the status quo by considering critical and solidarity theories (Laitinen & Pessi, 2014; Popkewitz, 2009; Strunk & Betties, 2019).

The focus of this discussion is on the importance of working relationships between paid staff and volunteers, examining the potential benefits, challenges of such partnerships, and possible future strategies for fostering ongoing successful collaborations. The key concepts that have been found within the study, from the literature review in chapter three and the participatory action research are:

- Volunteer involvement and integration in hospice power and hierarchy
- Creating meaningful opportunities for paid staff and volunteers to mix
- The impact of silos on working relationships within hospices
- Building a sense of mutual belonging for paid staff and volunteers

These concepts are discussed within this chapter in light of wider surrounding evidence.

7.2 Volunteer involvement and integration in hospice power and hierarchy

The findings of the participatory action research centred on power and hierarchy, highlighting both positive aspects, like the hospice Chief Executive as a role model, and challenges, such as the management's permission-giving. The role of volunteers in hierarchical structures can present a complex and often challenging dynamic, particularly for healthcare-based organisations to manage and interpret policies and governance (Strkljevic et al., 2024). While volunteers are essential to many organisations, their position within the hierarchy can be ambiguous and fraught with challenges (Merrell, 2000). The various ways in which volunteers are integrated into hierarchical structures, the potential benefits and drawbacks of these arrangements, and the implications for organisational effectiveness, particularly concerning hospice settings are explored.

Volunteers often felt a sense of ambiguity about their status due to “organisational hierarchy” and, at times, felt they had a lower status than paid staff. Volunteers were unsure where they fit within the inpatient unit hierarchy, and it was later questioned where they should be placed within the wider hospice structures. Volunteers often wished to be alongside paid staff, rather than above or below, reflecting the supportive, yet separate and distinct role that they had at the hospice. Healthcare organisations are traditionally hierarchical, in terms of organisational structures, with a Chief Executive at the top, managers and team leaders in the middle, and often volunteers at the bottom (Essex et al., 2023). The traditional hierarchical structure has been seen by many as helpful in ensuring that care is effective, organised, and prioritised (Fernandopulle, 2021). Hierarchy in healthcare is well recognised as a means of supporting efficient and stable ways of working. However, this could create tensions by creating a rigid 'pecking order' (Essex et al., 2023). Flattening hierarchies may be a way of 'levelling out' structures (Fernandopulle, 2021; Reitzig, 2022), but overly flattening the hierarchy may also cause issues, such as blurred decision-making processes and reduced understanding of responsibilities. Lessening the gradient could be helpful within healthcare settings (Green et al., 2017) because small hierarchical shifts can have a significant impact, such as using first names and meeting in neutral areas for joint meetings (Noyes, 2022).

Both using first names and joint meetings were found to be beneficial within the participatory action research as effective ways of building relationships between paid staff and volunteers, which in turn helped to create shallower authority gradients. As the participatory group built stronger relationships with each other and with others, they grew in confidence in raising issues and 'fighting' for what they thought was important. Critical theory is often associated with questioning and challenging societal issues. It has been questioned if contemporary use of critical theory has in some way become diluted in its emancipatory and empowering edge (Jahn, 2021). However, critical participatory research approaches support researchers in creating new ways to empower groups and individuals to find their own ways to make changes. Thus, enabling group members to 'fight' effectively when seeking to reduce authority gradients (Call-Cummings et al., 2023; McTaggart, 1994).

The term authority gradient was first defined in aviation when it was noted that co-pilots did not challenge pilot errors effectively, due to pilot seniority (Green et al., 2017). Similarities between perceived difficulties in questioning authoritative figures have also been found in healthcare (Hubbard & Chicca, 2022). Greater opportunities for open communication and openness can help build a common understanding and greater ‘situational awareness’ can help reduce authority gradients (Cosby & Croskerry, 2004). Encouraging paid staff (including those of different hierarchical statuses in a hospice) and volunteers to join together more frequently could potentially create joint perceptions, understanding, and responses to challenging situations they encounter (Coleman et al., 2022).

Hierarchy was seen positively when used as a way of leading by example, creating a constructive driving force for initiatives, and acting as an advocate for volunteers. Discussions around managers leading from the top have been seen as both positive and negative, some instead advocating bottom-up approaches to encouraging empowerment. Within the sports coaching area of leadership, a positive alternative to top-down leadership is to encourage leadership from within. By sharing leadership responsibilities, those previously seen as subordinate followers are empowered with leadership responsibility, strengthening the belief that the input of everyone contributed to the team’s functioning, which, in turn, caused a higher commitment to the team's goals (Cummins & Spencer, 2015; Fransen et al., 2016). Leadership from within has been linked with enhanced role clarity, higher satisfaction, improved communication, and higher team cohesion (Loughead et al., 2016). Whilst there are many differences between the world of sport and hospice settings, there is a potential that encouraging leadership within those traditionally seen as lower down the hierarchical order, such as volunteers, may encourage ownership, empowerment, and greater buy-in to hospice initiatives.

Volunteer leadership could take place through volunteer-led task groups (Wilks, 2015). However, this was discussed during the participatory action research groups as being tried and was thought to be unsuccessful due to a lack of volunteer availability. Volunteer leadership could provide volunteers with a clear sense of purpose and responsibility, and it can also help to ensure that their contributions are aligned with the hospice’s goals (Dixon, 2021). This can give volunteers a greater sense of autonomy and identity, and it can also help to ensure that their needs and interests are being met. Creating teams solely consisting of one group (paid staff or volunteers) may also lead to feelings of isolation or fragmentation, as volunteers may be disconnected from the main operations of the organisation. This approach can also lead to feelings of exclusion or marginalisation, as volunteers may be perceived as outsiders or helpers rather than as full members of the team. Creating joint teams of paid staff and volunteers, where leadership is shared may help with ensuring volunteers are not ‘token’ members of groups, but that power and ownership are shared. Sharing power in this way would further encourage meaningful citizen control (Arnstein, 1969; Jackson, 2000; McAllum, 2012).

Some volunteers in the participatory action research had relevant skills and experience from previous roles, making their contributions feel like 'second nature.' At times utilising these skills may take volunteers outside their usual role description, such as organisational skills, relative support, and expert knowledge of other sectors. Here, volunteers were often encouraged to use skills, and having experience in healthcare was seen positively; whereas in a previous study, volunteers with nursing knowledge were seen with suspicion and not to be used within the hospice setting (Overgaard, 2015). Perceived challenges were thought to be linked to fear of stepping outside of governance and role boundaries (Elliot & Umeh, 2013; Field-Richards & Arthur, 2012; Stølen, 2021). Understanding the origins of barriers and challenges, (for example, if they are organisational, cultural, political, or personal) could help develop strategies to reduce or remove some of the uncertainty surrounding volunteering in healthcare settings (Nelson et al., 2020).

A further approach may be to adopt a more flexible and adaptable model that allows volunteers to move between different roles based on their skills, interests, and availability, within the bounds of clinical governance (Hustinx et al., 2010). Clinical governance in healthcare is essential for accountability, quality improvement, and creating environments in which hospices will ‘flourish’ (Munday, 2018). Allowing greater role flexibility may provide volunteers with a greater sense of variety and challenge, and it can also help to ensure that the hospice is making the most of their contributions. Although this approach may be challenging to manage, with training, support, and planning, it would be rewarding for both volunteers and hospices (Johnson, 2015; Vanderstichelen et al., 2018).

Some volunteers appeared to ‘thrive’ when deeper engagement was facilitated, whereas others wished for their voluntary status to be respected for what they were able to offer. Consideration of how volunteer involvement in decision-making could be successfully implemented would be needed on an individual basis, rather than a generalist, one-size-fits-all policy (Brudney & Sink, 2017). In most employment settings, paid staff have annual reviews where employees and employers consider how to best utilise their skills, knowledge, and experience. Staff appraisal has been linked with individualised development, staff satisfaction, and is a source of personal motivation (Anstey et al., 2017; Dangol, 2021; Majidi et al., 2021). Challenges may occur when attempting to directly apply paid staff appraisal approaches to volunteers, which may be regarded as too fixed, formal, and ridged. Consideration of the aim and intent of appraisals would be needed to ensure it is of benefit to all involved and for it to be worthwhile. Hospice management teams would benefit from gaining better understanding of their volunteer motivations, to help improve volunteer retention (Ward & Mckillop, 2011). Hospices need to recognise that volunteer motivations may develop and change over time as they grow in experience and awareness of the setting. Therefore, hospice leadership should regularly engage with their volunteers, asking about their motivations and development requirements to create deeper bonds between the volunteers and the hospice (Planalp & Trost, 2009).

The ambiguity of hierarchy can be challenging for volunteers to understand where they fit in wider hospice settings (Burbeck, Candy, et al., 2014; France, 2020). Within the research, the issue of where volunteers should be on the hospice organisational charts was discussed and volunteers were found not to be represented. If volunteers cannot see themselves represented in relation to paid staff, it may cause difficulty in understanding where they fit in the wider hospice structure. Linear styles of organisational hierarchies are often used within hospices and other healthcare settings, reflecting traditional approaches (Graham, 2003). Where to place volunteers in hospice hierarchical charts may be challenging due to the uniqueness volunteers bring. Doyle (2002) stated that every hospice needs to have an organisational structure and a clearly defined hierarchy of authority, adding that unclear reporting lines could confuse. Therefore, hierarchical structures should be presented visually by including the volunteer roles in hospice organisational charts. On scoping hospice organisational charts, I found that many hospices still do not represent volunteers on their organisational hierarchical charts. Some only included paid volunteer coordinators, but not volunteers, potentially creating further ambiguity.

Where volunteers were located on organisational charts was considered in the participatory action research. Whilst unintended, meaning may be attached by volunteers about where paid staff place them on hospice charts and other visual representations of hierarchical structures. Volunteers being at the bottom of charts may suggest to outsiders that this is where the hospice views them belonging. Challenges can arise from trying to find where paid staff and volunteers fit, recognising the differences between them but also the areas where they overlap and integrate (Bloomer & Walshe, 2020; Vanderstichelen et al., 2020b). Care is needed to prevent status conflict between paid staff and volunteers, which can occur through frustration about position ambiguity, leading to poor communication and decision-making (López-Cabrera et al., 2020). Hospices should think about where they represent volunteers on their organisational charts.

The participatory action research group and deliberative panel found that volunteers could be visually represented as surrounding the traditional hospice hierarchical structure (see Figure 7.1). Here, volunteers encompass paid staff, showing a more fluid understanding of volunteers, which is reflective of the liminal space that volunteers occupy between paid staff and others in the setting (Dixon-Woods et al., 2006; Vanderstichelen et al., 2020b).

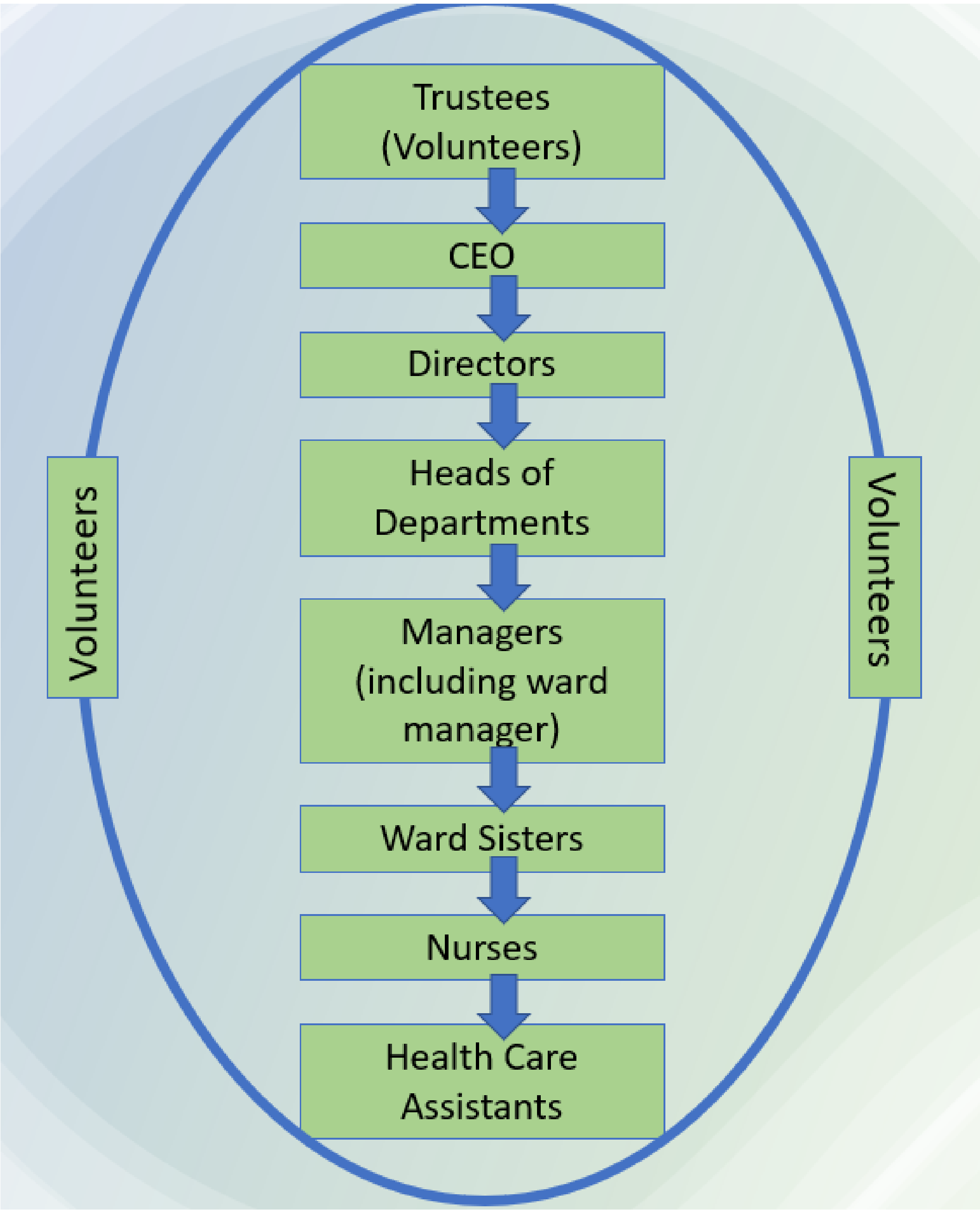


Figure 7.1: Where volunteers 'fit' in wider hospice hierarchical structures.

Regardless of the specific approach taken, several key challenges must be addressed when integrating volunteers into hierarchical structures. One challenge is to ensure that volunteers are adequately informed of and supported in understanding hospice hierarchies and structures. Inductions and training should "help [and] have a universal understanding of the philosophy, work, values, and role of the organisation” (Doyle, 2002, p. 84). Creating a learning culture in hospices needs to be developed and the contribution of both paid staff and volunteers need to be valued. Whole organisation learning is achieved through developing a shared understanding throughout organisations. Whilst team learning, leading to team decision-making may not be faster, it often results in better decisions, reflecting the wider complex nature of the whole organisation (Gill, 2010).

Within the participatory action research, the phrase “them upstairs” was used to describe a collective group of people who were believed to make decisions about how the hospice, and they were led. The hierarchical structure, often characterised by the metaphor "them upstairs," has been a prevalent feature of different workplaces for many years (Common et al., 2018). Within the research, the phrase was not only used in a metaphorical sense, but also to describe the physical structure of the hospice, which predominantly divided the building into the in-patient services, downstairs offices, and management upstairs. The division appeared to be a practical solution to the space provided but did create clear barriers and boundaries within the organisation. Some volunteers in the participatory action research group described the experience of occasionally going upstairs as an event, which seemed to be surrounded by mystery about what took place behind the doors. The sense of unknown about others, particularly those with positions of authority, appeared to create another layer of separation between them and others in the setting. At times, a sense of mystery within organisations can be helpful and as such should not be fully removed. Whilst mystery can interrupt free-flowing communication it also creates different opportunities within organisations (Meyer, 1996). This fits with a traditional model of leadership, where leaders should be separate and distinct from others in the workplace to enable them to lead effectively (Fiedler, 1957). However, whilst mystery may be beneficial in some larger organisations, within hospices, senior leaders having a sense of ‘being outside’ of what occurs with paid staff and volunteers could hinder empathy, which is a key characteristic of hospice care (Ricci, 2024).

Some workplace territories were seen within the participatory action research, as participants described boundaries and ownership of areas in the hospice. Territorial behaviours may lead to conflict and tension between colleagues when unseen boundaries are crossed (Ashkanasy et al., 2014). Open offices and single-level working have been common in some work environments for many decades, but this proliferated in many other working environments in recent years when cubicles were deemed too restrictive and closed offices for management were often seen by some as too hierarchical (Ashkanasy et al., 2014; Hedge, 1982). Open offices do not suit all working environments, as at times they have the opposite effect intended, causing reduced communication due to prohibiting private discussions (Brennan et al., 2002). This may be relevant for hospice settings, which often involve highly sensitive and confidential information to be discussed. New hospices or those rebuilding can imagine and create architectural ideals (Verderber & Refuerzo, 2019; Worpole, 2023). However, many well-established hospices are often restricted by building and financial constraints on how available space can be changed and considered compared to large profit-generating organisations (McLaughlan & Kirby, 2021). Consequently, alternative ways of normalising upstairs and downstairs need to be introduced through frequent interaction between the different groups. Greater integration of upstairs and downstairs teams could be encouraged by finding neutral spaces that do not belong to either group.

7.3 Creating meaningful opportunities for paid staff and volunteers to mix

The importance of the break room and its accessibility to all in the hospice building, became apparent throughout the participatory action research. The participatory action research group sought to explore ways that paid staff and volunteers, as well as those "upstairs" and "downstairs" could mix, whilst also trying to do so without the dominance of one group. Finding neutral spaces for paid staff and volunteers to be together out of the sight of hospice users was a valuable way of fostering relationships. Break rooms can be a space that "twists the hierarchy of a workplace" and develop a shared experience, confirmed using the term 'our' when discussing this space (Peteri et al., 2024, p. 47).

Discussions by paid staff about patients were found to cause discomfort for volunteers using the break room, as this was believed to be information they should not listen to. Break room users should not behave in the space as if they were in a meeting, as work-related activity would be “bizarre behaviour” which could disrupt break room customs (Peteri et al., 2024, p. 52). Often break room etiquette relates to cleaning and tidying spaces. There is potential that break room rules could also help explain the intent and way the informal space should be used to cultivate non-work-related discussions and deeper relationships between paid staff and volunteers.

Different people have different ways of resting, whilst some benefit from spending time socialising and talking, others may need time on their own (Hills & Argyle, 2001). Needing space is particularly relevant in the hospice environment, which can be emotionally challenging and complex. Consequently, whilst having shared space was seen in the research as a positive step towards building relationships, it was also acknowledged that alternative spaces should be available without pressure or obligation to socially interact with others. Historically, nursing staff have made use of linen or sluice rooms on wards when needing to get away from emotionally challenging situations. These small, cramped, and often unpleasant spaces were not ideal but provided a brief moment to re-gather and prepare for going back to a public space (Kirk et al., 2022). During COVID-19 there was a rise in the number of healthcare organisations providing ‘wobble rooms’ for paid staff and volunteers who were finding the pressures of care overly demanding and needed space to escape (Blake & Dennis, 2021; Rahane & Alam, 2024). Many of these spaces included psychological and well-being support if individuals wished to access it (Blake & Dennis; Veitch & Richardson, 2020). Whilst these safe spaces were highly utilised during COVID-19, there is an ongoing need for paid staff and volunteers to have space to deal with the ongoing emotional labour demands of being in a hospice environment, either together or alone (Maben & Conolly, 2024).

Break rooms often have the primary aim of resting, eating, and drinking, with a secondary ‘side-effect’ of creating a space for interactions between users. Swedish culture has sought to intentionally cultivate social relationships through the tradition of Fika, which has been described as a ‘social lubricant’ and is an uncomplicated meal, often involving coffee and cake, taken with others (Nilsson, 2022). In Swedish workplaces Fika often occurs twice a day for all staff, where there is no agenda, and ‘small talk’ is encouraged. These gatherings aim to be non-hierarchical and are different from common tea breaks, which are part of many workplace settings. Fika culture sees food and drink as secondary to the main goal of creating and reinforcing relationships between people (Blom, 2024; Nilsson, 2022; Yngve et al., 2023). Some other countries (including the UK) and organisations are now slowly introducing Fika into their practice, which is often ad-hoc or weekly (Wettermark, 2024). At present, whilst much of the evidence on the benefits of Fika outside Sweden is anecdotal, personal experience of Fika suggests that there may be scope for its use in hospice settings. Consequently, further research exploring how Fika impacts the working relationships of paid staff and volunteers in hospice settings may prove beneficial.

Within the participatory action research Schwartz centre rounds were already in use within the hospice. When these were conducted face-to-face, they were beneficial and a positive way of getting to know others at the hospice. Schwartz centre rounds were developed in America in the 1990s to give healthcare staff the opportunity to reflect and share their experiences (Lown & Manning, 2010). One description of the benefit of Schwartz centre rounds in a UK hospice stated that they felt like a little part of a jigsaw puzzle, but through accessing Schwartz rounds they got to see all the other parts of the puzzle to get the whole picture (Reed et al., 2015). The choice of metaphor reflects that used within the participatory action research, describing volunteers as an important piece of the hospice jigsaw. Therefore, the use of Schwartz centre rounds appears to be a way of encouraging paid staff and volunteers to build a deeper understanding of how they fit together to provide care within hospices (Goldberg & Galchutt, 2024).

Schwartz centre rounds and other forms of storytelling were found to help build a sense of belonging to the wider hospice. Storytelling enables groups involved in difficult situations, such as those faced at hospices, to make sense of what happened together (Liddington &

Morrison, 2024). Storytelling enables groups to develop a sense of connection related to "feelings of trust, empathy and solidarity." Individuals can connect through the stories they tell, creating bonds with others as they recognise the similar experiences others share (Richardson & Wilson, 2024, p. 6). Storytelling can help to find similarities between people from different backgrounds, making deeper connections by narrowing communication gaps between different groups (Sharma, 2019). Paid staff and volunteers joining together in Schwartz rounds and having other opportunities to share stories, both face-to-face or through written shared stories could create bonds through recognising shared experiences and mutual understanding of the hospice.

Face-to-face Schwartz centre rounds were found to be helpful, although the research also showed that individuals often identified online meetings as challenging. This was particularly true when emotion or feelings were expressed. While online meetings could help deliver information, they could equally get in the way of developing empathy for others (Tammaru, 2024). Many workplaces have changed, particularly since COVID-19, where organisations engaged with virtual methods of meeting and collaboration in new ways. Initially, many struggled with the change and found it a steep learning curve to adapt to working away from others. As time progressed, virtual working became the 'new norm,' highlighting the potential for cost and time savings long term (Döring et al., 2022). Many workplaces have now adopted hybrid working, creating a mix of home and face-to-face working (Shirmohammadi et al., 2022). Whilst benefits and ease are acknowledged, it also appears that something of the personal relationship with others has been lost.

The term 'lurking' in online meetings has been used to describe when individuals do not put their cameras on in meetings (Karl et al., 2022). This may be felt by some to be a sign of disinterest and non-engagement; however, others find that constantly fixing a gaze at the screen is exhausting (Beyea et al., 2025). There is potential that collaboration and opportunities to meet and engage with different people have been impacted by working online (Adisa et al., 2023). Some workplaces have tried to introduce online social spaces for colleagues to meet, including online Fika (Schützler & Reis, 2021). However, challenges were found, such as the use of same desk for work and social time, which prevented participants' ability to fully separate the two. The term 'Zoom fatigue' has been used to describe the physical and mental exhaustion caused by constant online working (Döring et al., 2022; Karl et al., 2022). The implications of 'Zoom fatigue' may include reduced productivity due to lack of engagement (Lim et al., 2025). In response to this, the management team at Amazon mandated that all staff return to on-site work to aid invention, collaboration and increase connections (Espiner, 2024). Many workplaces have introduced hybrid working, creating greater flexibility and choice in where and how people work. However, loneliness and isolation can still occur for hybrid workers. Consequently, managers will need to regularly assess staff to ensure they feel a sense of belonging and connection (Urrila et al., 2025).

Throughout the participatory action research, working from home was described as a barrier to relationship-building with others. Previously, paid staff and volunteers would build familiarity by seeing each other around the building or they would be able to drop into someone's office if they needed to ask a question. Due to the increase in hospice paid staff working from home the 'incidental' opportunities to mix decreased. Researchers have explored the benefit of 'water cooler moments,' the times when unintentional, unplanned conversations happen that facilitate relationship-building with others (Waring & Bishop, 2010; Wu et al., 2011). It has been discussed that informal face-to-face interactions help others notice social cues that would be otherwise missed online (Wu et al., 2011). Therefore, whilst online and home working can be helpful, it cannot replace the benefits of face-to-face contact with others for relationships, creativity, and communication.

7.4 The impact of silos on working relationships within hospices

The Participatory Action Research group examined how working in silos at the hospice affects the consistency of support provided to staff and volunteers across teams. Silos prevented sharing best practices and having an overall awareness of what was happening at the hospice.

This was particularly relevant in how different teams inducted their volunteers into the hospice, as there was some concern over inconsistency and lack of opportunity for teams to share best practices. Breaking down established team processes proved challenging, largely due to issues with information sharing and understanding the impact of actions on others. Silos often emerge if individuals or individual teams view their own goals as more important than those of an organisation as a whole. Silos can lead to power struggles, creating poorer cooperation and willingness to work with other teams (Stone, 2004).

Some separation was found between 'them upstairs' and between different teams within the hospice. It was evident that the hospice leadership had made attempts to reduce vertical silos (between upstairs and downstairs) through senior leaders spending time shadowing different teams. However, horizontal silos (between different teams) were still apparent and at times prevented different teams from knowing what others were doing or the rationale behind it. Whilst silos cannot always be avoided, senior managers should monitor and intervene when, or if, conflict occurs between different groups (Jones et al., 2024; Pedersen et al., 2024).

I personally found that it is easy to unintentionally form silos, when I became concerned that I had *"stepped on another team's toes"* by failing to communicate the participatory action research group's intentions effectively. Failure to share information may have created an amount of mystery about the group to others in the hospice who may have wondered what we were doing and why. Silos promote misunderstandings, reduce collaboration, make achieving tasks harder, and create possible over-lap or waste (Gill, 2010; Willcock, 2016). "Collaborative groups allow co-workers in all departments and at all levels of expertise to ask questions, share information, and tackle significant problems." Through intentional collaboration, silos are broken down and communication improves (Proman et al., 2019, p. 24).

Over the year, the group built an identity and shared understanding of terms, vision, and intent. Thus, demonstrating the ease of inadvertently creating micro-cultures within wider cultures and teams in hospices and other organisations. Individual teams often develop their own language, terminology, or understanding of what they do, which is not always shared with the wider team (Stone, 2004). Sharing information and full openness in hospice settings can be challenging due to teams managing personal, private, and highly confidential information. Sharing confidential information with those who do not have an essential need to know it would be highly inappropriate. Consequently, there is an automatic restriction on fully open communication between teams and individual roles. Bureaucracy and 'red tape' may be contributing factors to silos in healthcare (Jones et al., 2024). Paid staff at times may have restricted the information shared with volunteers about patients/residents, creating negative feelings that volunteers were not trusted (Elliott & Umeh, 2013; Field-Richards & Arthur, 2012; Stølen, 2021). Teams need to build greater levels of trust between both vertical and horizontal teams as a way of reducing silos, which should be led from 'the top' (Jones et al., 2024; Stone, 2004).

Micro-cultures can, in extremes, take on some characteristics of gangs. Whilst this may not go to the extent of 'gang wars,' it may lead to teams 'jibing' against others, so further exacerbating separation and silos (Cilliers & Greyvenstein, 2012; Stone, 2004). Silos may create their own version of the truth based on what they believe to be happening in other teams. Teams in silos may think that others are being consulted about changes or part of something that they are not, adding to feelings of 'them and us.' A united front may be presented to 'them upstairs,' even if there are issues between individuals 'below stairs,' again highlighting the separation between groups (Powell, 2011). People may feel threatened by 'them' when a bigger vision is missing (Cilliers & Greyvenstein, 2012). Building a greater sense of collective responsibility can help to reduce silo mentalities (Elkjaer et al., 2021). This could be achieved by ensuring all individuals at the hospice, including paid staff and volunteers at all levels, are given ample opportunity to fully connect with the hospice values and vision.

The hospice vision terminology was not always fully understood by all paid staff and volunteers. The phrase intended to show a desire of the wider hospice to be a united team and to avoid silos. However, due to a lack of understanding of the terminology, it was unclear if this was an aspiration of unity or what senior leadership at the hospice believed was already happening. Hospice paid staff and volunteers would benefit from having a greater shared understanding of the hospice, helping create a further sense of being part of something bigger and connections to others. Having a clear understanding of the vision helps to give direction and cohesion, but commitment from leadership is also necessary to achieve the vision and goals (Gill, 2010).

Individuals will develop greater attachments to the hospice when they can incorporate the hospice vision into their own values. As Kim et al. (2010, p. 413) add that "when a person's self-concept contains the same attributes as those in the perceived organisational identity, this cognitive connection is defined as organisational identification. Organisational identification is one form of psychological attachment that occurs when members adopt the defining characteristics of the organisation as defining characteristics for themselves." For integration to be possible, individuals need to have a sound understanding of what they are identifying with.

There is potential that the term 'integration' should be challenged, as it suggests that individuals need to 'fit in' to the dominant culture (Covarrubias, 2024). As previously discussed, volunteers hold a liminal space and uniqueness that can be beneficial and add another dimension to hospices. For some, there is a tension between wanting to be similar to others and wanting to be different. The tension between the desire for belonging and individuality can foster innovative perspectives and approaches, challenging the status quo and over-acceptance of 'that is how *we* do things' (May, 2011). At times, solidarity theory is misunderstood or overly simplified as only being concerned with group identity without considering individuals. Within this view, individual thought, perspectives and understanding may be lost in the search for creating shared goals and vision (Sangiovanni, 2015). However, the reverse is often considered, as solidarity theorists view individuals as the foundation and base of society. Encouraging individuals to develop their skills, talents and understanding would be beneficial overall by each focusing on their strengths (Nickerson, 2024). Consequently, whilst hospices should ensure that all volunteers and paid staff understand the vision, in order to prevent misunderstanding and the original intent being lost, individual groups should also be able to maintain their own identity.

Individual hospices need to foster relationships with other hospices to help them to share best practices and learning. Hospice networking increases the sense of being part of something bigger. It has been previously noted that there is significant variation between hospices across the world and within the UK, including how they involve volunteers (Howlett, 2018; Scott, 2018). The aims of organisations such as Hospice UK (2025) and The European Association for Palliative Care (2025) are to support members and hospices to deliver the best care and support them to 'thrive,' and make sure they have the support and encouragement to share knowledge and learning, creating a community of collaboration. Therefore, increased networking for hospices would help to reduce silos between hospices, whilst also retaining the individual characteristics that make each hospice unique (McGivern, 2009; Röwer et al., 2024).

7.5 Building a sense of mutual belonging for paid staff and volunteers

The term belonging is commonly use in research; however, the researcher's original meaning of belonging is often assumed, without full explanation of their understanding being given. Belonging has been described as an 'emotionally loaded term,' particularly as it can be challenging to describe (Antonsich, 2010; Bennett, 2013, p. 25). Often belonging is linked to a sense or feeling that is related to connectedness to people or places (Allen et al., 2021). As belonging is often based on subjective feelings, it has been thought that it is not fixed and therefore can shift or be lost (Covarrubias, 2024). This idea that belonging is not a constant state is important when considering the relationships between paid staff and volunteers. Consideration of how a sense of belonging can be encouraged and maintained in a hospice may help develop deeper feelings of connection between paid staff and volunteers (Andersson & Ohlen, 2005; Coleman et al., 2022).

It is possible to be a fully established member of a team at a hospice, with sound knowledge of their role, and yet feel that they do not fully belong. There may be situations and encounters between paid staff and volunteers that may either create feelings of isolation or belonging (Sadler & Marty, 1998). It was interesting to note that some participants seemed to suggest that it was harder than others to feel integrated into the wider hospice team and to feel part of the hospice. There appeared to be a distinction between what they did and what was felt. Feelings of belonging are more than just related to being 'old guard' and the length of time someone is at the hospice, but more to do with connections and relationships. For individuals to feel a sustained sense of belonging within a community they need to have ongoing interactions with others (Painter, 2013). However, for belonging to happen within groups, relationships need to be frequent, face-to-face, long-lasting, stable, and significant (Antonsich, 2010). Therefore, within a hospice setting, paid staff and volunteers need to have opportunities for regular and meaningful interactions with each other. Again, this suggests that working from home would make building a sense of belonging more challenging, needing more creative ways to manage relationships within hospice settings.

Volunteers described times when they were not expected at the hospice by paid staff. Whilst participants stated they were not overly affected by this as they were confident in how to manage the situation, not being expected may have led to feelings of not being welcomed by less confident volunteers. An individual's sense of belonging is not just their choice, as they also need to be accepted or recognised by others (Bennett, 2015). Some concepts of belonging regard people as active participants in society (May, 2011). Belonging requires active involvement from both paid staff and volunteers, with staff knowing and expecting volunteers on the ward and equally, volunteers being willing to initiate conversations when they arrive at the hospice.

The participatory action research group explored the role that names have in fostering a sense of belonging and the potential consequences of neglecting or misusing them. The core change that the group wanted to introduce was related to knowing the names of paid staff and volunteers as they deemed it to be important for improving the working relationships between paid staff and volunteers. Furthermore, this change was connected to developing a greater sense of belonging, both to the wider hospice and to each other. “Belonging is appropriate for describing group membership, whereas bonding is preferable when discussing close attachments... belonging, in the sense of fitting in with others”(Lambert et al., 2013, p. 1427). People want to ‘be seen, be known, and be included’ (Kim, 2023). Being seen and recognised by name can help group members feel included and acknowledged.

Knowing names and the correct pronunciation is important within teams, as names serve as a unique identifier that connects an individual to their identity, culture, and community. It is a symbol of belonging, a way to affirm an individual’s place in the world. Names are deeply personal and so when individuals are addressed by their correct name, they feel respected, valued, and acknowledged (Najjar et al., 2023). Recognition can have a profound impact on individuals' self-esteem and their ability to connect with others. Not knowing someone's name or mispronunciation of names can lead to feelings of alienation and exclusion (Carter et al., 2023). Teaching and education research shows that not knowing or mispronouncing names can be harmful to student learning and feelings of belonging (Pilcher et al., 2024; Sok & Bonnett, 2022). This can also extend to other settings to indicate who belongs and who does not belong in a particular environment. Knowing the names of paid staff and volunteers can be linked to feelings of being respected and valued in a space (Ruedas-Gracia et al., 2022). When paid staff and volunteers are addressed by their correct and preferred names, they feel more connected to their colleagues and the wider organisation, leading to increased work and role satisfaction and lower attrition rates (Lynch, 2000).

Whilst not belonging or having a shared identity is often thought of only in a negative way, there is potential that differences can become more proactive and productive as it creates questions as an outsider that those inside could not see (May, 2011). I was an outsider to the hospice, so due to my different perspective, I could question how and why the hospice supported the working relationships between paid staff and volunteers in a unique way. There appears to still be a benefit of outsider researchers working with hospices to explore internal issues, such as the relationships between paid staff and volunteers to challenge seeing what could be, rather than just what is (May, 2011).

7.6 Contribution to knowledge

This study contributes to the volunteer and workforce knowledge base in palliative care research by developing knowledge and understanding of the impact of hierarchical relationships between paid staff and volunteers in hospice environments (see Figure 7.2). Those in senior positions in hospices can have a significant influence on how volunteers are perceived in the organisation, by acting as role models for other paid staff to follow. Through conducting the study, I was able to consider the interaction between paid staff and volunteers in shared spaces that foster relationships enhancing their collaborative effectiveness. Hospices need to observe for unhelpful silos being created within teams, which can form barriers to effective communication, wider hospice working relationships, and creativity. Both paid staff and volunteers need to understand where and how they 'fit' in hospice teams and the wider hospice organisation to develop their own sense of belonging. Feelings of belonging are not static and can be fluid, therefore individuals and hospices should continually work at maintaining and building opportunities to develop a joint identity within the hospice.

The collaborative efforts between paid staff and volunteers can be a powerful force for positive change within hospices. Volunteers often have unique experiences and backgrounds that can provide fresh insights and ideas. While each group offers different skills and perspectives, the combined efforts of paid staff and volunteers can often lead to increased efficiency, innovation, creativity, and overall effectiveness. As well as benefits to the workplace, there are more personal improvements such as well-being, feelings of value, worth, and belonging. However, whilst there are many positives, there were also challenges that have been explored within the participatory action research, which sometimes lead to misunderstandings and potential for conflict. One challenge was the perceived power imbalances between paid staff and volunteers and thoughts about hospice hierarchies. Paid staff may be viewed as having more authority or influence within the organisation, which can sometimes lead to feelings of exclusion among volunteers. It is important to address these power differences and ensure that both paid staff and volunteers feel mutually valued and respected.

I have created a visual overview of the main motivations, facilitators, benefits, and barriers that have been explored throughout this thesis (figure 7.2). I have sought to visually represent how each the ways that each factor influences each other and are interconnected, all originating from the way individuals (both paid staff and volunteers) think and feel about their own experiences with others and the wider hospice. Consequently, the impact of the main concepts have been shown on an individual basis (including both paid staff and volunteers), on joint relationships between paid staff and paid staff, the impact on the hospice as an organisation, and on how the hospice engages with the wider hospice community. The image depicts that the whole thesis (both in the meta-ethnographic review and participatory action research) has been influenced by solidarity and critical theories.

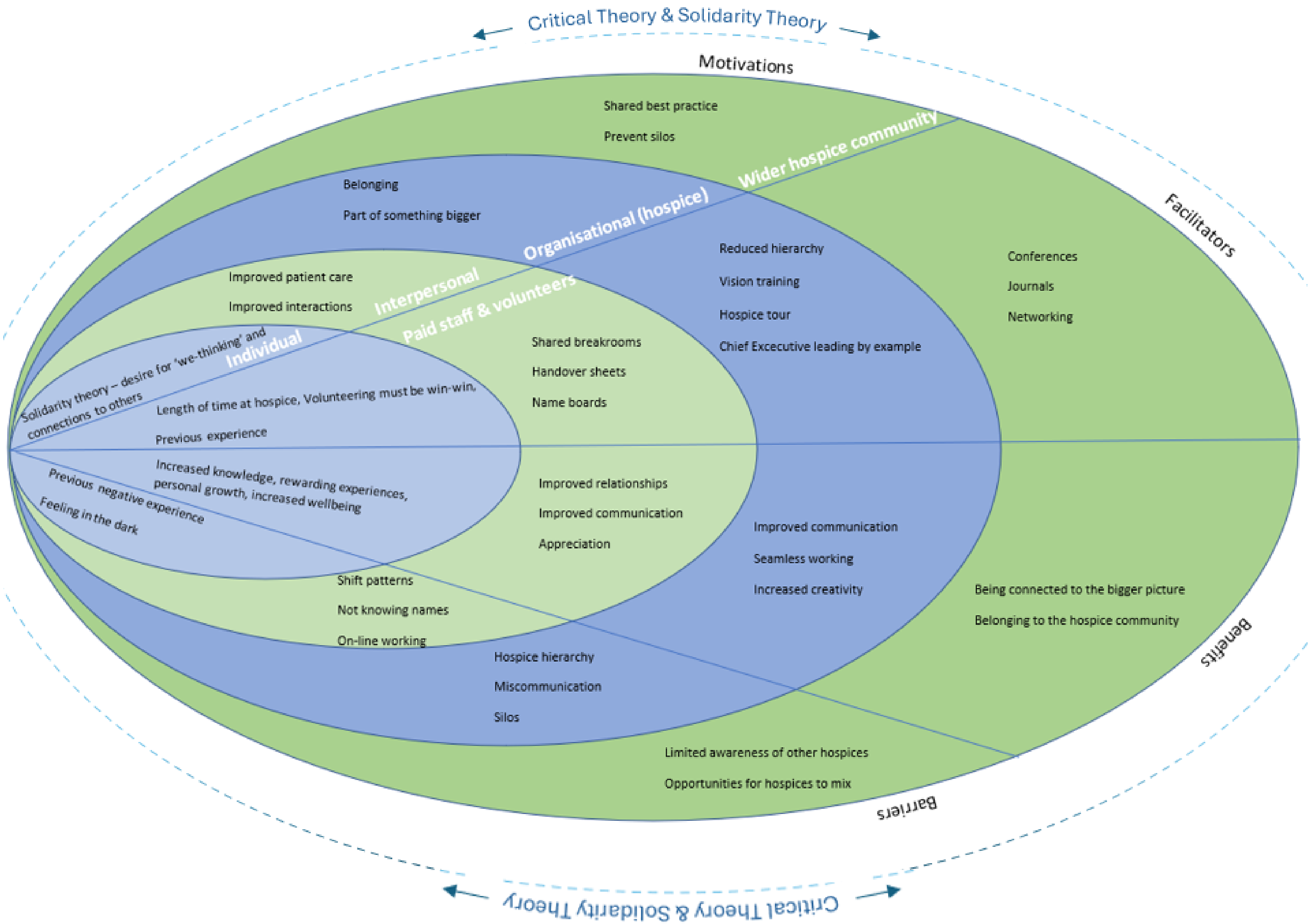


Figure 7.2: Image showing an overview of the impact of the key themes of the thesis for individuals, interpersonal relationships (paid staff and volunteers), the organisation (hospice), and the wider hospice community. Adapted from Strkljevic et al. (2024)

In this chapter, I have situated four key themes within the context of wider, relevant evidence. Discussions explored ways volunteers can be involved and integrated into hospice power and hierarchy structures. Approaches to creating meaningful opportunities for paid staff and volunteers to mix were considered. I reflected on the impact of silos on working relationships within hospices and how this may also influence how hospices engage with the wider hospice community. Lastly, I explored ways a sense of mutual belonging for paid staff and volunteers can be developed.

Chapter 8. Implications for practice, policy, and research

I have found that participatory action research is a positive research approach to help an individual hospice to create a 'mini revolution' in their setting and support transformation, which was beneficial for both paid staff and volunteers (Herczeg, 2023). There is need for wider 'evolution and revolution' in hospice settings seeking to support, encourage and retain both paid staff and volunteers. Consequently, further research is recommended to take even more bold steps in development and trailblazing in different areas (Bleakley et al., 2019). In this chapter I consider the implications of the wider evidence base discussed in the introduction and background chapters, the meta-ethnographic review, and the participatory action research, for practice, policy and guidance, and further research. The chapter concludes with an examination of the research's strengths and limitations.

8.1 Implications for practice

1. **Including volunteers in hospice meetings of both paid staff and volunteers – lessening the hierarchical gradient:** As hospice settings become more dynamic, collaborative, and innovative, alternative models may emerge that offer greater flexibility and empowerment for both paid staff and volunteers.
2. **Including volunteers on hospice organisational charts:** This is recommended to show where volunteers 'fit' within hospice hierarchies. Volunteers are usually shown in a lower position in hierarchical images, which does not show how volunteers see themselves or how they would want to be seen by others. Volunteers need to be visible as a core part of hospice teams, rather than tagged on.
3. **Introducing formalised, structured, and individualised annual reviews for volunteers:** Hospices should support volunteers to flourish in their personal development, which would be beneficial for both individuals and the hospice. Recognising the individual experience, skills, and knowledge that many volunteers

have, rather than having a blanket approach to where and what volunteers can be involved in.

4. **Holding regular vision days for both paid staff and volunteers:** When changes are made, or wording altered within the aims and vision of the hospice, a clear explanation of intent is needed to avoid misunderstanding of meaning. Explanation of vision should not only occur during induction but at regular intervals where there is an opportunity for all paid staff and volunteers to discuss them.
5. **Creating neutral, non-hierarchical shared spaces for volunteers and paid staff to meet:** Whilst online working has many benefits, interactions aimed at building relationships, such as Schwartz centre rounds are more effective and beneficial for improving the working relationships between paid staff and volunteers when they are face-to-face. There is potential to take this one step further and introduce Fika in hospices where the aim is to develop conversation and relationships.
6. **Introducing regular 'health checks' in teams to consider the working relationships between teams, between paid staff and volunteers, and the wider hospice:** Conscious reminders for teams to give regular consideration to the risk of silos developing should be made. Reminders may consist of regular information on potential risk factors and recommendations to remove barriers between groups.
7. **Photographic name boards for both paid staff and volunteers:** Knowing others and being known by name was found to be a key element of building a sense of belonging to each other and the hospice. Finding ways to help paid staff and volunteers to recognise each other and to use their names would help to foster a sense of belonging, build stronger relationships, and create more inclusive environments.
8. **Local hospices reducing silos between themselves and the wider hospice community:** Hospices intentionally joining together creates a greater sense of belonging to the wider hospice community and enables them to feel part of something bigger. This would encourage hospices to share best practices on the working relationships between paid staff and volunteers in different settings.

8.2 Implication for United Kingdom and local policy and guidance

1. **National policies and guidelines need to show volunteers in clearer and more explicit ways:** The World Health Organisation (2020) state that a mix of both paid staff and volunteers is best for delivering effective palliative care. They recognise that their guidance needs individual adaption to each location and setting. However, while volunteers have been specifically named by WHO (2020) as a key part of an effective team, when applied to the UK setting some of the wording becomes less specific. Although recognised that volunteers should be involved, the specifics of how and where are not always clear. Some palliative guidance only discusses volunteers at the end, or in the appendices, rather than integrating them throughout the main guidelines. For example, the Ambitions for Palliative and End of Life Care discusses volunteer contribution is added to the end of Ambition 6 (National Palliative and End of Life Care Partnership, 2021). If volunteers are only at the end of guidance, it is not surprising that hospices echo this approach when representing volunteers. Hospices need to see in guidelines and policies where volunteers fit, so that they can interpret this in their local setting.
2. **Local policies and guidelines need to show volunteers in clearer and more explicit ways:** Volunteers value being able to see themselves in structures to see where they fit. Some UK guidelines separate information for healthcare professionals and 'others' or 'wider workforce' (Local Government Association, 2020; National Institute for Health and Care Excellence, 2019). Volunteers would probably fit under the non-specific categories; however, clearer word choices would remove ambiguity. There have been end-of-life care tool kits created for some UK counties, which include relevant information in one location. Whilst these are highly valuable, the information is separated into information for professionals or the general public without evidence of where volunteers would fit in (Derbyshire Alliance for End of Life Care, 2025a, 2025b). It may be helpful for future tool kits to also show applicable information for volunteers, recognising their valuable contribution to palliative care settings.

8.3 Recommendations for further research

1. **An ethnographic study, exploring different organisational hierarchical structures in a range of hospices:** This study could consider the rationale for choices and influencing factors that may enable the development of a greater understanding of where volunteers fit in hospices. Also, such a study could seek to determine whether there is a best way of representing volunteers in hospices through focus groups of hospice management, paid staff and volunteers.
2. **Participatory action research considering the introduction of Fika meetings in hospice settings in the UK:** I have found participatory action research effective in encouraging groups to have ownership of initiatives and to enable those directly impacted by the change to direct and make it their own. Participatory action research would enable those directly using Fika to determine whether it was fit for building the working relationships between paid staff and volunteers in their settings.
3. **Participatory action research exploring community palliative care services, looking at the working relationships between paid staff and volunteers:** The current research shows that face-to-face work and being in the same setting helps build relationships between paid staff and volunteers. Community palliative care settings may find these relationships and building a sense of belonging more challenging.
4. **An evaluation of the impact or effects of interventions addressing paid staff and volunteer relationships**. A trial of the name board introduced in this participatory action research in other hospice settings may be beneficial. Inclusion of pre-and-post trial questionnaires, exploring both paid staff and volunteers' sense of belonging and relationships would further evaluate its effectiveness in a wider context.

8.4 Strengths and Limitations

Strengths:

Using participatory action research, influenced by critical theory, enabled those directly impacted by the research to have an active role in it. It is believed that individuals engaging in the research process itself was empowering and insightful for their own development. The action research cycles were led by the participatory action research group, therefore the actions carried out were those wanted by them. They felt that the change they wanted would benefit the hospice by improving the working relationships between paid staff and volunteers. Group members learned critical skills and ways of introducing positive change that I hope they will continue to develop and draw on in the future.

Solidarity theory underpinned the study and can be seen in the group's development of relationships and bonds through meeting together over a year. The group developed 'we-thinking' as they formed group identity, support, and understanding. However, the group also valued and acknowledged individual identity and contributions which was also congruent with solidarity theory.

Whilst the aim was not to create generalisable findings, I believe that there are insights that may help other hospices understand some of the issues and challenges related to the working relationship between paid staff and volunteers. It is hoped that this study will give other hospices a different starting point and insight to further their own work in improving these important relationships.

Members of the participatory action research group were emailed the presentation given to the deliberative panel in advance and given the opportunity to comment and confirm if this was a 'true' representation of the research. All individuals who had quotes and comments included in the final analysis were emailed, offering them the opportunity to review and discuss the research report if they wished. Meetings were held with stakeholders at the hospice who wanted to discuss the research analysis, findings, discussion, and recommendations.

Some of the recommendations made during the participatory action research group have already been actioned by the hospice, including changes to the induction process for volunteers. Also, face-to-face vision days for both paid staff and volunteers have been re-introduced. The speed at which positive change can be made through participatory action research again shows the strength of this process.

I am grateful for the support from a palliative care research group and a participatory research network that has allowed me to join in their meetings and share knowledge and insight that has influenced this participatory action research. The informal input from these external groups has helped to add different perspectives and advice, adding additional rigour to the study.

Limitations:

During my PhD studies there are aspects of the research that I have now learned that would have been helpful for the project. For example, I believe that sharing the leadership of the participatory action research group meetings with other group members earlier on in the research process, may have been a further way of empowering individuals. Negotiating the power balance within the participatory action research group took time to establish. Originally, some of the group felt that I should lead and direct the project as it was felt that it was my project, due to being an academic. However, after discussion with the group and further explanation of the aims and intent of the group to share power and ownership, time, and developing ideas, the power felt more equally shared.

This project specifically looked at the working relationships between paid staff and volunteers. Consequently, engaging a patient advisory group would have involved the patient's voice in the project and would have provided another level of quality assurance as the participatory action research group would have been able to ‘test’ our ideas and processes. This is a step that I will aim to integrate into future studies I am involved in.

I occupied my own liminal space between being an ‘outsider’ as a researcher, who did not work at the hospice, but with ‘insider’ knowledge and influence due to previously working at the hospice. McIntyre (2007, p. 8) added that academics involved in participatory action research who are also practitioners need to continuously make decisions about how these different roles are managed and negotiated. Consequently, I was aware that I had my own assumptions as a hospice nurse about the hospice that needed to be questioned and challenged throughout the project.

This study was situated in one single site to enable depth and breadth of insight; however, the addition of a second sight might have added another level of knowledge and comparison.

8.5 Summary

In summary, my research has yielded several recommendations for practice, policy and guidance, and future research. I have found that successful working between paid staff and volunteers providing palliative care should not be taken for granted. Proactive and intentional engagement, encouraging interaction between paid staff and volunteers is needed. Individual and organisational responsibility is important to help the role of volunteers in hospices to be ‘win-win’ within hospice settings. Both paid staff and volunteers need to be known and recognised to create a deeper sense of belonging to each other and the wider hospice. Volunteers need to be meaningfully involved and visible throughout hospice teams to help them see where they fit in the hospice context. Hospices should encourage mutually beneficial relationships between paid staff and volunteers, with senior management leading by example. In this study I have demonstrated how participatory action research, guided by critical theory and solidarity theory, can help to explore the working relationships between paid staff and volunteers in a hospice setting.

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Appendix A Meta-ethnographic review

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Review Article

A Meta-Ethnographic Review of Paid Staff and Volunteers Working together in Palliative Care

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Abstract

Context. Volunteers in palliative care settings are an essential part of care provision for patients and those important to them. Effective collaboration between volunteers and paid staff has been regarded as an important element of successful working, however, at times failures in coordination, information sharing and tensions within teams have been highlighted.

Objectives. To explore the views expressed by volunteers and paid staff about their experiences of working together in palliative care settings.

Methods. A systematic exploration of qualitative research using a meta-ethnographic approach. PsycINFO, CINAHL, Medline Complete, and AMED databases were searched from inception to December 2021 for the concepts "volunteers" and "palliative care." Repeated in-depth reading and appraisal of papers identified metaphors and concepts, providing new interpretations.

Results. Included papers (n = 14) enabled the construction of five storylines: 1) "we are the cake, and they are the cream": understanding the volunteer role—separate, but part of a whole. 2) "...we don't know what's wrong with people but sometimes we need to know": access to information and importance of trust. 3) "everybody looks out for each other": access to paid staff and their support. 4) "...we don't meddle in the medical": boundaries. 5) "it's the small things that the staff does for me that makes me feel good about my work": sense of value and significance.

Conclusions. For effective working relationships between paid staff and volunteers, proactive engagement, recognition of each other's role and contribution, mutual sharing of information, and intentional interaction between both groups is needed. J Pain Symptom Manage 2023;66:656–670. © 2023 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY license (http://creativecommons.org/licenses/by/4.0/)

Key Words
Palliative care, volunteers, health personnel, collaboration, meta-ethnography

Key Message

This systematically constructed meta-ethnographic review identifies that successful teamwork between paid staff and volunteers requires consideration of what palliative care teams are and who they should include. Also, the importance of intentionally building relationships between volunteers and paid staff should not be taken for granted to prevent potential relationship problems.

Introduction

There is a long history of volunteers working in palliative and end of life care; however, their role is

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continuously changing and evolving. Volunteers frequently become involved in providing practical and emotional support to patients and their families, also acting as an important link between them and the various healthcare teams.[1,2] However, the role of volunteers connected with palliative care is often challenging to quantify. Often volunteers are able to make a unique contribution due to their unpaid role, and in this way, they are often able to complement the work of paid staff.[3] The involvement of volunteers in settings providing palliative care is regarded as a vital part of the care provided to patients and those important to them.[1] However, the relationship of volunteers with other team members, including paid staff, providing palliative care has at times been reported to be challenging.[4] Whilst collaboration between volunteers and paid staff team members has been highlighted as an important element of successful working, volunteers have commented that at times failures in coordination and tensions within teams may lead to them not being able make an effective contribution.[5, 6, 7] Volunteers have reported that they felt they received insufficient information to prepare them for patient contact.[8] Furthermore, the information volunteers deemed to be helpful to be able to successfully fulfil their role differed from what staff gave or thought necessary for them to know.[9] Volunteers and paid staff have both suggested that greater opportunities for contact and integration between teams would be beneficial to improve their working relationship and understanding of each other's needs.[9]

Previous reviews looking at volunteers in palliative care settings have tended to focus on the role of volunteers and their experiences, with only elements of the findings discussing volunteer relationships with the wider healthcare team.[10,11,12] However, no qualitative reviews had been found that specifically explored the way paid staff and volunteers work together when providing palliative care. This is an important contributing factor in the effectiveness and satisfaction of volunteers.[9] Previous literature review recommendations have been for further research into improving communication and co-operation between paid staff and volunteers.[12] A meta-ethnographic review is an appropriate method for exploring this phenomenon as this approach seeks to "derive substantive interpretations" that may be seen as a complete and standalone study.[13] Consequently, the purpose of this meta-ethnographic review is to develop a deeper understanding of the views expressed by volunteers and paid staff about their experiences of working together in palliative care settings.

Methods

This systematically constructed review follows the principles of meta-ethnography, and the methods are reported below according to the seven phases of metaethnography.[13] This review is reported in line with the eMERGe guidelines on improving reporting in meta-

ethnography.[13,13]

Phase One: Selecting Meta-Ethnography and Getting Started

The aim of this study was to explore the views expressed by volunteers and paid staff about their experiences of working together in palliative care settings. Meta-ethnography was chosen as the method to enable a robust way of exploring these experiences and developing an understanding of this social phenomena.[11] Meta-ethnography also enabled the researcher to retain the context and meaning of the original participant's and author's voices, which was deemed to be important in developing new understandings of this relationship.[14] Within meta-ethnography this is achieved by translating, transferring concepts, metaphors and understanding across selected studies through a seven-step process (Table 1).[13]

Phase Two: Deciding What is Relevant to the Initial Interest

Based on the aim of the study, the review question was constructed: How do volunteers and paid staff working in palliative care settings describe their experiences of working together?

The Literature review question was developed and guided by using PICo (Population, Intervention, Context) (Table 2).

Search Strategy. A search strategy was developed with the advice and guidance from a Lancaster University librarian who has specialist subject knowledge of health research. PsycINFO, CINAHL, Medline Complete, and AMED (The Allied and Complementary Medicine Database) databases were searched since the beginning of the databases up to the December 5th, 2021. These databases were selected to give a range of allied health and nursing perspectives, also the inclusion of databases that consider palliative and multidisciplinary approaches. Search terms such as "volunteers" and "palliative care" were developed with MeSH terms and other synonyms to capture potentially relevant papers for this review. The use of phrase searching was also used in the searches and words were truncated to ensure that variations of words were not excluded. Medical subject headings (MeSH) were modified according to each database which were used in combination with free-text search terms to build a comprehensive search approach. Database limiters were applied to only include academic journals, written in English language, and peer reviewed. Boolean operators (AND, OR) were used as they are beneficial in

Table 1
An Overview of Research Process of Meta-Ethnography

Phase of Meta-Ethnography (Phases May Overlap and/or Run Parallel)	Purpose and Requirements of the Phase
Phase one: "getting started'	Identifying an area of exploration in which qualitative research can be employed to inform. This aims to find something which is worth studying through meta-ethnography.
Phase two: "deciding what is relevant to the initial interest"	Determining the studies relevant and of interest to the chosen area of exploration.
Phase three: "reading the studies"	In-depth reading and rereading of selected papers to begin identifying interpretive metaphors.
Phase four: "determining how the studies are related"	Studies must be put together by deciding the key metaphors, concepts by comparing, and contrasting them. Initial assumptions can begin to be made.
Phase five: "translating the studies into one another"	Translating studies whilst also maintaining the main concepts and metaphors of each paper.
Phase six: "synthesising translations"	The various translations are compared to determine if larger concepts can incorporate and encompass some of these separate translations.
Phase seven: "expressing the synthesis"	Express the translation and synthesis in an appropriate way to the identified audience.

Table 2
Population, Intervention, and Context of Interest

Population	Volunteer and paid staff providing palliative care to patients
Intervention	Collaboration/working together
Context	Any care settings providing palliative care to patients

building or limiting searches.[15] (Full details of the search strategy are found in Supplement 1).

Inclusion and Exclusion Criteria. The inclusion and exclusion criteria were applied to the studies located (Table 3).

Search results were downloaded into Endnote X9, combined and deduplicated. Two reviewers (KO and MB) reviewed the first 500 titles and abstracts independently to ensure consistent and congruent application of the inclusion and exclusion criteria. KO then reviewed remaining titles, abstracts and subsequently full texts for inclusion or exclusion. Any disputes were checked with CW or YS and agreement reached on papers to include.

Quality Appraisal. Included papers were appraised for quality using the Critical Appraisal Skills Programme (CASP) tool for qualitative research, which aids assessment of the quality of research across 10 relevant domains. This quality appraisal tool has been regarded as a nonspecific tool for the varied range of qualitative research approaches, and as such may only be used to provide an uncomplete assessment of the quality of research.[16] Furthermore, the value of using "checklists" has been questioned in meta-ethnographic studies due to the risk that insightful studies would be excluded based on quality criteria.[17] Consequently, the CASP scores generated were not used as a means of excluding papers, but to aid understanding of the strengths and weaknesses of each paper. A table of the of the main characteristics of the included papers was constructed, providing an overview of the research approaches, participants, location of research, and the author's main findings and CASP scores (Table 4).

Phase Three: Reading the Studies

Data Abstraction and Synthesis. The process of data abstraction followed Noblit and Hare's[13] guidelines for synthesizing qualitative data. The papers were repeatedly reread and the main components, comments and experiences from the different papers were compared aiming to ensure no relevant findings were missed or

Research exploring volunteers (considered for this review as a person who works for an organization without being paid) providing direct patient care (inclusive of physical care/verbal support/meal and

Table 3
Inclusion and Exclusion Criteria

Inclusion	Exclusion
drinks provision), in collaboration (working directly with or alongside) paid staff in palliative care settings.	
Any care settings providing palliative care may include care provided to any patient (adult or child) with any formal terminal diagnosis (not limited to cancer).	
Primary research employing any qualitative approach.	
Research published in English language.	

Published, peer-reviewed research.

All quantitative research, including those with a combination of qualitative and quantitative research methods, as meta-ethnography only enables the inclusion of qualitative studies.[16]

Literature reviews (however, the reference lists may be used for "snowballing.")

Grey literature.

Table 4
Included Papers and CASP Score

Author, Year, and Country	Aim/s	Setting/Context/Service Description	Sample	Methodology and Method	Themes/Key Findings	CASP Score
Sangild stølen 2021 Denmark	To explore the challenges experienced in volunteerprofessional care-giver cooperation in the general palliative care provided in nursing homes.	Looking at care provision in two nursing homes as part of general palliative care offered in Denmark.	Observations of volunteers (n = 50 −60) Interviews with volunteers (n = 9) Professional caregivers (n = 13)	Participant observations and interviews Sociological phenomenological approach	Symbolic indications of "them-andus." Unspoken boundaries. Volunteers do the fun stuff. Meanings and actions regarding residents" best interests. Social activities support the wellbeing of the individual resident. Shielding the residents from excessive activity. The link, which was seen as the activity co-ordinator.	9
Vanderstichelen et al., 2020 Belgium	To describe volunteer roles across care settings through the perspective of those closely involved in the care of terminally ill people.	Participants were recruited from hospital, home, day care and live-in services	Volunteer (n = 28) Palliative care nurse (n = 4) Palliative care psychologists (n = 6) Family	Focus groups and individual interviews using a phenomenological epistemology.	Volunteers as "the other face of care," focus on psychological, social and existential care, and building relationships/ The liminal space of volunteers. Barriers to and facilitators of volunteer role performance.	10
Vanderstichelen et al., 2019 Belgium	To explore what constitutes volunteer-professional collaboration around palliative care	Palliative care volunteers in Belgium provide direct patient care. Their contribution comprises of a wide range of tasks, including practical and nursing tasks. Their main contribution is psychological, existential and signposting care tasks.	Volunteer (n = 28) Palliative care nurse (n = 4) Palliative care psychologist (n = 6) Family physician (n = 12)	Semi-structured focus groups and interviews a qualitative descriptive design with "grounded theory and phenomenological overtones"	Contact with professional caregivers. Support from healthcare professionals. Information sharing and coordination. Barriers to and facilitators of volunteerprofessional collaboration.	9
Cloyes et al., 2017 USA	To describe how inmate volunteers learn hospice care through formal education and training, supervised practice, guidance from more experienced inmates and support from correctional staff.	The Louisiana State Penitentiary Prison Hospice Program (largest maximum-security prison in the US)	Observational data In-depth interviews with: Correctional officers (n = 5) Medical and hospice staff (n = 14) Inmate hospice volunteers (n = 24)	Ethnographic study including in-depth interviews and observational data	Learning to care: included formal training and education for prospective volunteers, practical experience at the bedside, formal and informal peer mentorship, interactions with medical and correctional staff.	5

Overgaard 2015 Denmark and Australia	To develop an understanding of the principles and conflicts that shape the division of labour (between volunteer and paid staff).	Two hospices—one located in Denmark and one in Australia	Volunteer co-ordinator (current and former) (n = 3) Hospice leader (n = 1) Nurse unit manager (n = 2) Social worker (n = 1) Diversional therapist (n = 1) Pastoral care manager (n = 1) Nurse (n = 5) Volunteers (n = 26) Kitchen staff (n = 1)	A comparative case study approach involving nonparticipant observation and unstructured interviews.	Within the Danish hospice the boundaries between volunteers and paid staff were discussed as a means of preventing volunteers from participating in direct caregiving. This was in contrast to the Australian hospice, in which direct personal patient care was "not off-limits to volunteers."	8

(Continued)

Table 4
Continued

Author, Year, and Country	Aim/s	Setting/Context/Service Description	Sample	Methodology and Method	Themes/Key Findings	CASP Score
Elliott & Umeh 2013 UK	To examine the psychological experiences of volunteer carers in a UK hospice.	Participants were from one UK hospice in the Northwest of England	Voluntary carers (n = 9)	Qualitative design Unstructured interview format. Data were analysed using a grounded theory protocol.	Motivation to volunteer, which included feeling that they were giving something back. Volunteering skills, including being aware and adhering to boundaries between their roles and those of paid staff. Psychological support and holistic care. Perceptions of the hospice. Performance hinderances, this theme included relationships between the paid staff and volunteers were occasionally a source of tension.	10
Field-Richards & Arthur 2012 UK	To explore the nurse—volunteer relationship in a day hospice.	One day care hospice in the East Midlands in England.	Day hospice volunteers (n = 12)	Underpinned by a qualitative interpretive approach Semi-structured interviews	Formalization, which included a structured induction, interview process and regulations. Division of labour. Working relationships, including those between volunteers and nurses.	9
Brown 2011 USA	To examine the coping techniques utilized by hospice volunteers.	Study participants were recruited by a letter invitation sent to 70 volunteer coordinators who were members of the western state Hospice and Palliative Care Association.	Hospice volunteers (n = 15)	A combination of Phenomenological and hermeneutic methods semistructured interviews	Volunteers used problem-focused coping, which included seeking advice from members of the hospice inter-disciplinary team. Emotion-focused coping, meaning making through appraisal and physical techniques. The most significant coping mechanism was talking with the volunteer coordinator.	10

McKee et al., 2010 Canada	To better understand the role of hospice volunteers in the rural context. Especially in what ways their contribution to end-of-life care is unique or irreplaceable.	North-western Ontario	Included hospice volunteers, Family members, members of the senior's club, Health professionals, a hospital administrator, members of the clergy, funeral director, police, and ambulance personnel.	"focused ethnography" 13 individual "loosely structured" interviews and 8 focus groups, field notes, photographs.	Volunteers have time to be there, "just sit" and time to listen. Time for a real relationship. Volunteers hold the dying person in community. Between friends and professionals: a unique circle of care.	9
Duggal et al. 2008 USA	To present the unique volunteer roles and experiences at the children's hospice and share ways that volunteers work to support the efforts of the clinical team.	Based at a hospice providing free of charge hospice care to children and their families living with life threatening illness.	Volunteer director ($n = 1$) Volunteers (not stated)	Descriptive design and interviews	Volunteer selection is important to ensuring a cohesive workforce. Training equips volunteers to work with confidence. It is important to ensure volunteer stability and satisfaction.	2

(Continued)

Table 4
Continued

Author, Year, and Country	Aim/s	Setting/Context/Service Description	Sample	Methodology and Method	Themes/Key Findings	CASP Score
Anderson & Ohl€ en 2005 Sweden	To obtain an understanding of what it means to be a hospice volunteer in a country without a tradition of hospice or palliative volunteer care services.	Three hospices in central and western parts of Sweden	Volunteers ($n = 10$)	Phenomenological hermeneutic approach Interviews	Why volunteers get involved in hospices, including their motives for becoming involved in hospices. Encountering the hospice, which included subthemes of "getting to know the atmosphere of the hospice," "being assigned a constructive task' and "longing for fellowship." Encountering the patient, which included three subthemes of "wanting to understand the needs of the patient," "imagining what fills the patient's thoughts and time" and "retaining the encounter with the dying patient."	9
Dein & Abbas 2005 UK	To establish the stresses that volunteers have to cope with in a hospice setting. To examine the ways that volunteers cope with these stresses. To examine the perceptions that volunteers have about the support provided by qualified staff at the hospice.	Volunteers from an 8-bedded in-patient unit and 10 day places.	Volunteers ($n = 17$)	Two focus groups. Data were analysed using thematic analysis. Groups were facilitated by a psychiatrist and two palliative care doctors.	Stressors included losing patients and dealing with disfigurement. Work was generally reported ass satisfying and stress-free. Coping strategies included keeping a distance from clients & religious faith. Support was generally perceived as adequate.	9

Sadler & Marty 1998 USA	To examine the turning points volunteers found important in their hospice training and volunteer experiences.	The study took place in a small hospice organization with 8 paid staff and approximately 40 volunteers.	Volunteers (n = 17)	Semi-structured interviews Turning point analysis	Pre-hospice turning points— personal events, such as personal experiences with death and dying. Interpersonal turning points— interpersonal events, including interaction with hospice staff. Group turning points—included small group interactions, structural support, recognition, and status and membership.	9
Paradis, Miller & Runnion 1987 USA	To explore the primary stressors experienced by volunteers providing direct patient care.	Data collected from 5 research sites in Kentucky and New York	Volunteers (n = 17)	In-depth interviews with four open-ended questions.	Volunteer stress found to be in four main areas—role ambiguity, status ambiguity, patients and families, and stress related to the volunteer's personal circumstances.	4

ignored. Data were extracted and recorded from the papers, initially using mind maps and later a table of first and second order constructs for each paper was created, which then was amalgamated into a summary of all papers, showing how they relate and providing examples of the overarching concepts identified, using direct quotes to avoid misinterpretation. Data were extracted across the whole paper, including the methods and discussion sections of papers, rather than limited only to the findings,[14] to avoid the loss of relevant conceptual data. This process was discussed and confirmed between KO and MB. KO and MB initially considered the papers independently before comparing emerging metaphors, concepts, and story lines to those created by KO and then discussed to ensure agreement (Supplement 2).

Phase Four: Determining How the Studies are Related

The papers and data extraction forms were repeatedly read and the main components, comments and experiences from the different papers were compared aiming to ensure no relevant findings were missed or ignored (example of initial data extraction form in Supplement 3 which were then further refined based on repeated reading of papers). The papers were assessed for reciprocal (where the accounts given are directly comparable) and refutational translation (where the accounts given are opposed to each other) across the studies. Furthermore, it was considered if there were lines of argument developing, which has been described as "a "whole" among a set of parts."[13]

Phase Five: Translating the Studies Into One Another

The original papers were reread again to ensure comments had not been taken out of context. This aimed to "protect the particular, respect holism, and enable comparison."[13] In this way the study aimed to uphold the main concepts and metaphors from each paper during translation and comparison. Meta-ethnography aims to construct interpretations rather than provide an analysis.[13] Concept mapping was used to aid this process to help visually represent the relationships between the different concepts (Supplement 4). KO and MB discussed and confirmed this process.

Reflexivity. Within meta-ethnography reflexivity is regarded as an important aspect of the research. This was acknowledged by Noblit and Hare,[13] who stated that "the analyst is always translating studies into their own word view." Therefore, it is acknowledged that findings of the review are based on personal interpretations of the selected studies and as such subjectivity and personal understanding of the topic will have impacted on the interpretation of data. KO and MB both have a background as adult nurses and working in palliative care settings. Furthermore, the KO was employed as a nurse based on an in-patient hospice unit in England. Consequently, a reflective diary was kept aiding transparency.

Results

Search Outcome

A total of 4575 papers were identified from the databases (CINAHL: 1882; PsycINFO: 1212; Medline: 1008; AMED: 473). Of these results, 1140 duplicates were removed. This led to the inclusion of 14 papers in the final review (Table 4). A systematic approach was used to and recorded using an adapted version of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram (Fig. 1).

Phase Six: Synthesizing Translations and Phase Seven: Expressing the Synthesis

Characteristics of Included Studies. Studies were published between 1987 and 2021 and were conducted in the United States of America (n = 5), United Kingdom (n = 3), Belgium (n = 2), Denmark (n = 1), Sweden (n = 1), Canada (n = 1), and one including both findings from Denmark and Australia. Study methods included interviews, often in combination with focus groups, field notes, and observations. Two studies included a combination of volunteers, paid staff, and family members as participants, five studies included volunteers and paid staff, however, seven of the included papers only included volunteer's perspectives. Settings included a nursing home which provided general palliative care, hospice in-patient settings, day hospices, the community setting, a children's hospice, and a prison.

This review intended to go beyond the findings of individual papers to create new overarching interpretations by translating concepts and metaphors into each other. Noblit[18] added that the selected studies need "to be translated into each other as wholes—that is create analogies between and amongst a set storylines that encompass the whole," thus providing a fuller interpretation. Final consideration of the storylines was undertaken by KO and MB (Table 5).

Storyline One - "We are the Cake, and they are the Cream": Understanding the Volunteer Role—Separate, but Part of a Whole

The first storyline illustrates the different ways volunteers and paid staff viewed the volunteer role, seeing it as distinct but also connected to paid staff. Volunteers often considered themselves integral to the team, using words such as "we" to indicate being part of the organization, with examples of this being enabled by senior management.[19,20] However, this relationship between

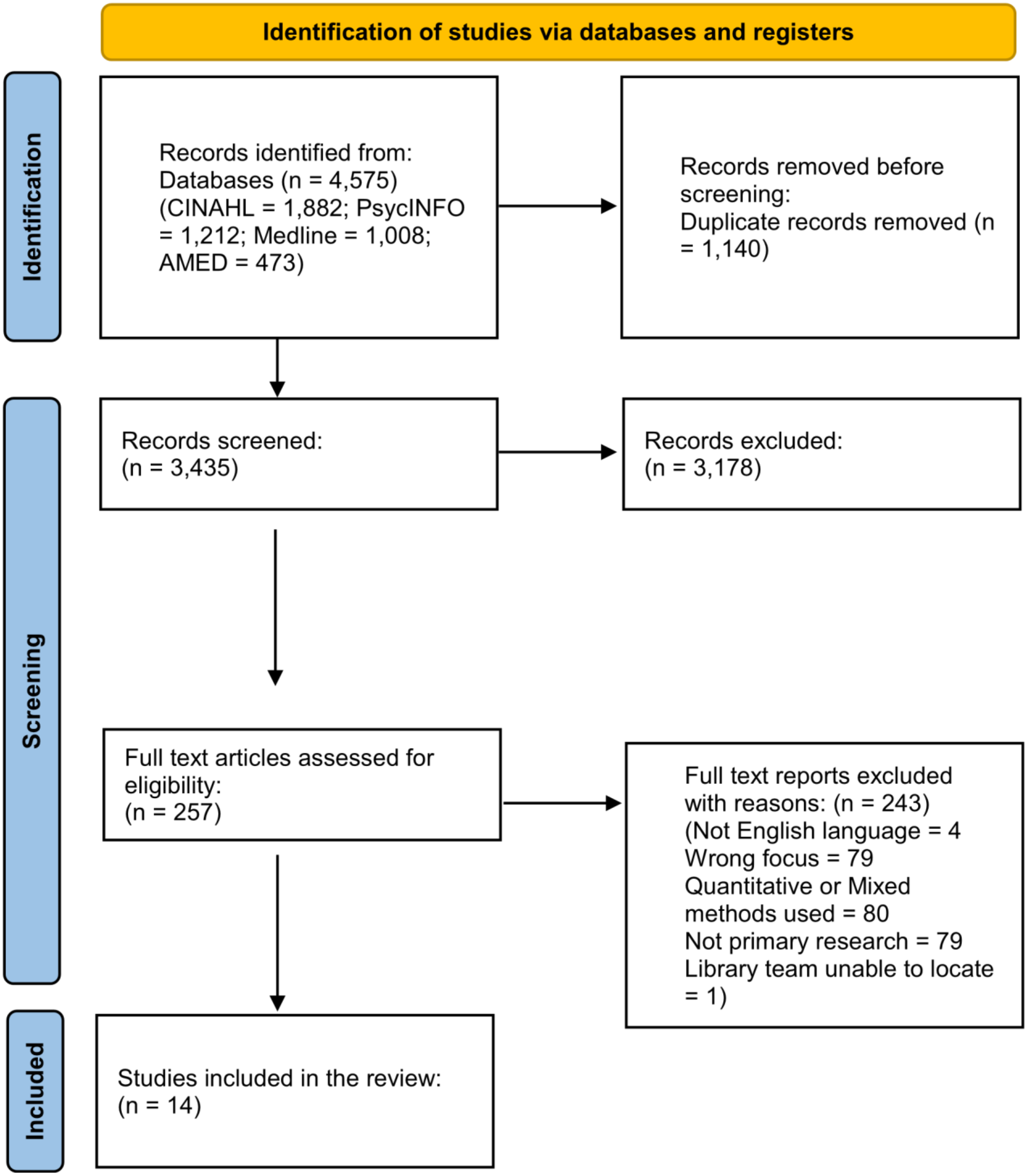

Fig. 1. Flow diagram of the review process. PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and registers only. Available from: http://www.prisma-statement.org/documents/PRISMA_2020_flow_diagram_new_SRs_v1.docx. Accessed July 27, 2023.

volunteer and organization could also be perceived as "them" and "us," where they "do not connect."[21] This could create separation and misunderstandings between the volunteers and other team members.

At times paid staff considered volunteers as having a supplementary role. The care and support provided by volunteers was seen as extra to the essential contribution made by paid staff.[22,23] For some, it appeared that paid staff valued being distinct and different, with separate roles as much as volunteers did:

> "We are the cake, and they are the cream. That is extremely important because they are not taking any piece of the cake.[22] That is the difference between volunteers and professionals".

Table 5
Storylines

Storyline 1	"we are the cake and they are the cream": understanding the volunteer role—separate, but part of a whole.
Storyline 2	"...we don't know what's wrong with people but sometimes we need to know": access to information and importance of trust.
Storyline 3	"everybody looks out for each other": access to, and valuing of, paid staff and their support.
Storyline 4	"...we don't meddle in the medical": physical and institutional boundaries.
Storyline 5	"it's the small things that the staff does for me that makes me feel good about my work": sense of value and significance.

Often when this sense of separation was expressed, it was noted that paid staff and volunteers worked separately, both in location (sometimes in the same building but different areas) or separate tasks.[21] It was not possible to characterize the type of setting this sense of separation took place, as both a hospice and a nursing home were involved.[19] However, it is noted that both care settings, showing the most clear and distinct lines between paid staff and volunteers were in Denmark.

Volunteer's distinctiveness was perceived positively, enabling them to overlap the worlds of paid staff and patients in way described as a "unique hybrid", and where volunteers could be the "eyes and ears" of paid staff.[7,24–26,27] Volunteers recognized this different function to paid staff, enabling them to perform different roles because they were not paid staff:

> "The nurses, they go into the home and it's like, 'Okay, I [the nurse] got to get this done and I've got to get that done...' It's very task-oriented... [But] I've seen [volunteers] just being there, that is what they do: they are being there; they sit, they listen".[24]

Both volunteers and nurses noted the importance of "being there" as a role of the volunteer that separates them from paid staff. In this way they saw the difference between "being", which was linked with volunteers and "doing" which was associated with nursing staff. However, at times volunteers also found expressing their unique role challenging with formal care providers, instead referring to the tasks they performed to give credibility to what they did. This may have contributed to the lack of understanding from paid staff about their role.[24,25] If volunteers felt uncertainty about the volunteer role, was believed to lead to a sense of insecurity.[28,29]

Although there was a generalized wish to be separate and different from each other, there was also a common feeling of mutual appreciation and regard.[6,23,24]

Storyline Two - "...Sometimes We Need to Know": Access to Information and Importance of Trust

This second storyline shows how paid staff and volunteers discussed information sharing and how for volunteers this was also connected to feeling trustworthy. Knowing what information could be shared was challenging for both volunteers and paid staff. Volunteers perceived that paid staff did not always share important information which they required to work effectively.[7,21,27]

Those that had volunteered for a longer period felt that they previously knew more about patients, but this changed due to an increased need for patient privacy and confidentiality. Ambiguity around confidentiality agreements or the perceived level of seriousness that volunteers took regarding patient confidentiality limited the information paid staff were willing to share. Volunteers found that this strict approach to confidentiality made it difficult to perform their roles safely:[4,21,22,27]

> "So, I [wasn't] meant to give her digestive biscuits but I didn't know that...we don't know what's wrong with people but sometimes we need to know".[7]

Some volunteers felt that the lack of information sharing was because they were not deemed trustworthy, despite signing confidentiality agreements:[27]

> "... obviously the nurses stick to the confidentiality and unfortunately volunteers aren't told and yet we have to take the confidentiality thing very seriously but we're not trusted with that, which is odd really as you're trusted so far with patients".[27]

Some paid staff did not feel it was important for volunteers to be informed about the details of patient's illness because this did not impact their ability to work effectively. Paid staff also tried to prevent any "wrongdoing" by sharing more information than they should.[21] However, this caused disappointment for volunteers, as they were interested in the people they met. The lack of information about patients led to volunteers misunderstanding the paid staff's rationale for their actions towards patients.[28] At times this was extended to paid staff not sharing information about an individual's death:[21]

> "if someone dies, they can't tell you. Then you happen to find out accidently. When you are in the house a lot, this is strange (...) You know the resident".[21]

Becoming a volunteer often involved learning to trust not only others, but also to trust themselves and the importance of being trustworthy. The setting that the importance of being trustworthy was particularly noted was in a prison setting, where prisoner volunteers work with paid palliative care teams to support prisoners approaching the end of life.[23] A sense of mutual trust was a foundational element of effective teamwork between volunteers and paid staff.[24,26]

Storyline Three - "Everybody Looks Out for Each Other":

Access to Paid Staff and their Support

The third storyline focuses on the views relating to value volunteers placed on different types of support received from paid staff.

Support offered to volunteers by paid staff was seen as either functional or emotional. Some volunteers sought assistance and advice from a variety of paid hospice workers including social workers, nurses, and clergy. Functional support was perceived as drawing on the experiences of paid staff about difficult situations, compared to emotional support, which focused on processing difficult experiences encountered. Some volunteers preferred to discuss their experiences with fellow volunteers. It was thought that those with similar perspectives were in a better position to empathize and support volunteers emotionally.[20,25,26]

Other volunteers felt that they wanted greater social connection with staff, which would increase a sense of belonging to the team:

> "You have a close relationship with the nurses, a one-onone interaction, which you may not experience in other healthcare settings...everybody looks out for each other".[23]

Volunteers desired fellowship with paid staff, which was one of the reasons for volunteering. Volunteering was not only about functional working with patients, but also about feeling connected to a wider team consisting of other volunteers and paid staff. When this need for fellowship was not met it could create feelings of rejection.[28] Some paid staff said they were readily available for volunteers to speak to, suggesting volunteers were given permission to engage with paid staff. However, despite this offer being made some volunteers felt awkward disturbing nursing staff, implying that further reassurance of the working relationship may have been needed for some volunteers:[29,30]

> "Also, the day hospice nurses. They are always there and say repeatedly that 'we are here, if there are any problems please come and speak to us'. We have a very good relationship".[30]

Volunteers found working with, or in the presence of, paid staff was reassuring. However, some volunteers reported having difficulty contacting paid staff. Infrequency of working together due to shift patterns was seen as a barrier to effective communication which was felt could lead to confusion and misunderstandings. Volunteers expressed concern that this may cause important information about patient care to be lost, putting excessive pressure and responsibility on the volunteers.[4,7,25,29]

The role of a volunteer coordinator facilitated communication when there was limited contact between paid staff and volunteers. In addition to seeking support from paid staff, volunteers referred to volunteer coordinators for problem solving and advice. This was often felt to be an important relationship for volunteers.[4,20,29] However, some of the paid staff felt that the role of the co-ordinator could create a "thirdperson" and become a barrier to joint co-operation and development of mutual understanding. Consequently, whilst coordinators were seen as an important part of aiding volunteers to solve problems, it was perceived that they should also encourage volunteers to make use of the interdisciplinary team when needed.[20,21]

Storyline Four - "...We Don't Meddle in the Medical": **Boundaries**

This storyline considers the perception that boundaries could be physical, institutional and at times unspoken.

At times there were perceptions of boundaries that kept volunteers outside the "professional domain," including multidisciplinary team meetings. This was 'valued" by some volunteers, as they wished to respect the boundaries.[7,21,27] Whilst another referred to it as "...we don't meddle in the medical."[25] Volunteers were aware that they should not "cross the line," although these boundaries were never strictly defined and at times exceptions occurred:

> "... you're busy in the kitchen with who knows what, but you hear the nurse that, er, someone is anxious, er, wishes for someone to be near, wishes –you drop everything...".[25]

Consequently, when requested by paid staff, volunteers appeared to function in a different domain than their volunteer tasked role. It was thought that when volunteers felt uncertainty about their boundaries, volunteers may be afraid that they would accidently stray into the "domain of the nurses."[28]

Volunteers used the expression "stepping on toes" of paid staff regarding invisible and unspoken boundaries:

> "There are lots of practical things I'd like to talk a little bit more about, like the boundaries between what a volunteer can do and what the professional caregivers do –to have a better understanding of the nature of their professional work (...) I'm afraid of stepping on someone's toes...".[21]

However, within another context, it appears paid staff were also concerned this could happen with volunteers. This was overcome through supervision, which was used to evaluate volunteer's strengths and weaknesses in a positive way, "without stepping on toes."[4,21]

Shifting boundaries, driven by an increased sense of formality through policy and restrictions, impacted on working relationships between paid and volunteer. However, change was often seen as a positive by some volunteers, appreciating an increased structure, which were clearly explained and defined.[7,22]

Some volunteers were not permitted to enter patient rooms, creating physical boundaries. Volunteers described feeling they had crossed an "institutional boundary" although this was unspoken, it represented a physical area specifically for paid staff. Lack of interaction from paid staff caused volunteers uncertainty of being welcomed into the physical space. However, some paid staff believed that if volunteers were not working in the same areas that they miss the opportunity to get to know each other. This suggests that there may have been misunderstanding between the two groups. Volunteers felt that having a shared physical space would make a"big difference" to working relationships.[4,21,22]

Storyline Five - "It's the Small Things That the Staff Does for Me That Makes Me Feel Good About My Work":

Sense of Value and Significance

The final storyline illustrates the sense of significance and value felt by volunteers as part of a wider hierarchical structure

Feeling appreciation from paid staff helped volunteers to see their own role as significant and worthwhile.[27] When appreciation was lacking volunteers felt unimportant and unnoticed. The desire for recognition varied amongst volunteers, some valuing formal recognition through newsletters and special volunteer events.[19,28] However, others felt that formal recognition in this way was not necessary, preferring more informal recognition:

> "it's the small things that the staff does for me that makes me feel good about my work".[19]

This suggests that whilst volunteer preference on how recognition is received is individual, the desire for it in some form from paid staff was more widely expressed.[7]

Recognition by paid staff of volunteer's individual interests, abilities and skills influenced their experience of volunteering and sense of value. Volunteers saw their role as unique and that their contribution should be guided by their personal strengths. When this was not recognized by paid staff it led to disappointment, however there was general acceptance of the tasks assigned to them that were not to their preference.[7,28] Volunteers felt that it was important to carry out tasks to the best of their ability, but at times paid staff did not appear to see the value their personal contribution, such as baking.[7,28] At times volunteers that had a healthcare professional background were regarded with apprehension:

> "Hang your uniforms outside. You simply cannot bring your old job in here".[22]

However, volunteers with nonhealthcare backgrounds were encouraged to use their skills within the hospice.

Often there was a deep mutual regard and respect between volunteers and paid staff.[7,23,24] Respect was also given to volunteers by paid staff due to the level of knowledge they had about the patients and how they were feeling. Volunteers saw that being regarded as "good volunteers" was linked to their continued willingness to learn about patients and from others. Suggesting that gaining respect was connected to demonstrations of commitment from volunteers.[26]

Some volunteers felt ambiguity over volunteer status due to "organizational hierarchy" created uncertainty and "status conflict."[29] However, some volunteers were aware of a sense of hierarchy:

> "you've got to make sure that [you] speak to the staff, not do something off your own bat".[27]

This suggests that they were required to seek permission from paid staff before acting. The metaphor of a tandem bike was used to describe the working relationship suggesting a closeness and connection between paid staff and volunteers for effective collaborative working. However, the paid staff member remains the lead in the relationship at the front of the bike with the volunteer at the back.[4] A high level of satisfaction from volunteers to the wider principles of the hospice movement was attributed to a nonhierarchical approach to multidisciplinary working, valuing individual contributions, rather than status or qualifications.[30] However, not all appeared to agree, as some volunteers and paid staff questioned if volunteers were "qualified" for certain discussions.[4,19,29]

Discussion

The aim of this meta-ethnographic review was to explore the views expressed by volunteers and paid staff about their experiences of working together in palliative care settings. Challenges for volunteers, paid staff and settings providing palliative care when seeking to work together were highlighted in this review. The overarching concept throughout all five story lines identified was of team and team working between volunteers and paid staff, which was evident with the use of the term "we" to describe their relationship. Teamwork can be seen threaded through three main issues identified; 1) redefining what palliative care teams are and who they should include, 2) the impact of power and hierarchy on teams, and 3) the importance of intentionally building relationships between volunteers and paid staff.

The desire from volunteers to work as part of a team with paid staff was evident within several of the storylines and seen by volunteers wanting to be connected in a meaningful and purposeful way. The importance of teamworking is often seen as a key element of effective palliative care;[31] however, teamworking is often limited to those regarded as "healthcare professionals" or paid staff. Within healthcare, the term "interprofessional team working" is often used and advocated and included as a core element of preregistration teaching.[32,33,34] This concept encourages healthcare professionals to view other professionals as having an equally valid contribution to make to patient care and to work collaboratively. It has been further suggested that trans-professional working, which seeks to transcend individual disciplines to form more integrated and cohesive teams would enable team members to develop greater knowledge and understanding of each other's roles and responsibilities.[35,36] However, this positive model still does not necessarily seem to fully remove barriers to fully include relationships between paid staff and volunteers. Consequently, many volunteers may still be seen as outside of the core team within a palliative care setting. This separation links with the metaphor used in storyline one of "we are the cake, and they are the cream", seeing healthcare professionals and paid staff as essential and volunteers as nonessential.

The boundaries of interprofessional teams within palliative care should be challenged to consider the unique and valid contribution volunteers make when included as integral members of the team. However, how to make this meaningful and preventing their inclusion being only a token or goodwill gesture would need consideration within each palliative care setting. Teams meet and work for different purposes, for example, to discuss patient care, to discuss staffing issues, or to discuss the running of the setting. Therefore, consideration and identification of which meetings and teams would be appropriate for different groups of volunteers and paid staff to be involved in to enable their contributions to be meaningful and mutually beneficial. Volunteers were often regarded as an additional element of care and as such absent from multidisciplinary (MDT) meetings.[38] They encouraged more joined-up thinking and volunteer inclusion in MDT meetings to give space for constructive conversations. Transparent communication of which meetings different volunteer groups would be included in would reduce the concern of stepping on each other's toes due to unspoken boundaries.

Recognition of a hierarchical and power imbalance between paid staff and volunteers was evident. Within healthcare there have been historical imbalances of power, notably between doctors and nurses. There has a long-standing perspective that nursing was an oppressed role and nurses were subservient to doctors.[37] Successful changes have been made to this relationship, seeking to eradicate the need for the "nurse-doctor game" within healthcare practice.[38] However, whilst improvements are evident in relationships between healthcare professionals, throughout the storylines it was seen that volunteers perceived they had a lower status in the organization than paid staff. Volunteers may experience feelings of subordination, leading to an opinion that they were controlled in their volunteering roles by paid staff.[7]

Throughout the storylines, the words "working together" was seen as significant, which appeared to be different from collaboration. Although the term collaboration is often used in research, the definition of what this means is not always clear. Collaboration maybe seen as "an integration of activities and knowledge that requires a partnership of shared authority and responsibility."[39] Furthermore, it has been suggested that collaboration involves four key elements of coordination, cooperation, shared decision making and partnership.[39] Most elements associated with this definition of collaboration were not frequently seen within the storylines, despite volunteers and paid staff being in the same working environment. Often within healthcare research the terms "teamwork," "working together" and "collaboration" are used interchangeably.[40,41] However, Davies[40] found that there are clear distinctions between the phrases "working together" and "working alongside" others, showing that simply working in the same location does not necessarily equate to collaboration.

The metaphor of the tandem bike, with the paid staff up-front, directing, and leading, with the volunteer behind following, implied a power imbalance and volunteers had less control. Volunteer empowerment is a key aspect in encouraging volunteer engagement, building an increased sense of control over their contribution within the setting. Highlighting that paid staff, of all levels, play an essential role in volunteers feeling empowered and an important part of the team. This may be achieved by volunteers and paid staff building shared goals and including volunteers in decision making processes. Within the Netherlands a hospice initiative includes a paid coordinator with oversight of large numbers of volunteers who receive training to carry out much of the patient care needed. Volunteers appear to be empowered to carry out care, make independent decisions. On occasion that something goes wrong it is regarded as "a situation to learn from."[42] Traeger and Alfes[43] suggests that volunteer empowerment can be aided by them having the skills, knowledge, and ability to carry out tasks effectively through training and development. Therefore, joint training for volunteers and paid staff during induction on relevant topics, such as the values and structure of the organisation, moving and handling and core principles of palliative care may help to reduce the sense of power imbalance.

Throughout the storylines, it was evidently important for volunteers and paid staff to intentionally build positive and meaningful relationships. Increasing social interaction between paid staff and volunteers was seen to be a constructive way of improving working relationships and further building a sense of fellowship that was deemed to be important to some volunteers. Over the last few years, COVID-19 restricted many volunteers ability to have face-to-face contact in palliative care settings, leading to reduced social interaction and changed the way communication with patients, paid staff and other volunteers occurred.[44,45] This change to an important aspect of volunteer's reason for volunteering in palliative care should be considered by palliative care settings to ensure volunteers feel the sense of community and camaraderie they felt was important within this review. Palliative care settings going through times of change or growth can reduce the sense of intimacy within these settings, which can negatively impact on the experience of volunteers.[12] Therefore, as demands for palliative care services increase and settings expand, there should be consideration for how a sense of fellowship and belonging can still be fostered.

The storylines show that a sense of recognition was important for volunteers to feel valued by paid staff, which is also echoed in other studies.[12,46,47] The findings of this review highlight the importance of acknowledging volunteers' individual contribution, which was linked to their sense of personal worth. Maslow's theory of human motivation views that for individuals to reach their potential they first need to feel they belong and find their place in a group, followed by meeting their esteem needs. This includes feeling a sense of esteem, attention, and recognition from other.[48] Volunteering can build self-growth and wellbeing by building their sense of individual purpose.[49] Therefore, for volunteers to reach their potential in their work as part of a palliative care team they need to feel acknowledged and appreciated by the wider team. Effective communication, successful utilization of volunteers and having joint social events between paid staff and volunteers may be effective ways of improving volunteer retention and satisfaction.[47]

Recommendations

Recommendations for Practice

There is potential that joint education, including the ethos of palliative care and the organizational values would develop a mutual sense of belonging to one team with a clear vison and intent. The inclusion of volunteers in team meetings should be considered to improve information sharing, enable volunteers to make a unique and valid contribution, also foster a sense of empowerment. The way volunteers are to be included in meetings would need to include transparency in communication verbally and written, such as during initial induction training and written job descriptions for both volunteers and paid staff to prevent misunderstandings.

Furthermore, encouraging volunteers and paid staff to be in each other's presence more, both during work and socially may encourage improved relationships, this may include simple initiatives, such as a shared room for breaks. Successful working between paid staff and volunteers should not be taken for granted to prevent potential problems and breakdown in their relationships.

Recommendations for Policy

Policy and guidelines regarding palliative and end of life care are often aimed specifically at health and social care professionals. The recommendations often include the benefit of multiprofessional working; however, this may exclude the contribution of volunteers. Consequently, including volunteers in relevant aspects of policy on how they can contribute to effective palliative care through working with paid staff may be useful. Volunteer inclusion in national policy and guidelines may also support individual palliative care settings navigating some of the challenges discussed throughout the storylines, enabling them to filter this into local guidelines.

Recommendations for Future Research

There were still problems with the working relationships between paid staff and volunteers highlighted in the review, such as power imbalances, ineffective communication, unclear boundaries, and not seeing volunteers as fully integrated members of the team. Therefore, further primary research seeking to further build an understanding of the working relationships between paid staff and volunteers and make improvements is recommended. Volunteer empowerment was raised as an area for consideration, which links with the aims of participatory action research. Action research can be used to encourage groups to feel empowered by enabling the participants to control and take ownership of the direction and focus of the research.[50] Therefore, participatory action research, exploring the relationships between paid staff and volunteers in a palliative care setting is recommended.

The papers that met the inclusion criteria originated in only seven high-income, Western countries. Whilst the culture and context of volunteering and healthcare provision across these countries has differences, it may be that similar findings would not be identified if there had been a broader range of research from other contexts available to synthesize. Research is recommended across a range of cultures and contexts to explore the relationship further between volunteers and paid staff.

Strengths and Limitations

Only qualitative studies were included in the review, it may be that some studies using quantitative or mixed methods may be of value in understanding volunteer − staff relationships. However, the methodological approach adopted in this study enabled an in-depth exploration of the phenomena of interest. Meta-ethnography is an iterative and interpretive approach; therefore, the world view of the authors would have influenced the findings of this review. Whilst our world view may not necessarily be a limitation of the research, this should be considered by readers. However, through following the eMERGe reporting guidance, we have sought to provide transparent reporting to improve the robustness of the review.[51]

Studies included in the final review are all Westerncentric cultural background, and whilst variations due to country of origin have been found, the inclusion of other cultures may have included a different insight and valuable perspective to the discussion. Therefore, future research considering a wider cultural context maybe beneficial.

Conclusion

The findings of this meta-ethnographic review show that whilst recognizing individual roles and purposes within a palliative care setting, being part of one collective team is important for both volunteers and paid staff to work together effectively. This encourages a sense of belonging, camaraderie, and common purpose. The discussion has also explored that Collaboration goes beyond “working alongside” others or “working together” by implying active cooperation and joint efforts towards shared goals. It was also highlighted that paid staff are key in empowering volunteers through building shared goals and including volunteers in decision making. Finally, for successful working relationships between paid staff and volunteers, proactive engagement and interaction between both groups is needed.

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Supplement 1. Search Strategy

Search Terms Used in AMED

Sequence	Search Terms	Limiters	Results
S3	S1 & S2	Peer Reviewed Journal, English	473
S2	Volunteers OR TI (volunteer* OR voluntary OR unpaid) OR AB (volunteer* OR voluntary OR unpaid)	None	6993
S1	"Palliative Care" OR "Assisted Suicide" OR "Euthanasia" OR "Terminally Ill Patients" OR "Hospice" OR "Bereavement" OR "Grief" OR "Respite Care") OR TI (Palliat* OR Terminal* OR bereave* OR endstage OR "end stage" OR "advanced stage" OR "last stage" OR "late stage" OR "final stage" OR dying OR "end of life" Or end-of-life OR hospice OR "supportive care" OR (death N5 (grief OR mourn* OR loss))) OR AB (Palliat* OR Terminal* OR bereave* OR endstage OR "end stage" OR "advanced stage" OR "last stage" OR "late stage" OR "final stage" OR dying OR "end of life" Or end-of-life OR hospice OR "supportive care" OR (death N5 (grief OR mourn* OR loss))	None	22,322

Search Terms Used in PsychInfo

Sequence	Search Terms	Limiters	Results
S3	S2 and S2	Peer Reviewed Journal, English	1212
S2	DE "Volunteers" OR TI (volunteer* OR voluntary OR unpaid) OR AB (volunteer* OR voluntary OR unpaid)		70,095
S1	DE "Palliative Care" OR DE "Assisted Suicide" OR DE "Euthanasia" OR DE "Terminally Ill Patients" OR DE "Hospice" OR DE "Bereavement" OR DE "Grief" OR DE "Respite Care") OR TI (Palliat* OR Terminal* OR bereave* OR endstage OR "end stage" OR "advanced stage" OR "last stage" OR "late stage" OR "final stage" OR dying OR "end of life" Or end-oflife OR hospice OR OR "supportive care" OR (death N5 (grief OR mourn* OR loss))) OR AB (Palliat* OR Terminal* OR bereave* OR endstage OR "end stage" OR "advanced stage" OR "last stage" OR "late stage" OR "final stage" OR dying OR "end of life" Or end-of-life OR hospice OR "supportive care" OR (death N5 (grief OR mourn* OR loss))		80,046

Search Terms Used in CINAHL

Sequence	Search Terms	Limiters	Results
S3	S1 and S2	English Language; Peer Reviewed	1882
S2	(MH "Volunteer Experiences") OR (MH "Volunteer Workers")) OR TI (volunteer* OR voluntary OR unpaid) OR AB (volunteer* OR voluntary OR unpaid	None	76,487
S1	(MH “Hospice and Palliative Nursing”) OR (MH “Palliative Medicine”) OR (MH “Palliative Care”) OR (MH “Hospice and Palliative Nurses Association”) OR (MH “Terminal Care”) OR (MH “Hospice Care”)) OR TI (Palliat* OR Terminal* OR bereave* OR endstage OR “end stage” OR “advanced stage” OR “last stage” OR “late stage” OR “final stage” OR dying OR “end of life” Or end-of-life OR hospice OR “supportive care” OR (death N5 (grief OR mourn* OR loss))) OR AB (Palliat* OR Terminal* OR bereave* OR endstage OR “end stage” OR “advanced stage” OR “last stage” OR “late stage” OR “final stage” OR dying OR “end of life” Or end-of-life OR hospice	None	149,402

Continued

Search terms used in MEDLINE Complete

Sequence	Search terms	limiters	Results
S4	S1 & S2 & S3	English Language; Scholarly (Peer Reviewed) Journals	1008
S3	(MH "Qualitative Research+") OR TI (experience OR interview* OR qualitative OR experience* OR “semi-structured” OR semistructured OR unstructured) OR AB (experience OR interview* OR qualitative OR experience* OR “semi-structured” OR semistructured OR unstructured)	None	1069
S2	(MH "Volunteers+") OR (MH "Hospital Volunteers") OR TI (volunteer* OR voluntary OR unpaid) OR AB (volunteer* OR voluntary OR unpaid)	None	297,492
S1	(MH "Palliative Care") OR (MH "Palliative Medicine") OR (MH "Hospice and Palliative Care Nursing") OR (MH "Hospices")) OR (Palliat* OR Terminal* OR bereave* OR endstage OR "end stage" OR "advanced stage" OR "last stage" OR "late stage" OR "final stage" OR `dying OR "end of life" Or end-of-life OR hospice OR "supportive care" OR (death N5 (grief OR mourn* OR loss)) OR (Palliat* OR Terminal* OR bereave* OR endstage OR "end stage" OR "advanced stage" OR "last stage" OR "late stage" OR "final stage" OR dying OR "end of life" Or end-of-life OR hospice OR "supportive care" OR (death N5 (grief OR mourn* OR loss)	None	856,435

Supplement 2. Summary of First and Second Order Constructs for Each Paper, and the Storylines Identified

Example of Participant quotes (First order constructs) indicated in italics

Example of Primary author interpretation (Second order constructs) indicated in normal text

Papers in Order of Date (Newest to Oldest)	Understanding of the Role ... Them and Us/ We/Separate but Part of Whole	Hierarchy/ Power/ Recognition/ Feeling “Qualified”	Access to Information/ Trust	Access to Staff/Support/ Role of the Volunteer Coordinator	Boundaries

Continued

Stølen (2021)	"We can do better. I feel we sometimes look at [the volunteers] as "them" and then there's "us". We do our work and focus on that, but we do not connect it to the volunteers' work. They're a great part of what we can offer" (care assistant) The analysis identified phenomena encapsulating features of meanings derived from interactions between volunteers and professional caregivers that communicated a "them- and- us" understanding. This made cooperating on care activities for residents more challenging for both groups	I'm afraid of stepping on someone's toes. I do not want my work to come at the cost of professional resources... (volunteer)	"They can ask me about things I'm not allowed to tell them about. It is about confidentiality. Then you try to find a way, so the resident does not lose their dignity" (care assistant). The professional obligation of confidentiality was a strong symbol for volunteers and professional caregivers alike, communicating their differing knowledge, roles, and authority, as well as the protection of the residents' personal integrity. Knowing what information could be given to volunteers was not always easy.	(About coordinators) "It's a barrier when we don't arrange encounters between volunteers and professional caregivers (...) It isn't enough for the activity coordinator to have third- person contact to the volunteers. If they are not on the ward, we do not get to know each other. It is about trust. It is about developing a mutual understanding." (Care assistant) For professional caregivers, the activity coordinator role communicated priorities about the primary contact and responsibility for volunteers and cooperating with them about offered social care activities. Some professional caregivers felt that this role could be a barrier to daily cooperation and mutual under-standing.	...I want to respect the boundaries' (volunteer) ... When volunteers went to the ward to pick up a resident to participate in an activity or deliver a resident to their room afterward, they reported feeling that they crossed an institutional boundary, which they understood as entering the professional caregivers' domain. In this space, they felt uncertain about whether they unknowingly crossed pre- established and unspoken boundaries.

(Continued)

Papers in Order of Date (Newest to Oldest)	Understanding of the Role ... Them and Us/ We/Separate but Part of Whole	Hierarchy/ Power/ Recognition/ Feeling "Qualified"	Access to Information/ Trust	Access to Staff/Support/ Role of the Volunteer Coordinator	Boundaries

Continued

Vanderstichelen, Cohen, Van Wesemael, Deliens, and Chambaere (2020)	Volunteers were found to represent an “other,” more approachable “face of care” and to occupy a liminal space between and overlapping the professional and the family domains.			“I think the problem for us is also, with us the nurses work- two nurses work, er, 2 days in the week, one works 3 days. Er, the occupational therapist, er, er, Monday, Wednesday and the week after on Wednesday, Friday. So, it’s a constant change of people. A lot has to be done and settled in between. And then I think that the communication, I feel, falls short...” (volunteer) Lack of support and coordination for the volunteers impeded their role of “being there” and the development of the relationship with the dying person... However, when support and coordination were present, participants indicated they facilitated volunteer role performance.	“The point is that we don’t meddle in the medical...” (volunteer) Professional care givers indicated that volunteers should not cross the line when providing psychological guidance. However, these boundaries were never strictly defined.
Vanderstichelen, Cohen, Van Wesemael, Deliens, and Chambaere (2019)	Our study shows that volunteers and nurses assume complementary roles, work together cooperatively	“You have a tandem bike. The nurse is at the front and the volunteer is at the back because you’re responsible for this together and together you brief each other.” (volunteer) Patients and family carers described the volunteer-nurse relationships as hierarchical, suggesting that volunteers are there to support nurses and that health care professionals provide directions to volunteers Family physicians were unclear about whether volunteers are allowed to take part in illness trajectory discussions with patients and whether they were qualified for this.	“What I have issues with sometimes, but I don’t have that much experience with palliative volunteers, but I think that maybe it applies to volunteering in general regarding professional confidentiality, I have issues with it. I once met a volunteer who really came into my practice: “Oh and that patient,” you see. And I was like whoah, whoah. I don’t have to tell you all of this. (.) No, regarding professional confidentiality, I sometimes think - Because you can be a palliative volunteer and be involved, but if you start	“Just your functioning in the group, what you think is good, what you think is bad, what they think should be improved. That sounds very, very harsh now, right? But it’s brought in a very soft manner and always ends (laughs) on a positive note. (.) But it gives you the chance, I think, to talk openly for once without someone else present, without stepping on toes” (volunteer) Participants described two types of support that health care professionals offered volunteers while working together: functional support and emotional support.	

(Continued)

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Papers in Order of Date (Newest to Oldest)	Understanding of the Role ... Them and Us/ We/Separate but Part of Whole	Hierarchy/ Power/ Recognition/ Feeling “Qualified”	Access to Information/ Trust	Access to Staff/Support/ Role of the Volunteer Coordinator	Boundaries
			spreading that around to everyone, then I think .. I think it’s tough. We’re so strictly bound to that, but they’re not. At least I think not, legally?” ... “They are in principle. (...) They don’t always take it that seriously, yeah” (Family physicians) volunteer-nurse collaboration was characterized by mutual informationsharing about the patient’s condition and its development		
Cloyes et al. (2017)	The inmate hospice volunteer role represents a unique hybrid between the roles of hospice volunteers, nurse assistants and family caregivers found outside the prison in community-based hospice programs.	“[b]e a resource to them. When they ask questions, answer the questions; give them the best answer that you can; and do the research that you need to do in order to give them that. They’re going to suck [the information] up like a sponge. And then they’ll be able to use it in the future. They want this to work.” (nurse) Volunteers described how an ongoing willingness to learn from their patients and each other was essential to being a “good” volunteer... This ethic of continuous learning is valued; good volunteers continue to educate themselves and each other as they gain more experience. “They get a very, very close relationship or rapport with the [patients]... That’s why we really respect whenever they say something’s wrong with one of the patients, they see those declining health issues.” (nurse)	The work of becoming a volunteer involves learning to trust; being able to trust not only others, but also trusting oneself and being trustworthy. This sense of trust is foundational to the teamwork and sense of stewardship described by inmates and staff, and to how they represent the hospice program to inmates outside the unit.	Despite the availability of grief counselling offered by the hospice social worker, every volunteer interviewed stated that they preferred to discuss their experiences with their mentors and fellow volunteers.	LSP nurses also stressed the importance of interacting with volunteers in a professional manner, maintaining appropriate boundaries while also recognizing the value of volunteers as the front-line members of the hospice care team.

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Papers in Order of Date (Newest to Oldest)	Understanding of the Role ... Them and Us/ We/Separate but Part of Whole	Hierarchy/ Power/ Recognition/ Feeling "Qualified"	Access to Information/ Trust	Access to Staff/Support/ Role of the Volunteer Coordinator	Boundaries
Overgaard (2015)	"We are the cake and they are the cream. That is extremely important because they are not taking any piece of the cake. That is the difference between volunteers and professionals." (Hospice Leader, Denmark) the volunteers at the Australian hospice perform work that overlaps with that of nurses and social workers in particular	Danish professionals have effectively managed to maintain a monopoly over care-giving, which has resulted in a successful professionalisation project	"A volunteer came up to me after dinner and asked, "How old is that patient?" It may seem like an innocent question,(...) but we are not allowed [to tell]." (Nurse, Denmark) The strict approach to confidentiality sometimes made it difficult for the volunteers to perform their roles.		"And it's the certainty that there is a razor-sharp line between being a professional and being a volunteer. The volunteers must of course not in any way interfere in the care." (Hospice Leader, Denmark) Boundaries between volunteers and staff at the Danish hospice were created and articulated primarily as a means to prevent volunteers from participating in any direct care-giving
Elliott and Umeh (2013)	Participants also believed that volunteers may sometimes bridge the gap between the patient and the nursing staff, acting almost as a "go between," thereby providing another form of psychological support to the patient	"She said basically the hospice would grind to a halt without the volunteers...and I think that's made it worthwhile" (volunteer) "And you've got to make sure that [you] speak to the staff, not do something off your own bat, that's the thing" (volunteer) Feeling appreciated by the paid staff not only facilitated good relationships between the volunteers and paid staff, but also helped the volunteers to regard their role within the hospice as valuable.	"We used to know more about the patients but it was intruding on their privacy and so...it's a question of need-to-know, and we don't always know what we need to know" (volunteer) The lack of patient information provided to volunteers also seemed to promote the feeling among some of the participants that they were untrustworthy despite having signed a confidentiality agreement.	Some participants mentioned having good relationships with other volunteers and the paid staff as essential for team working. This was considered an important asset for a good volunteer.	It is important that hospice volunteers are aware of and adhere to the boundaries between their roles and those of the paid staff.
Field-Richards and Arthur (2012)	"Maybe they felt a bit kind of threatened if you like, I don't know why they would because I mean we're not professional and you know we're not nurses...I mean we're only here to help you know...we're not looking to take their jobs off them" (Volunteer) there was consensus among volunteers that the current flexible and informal status of their role augmented the	"the nurses treat us with great respect and they're very glad of us and you know we're glad of them...they're wonderful with us" (volunteer) The nature of relationships between volunteers and nurses within the hospice was variable. Those reporting positive relationships with nurses felt that they worked well as a team, were appreciated, and were well supported in their role.	"so I [wasn't] meant to give her digestive biscuits but I didn't know that...we don't know what's wrong with people but sometimes we need to know" (volunteer) There was a perception among volunteers that staff did not always communicate important information required to work effectively within the broadening sphere of hospice volunteering.		There was a perception among volunteers that these boundaries were shifting in response to increasing formality and a changing interface between paid and unpaid work. These changes impacted directly on working relationships.

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Papers in Order of Date (Newest to Oldest)	Understanding of the Role ... Them and Us/ We/Separate but Part of Whole	Hierarchy/ Power/ Recognition/ Feeling “Qualified”	Access to Information/ Trust	Access to Staff/Support/ Role of the Volunteer Coordinator	Boundaries
	quality of nursing care provided				
		Volunteer coordinators should immediately notify volunteers regarding the death of a patient. In addition, providing information about funeral services and allowing volunteers to participate in such grief-related rituals may provide a sense of closure and emotional comfort.	“That is my main coping skill is to talk with out with my volunteer coordinator. When those things happen (stressful experiences) I try to get more information. If the information is something I don’t want to hear, I again, talk it out and that to me has usually been the best way to deal with the stress that I feel from these experiences that I have.” In addition to seeking assistance from the volunteer coordinator, participants sought assistance and advice from a variety of hospice workers including social workers, nurses, and clergy. One participant said she used the interdisciplinary team for assistance		

Continued

Papers in Order of Date (Newest to Oldest)	Understanding of the Role ... Them and Us/ We/Separate but Part of Whole	Hierarchy/ Power/ Recognition/ Feeling "Qualified"	Access to Information/ Trust	Access to Staff/Support/ Role of the Volunteer Coordinator	Boundaries
McKee, Kelley, Guirguis-Younger, MacLean, and Nadin (2010)	"The nurses, they go into the home and it's like, "Okay, I got to get this done and I've got to get that done..." It's very task-oriented... [But] I've seen [volunteers] just being there, that is what they do: they are being there; they sit, they listen." (nurse) It was a significant theme in these interviews that volunteers found it difficult to describe their work in a way that they felt has credibility with formal providers of care, and they were not sure if their role was understood by formal providers.		They know how to relay the needs of the dying and their family members in a way that nurses trust ("They are like our eyes and ears"; "They are very observant and they help us"), and they know how to interpret and manage the formal system in a way that families trust		
Duggal, Farah, Straatman, Freeman, and Dickson (2008)	The hospice has a large pool of active volunteers with diverse talents, skills, and abilities that supplement the work of the professional staff	"At Canuck Place Children's Hospice, I am respected, even though I am a younger member of the team." (volunteer) The morning family volunteer works under the supervision of the school teacher. The study suggests that hospice volunteers benefit from personal growth, as well as improved self-esteem and self-worth from their interactions with patients and staff		"You have a close relationship with the nurses, a one-on-one interaction, which you may not experience in other healthcare settings" (volunteer) forming stronger relationships between staff and volunteers so volunteers feel engaged as part of the overall team.	Evidence must be provided throughout the interview of the following examples of qualities and attributes: Selfawareness and ability to set personal limits and boundaries

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Papers in Order of Date (Newest to Oldest)	Understanding of the Role ... Them and Us/ We/Separate but Part of Whole	Hierarchy/ Power/ Recognition/ Feeling "Qualified"	Access to Information/ Trust	Access to Staff/Support/ Role of the Volunteer Coordinator	Boundaries
Andersson and Ohlen (2005)	Being assigned a constructive task. Volunteers contributed by performing a variety of tasks that were additional to or an enhancement of the work performed by the regular staff, including the inter-professional healthcare team. How positive the experience of being a volunteer was largely depended on how the staff and the volunteer mutually succeeded in identifying suitable tasks and if the volunteer was given clear guidelines on how to perform the tasks. Simply coming to a ward without having a defined task can be experienced as a burden.	She described feeling not important, "because nobody takes any notice what I think about the situation" (volunteer) One volunteer related how uncertain she felt about whether staff noticed that she was there or not. Positive encounters with the hospice are closely related to personal growth.	"That's right. You don't have to know that. But all the time those questions are there in the sick person and within me. I wonder what is wrong with him or her. It may be someone you see a lot, others you never see. I haven't felt OK to ask either, since somehow, we have got to know that we don't need to know what's up with people. I have been careful not to ask. It's as if it's none of my business" (volunteer) The volunteers from another hospice recounted how staff clearly told them that it was not that important for the volunteers to know what sickness the patients were afflicted with because the volunteer could still do a good job.	The social contact with the hospice, the security of being familiar with staff, and the opportunity of contributing something to compensate for the support that their own relative had been given, were important reasons.	Volunteers may feel uncertainty about what is expected of them and they are afraid to "cross over into the domain of the nurses."
Dein and Abbas (2005)	Several pointed out how their roles were different from or complementary to those of professional staff and they perceived little competition between the groups.	Much of this satisfaction might derive from the ideology of the hospice movement which involves three core ideas: ... the delivery of such care by nonhierarchical multidisciplinary teams which values the skills and contributions of individual team members rather than their status or qualifications in our study volunteers generally reported feeling valued and morale was perceived to be high in the hospice generally. A number of factors might relate to this high level of satisfaction and morale: ... positive feedback from professional staff	In relation to this there is a need for volunteers who will be working with patients to be given more information about the disease processes they will encounter and the issues of disfigurement that they will encounter in their jobs. Specifically, they should be taught the basic presentations of cancer, the common treatment modalities, cure versus palliation and alternative therapies. However, issues of confidentiality prohibit volunteers having direct access to patients' medical records.	"Also the Day hospice nurses. They are always there and say repeatedly that "we are here, if there are any problems please come and speak to us." We have a very good relationship." (volunteer) Generally, volunteers reported good working relationships with professional staff	One source of stress derives from "boundary conflicts" tensions between paid staff and volunteers over the work done by volunteers and the information (often deemed confidential) about patients that they wanted...

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Papers in Order of Date (Newest to Oldest)	Understanding of the Role ... Them and Us/ We/Separate but Part of Whole	Hierarchy/ Power/ Recognition/ Feeling “Qualified”	Access to Information/ Trust	Access to Staff/Support/ Role of the Volunteer Coordinator	Boundaries
Sadler and Marty (1998)	The use of the pronoun "we" when referring to hospice was common among all those interviewed.	“As a member of the team I feel that my reports are just as important as any of the other members. I can honestly say that no team member carries any more weight than anyone else. Each member has his or her area of expertise and then it is put on the table and we make a decision based on that information.” (volunteer) the executive director, despite her hierarchical role in the organization, made the volunteers feel like an important part of the organization. “it’s the small things that the staff does for me that makes me feel good about my work” (volunteer) ... In short, while people expressed different levels of desire for recognition, many of the volunteers admitted that the informal and formal recognition they received was an important part of their desire to be volunteers. “ .. as long as hospice allows me to grow and helps me to understand myself as an individual, I will continue my relationship with the organization.” (volunteer) it is important to make sure that volunteers attending team meetings arc made to feel comfortable, given advice on how to contribute to the meetings, and made to feel as much of an "expert" as the others at the meeting.		“Although (the coordinator and director] do a good job of setting us up for the realities of volunteering, I think they should spend some time with us at the end of training and discuss our needs. I think it would be very beneficial to me and to other volunteers if we could sit down one-to-one with (them] and discuss how we can meet both hospice’s needs as well as my needs.” (volunteer) All of the interpersonal turning points emphasized the importance of interacting with hospice staff, volunteers, patients, and patients’ families. Of these, the most important turning point, mentioned by all 17 volunteers, was the quality of interaction they had with hospice staff during training. In this study, the two main people involved regularly in training were the training coordinator and the executive director.	

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Paradis, Miller, and Runnion (1987)	Role ambiguity refers to conflicting obligations and responsibilities experienced by volunteers. For example, is the volunteer a patient advocate, a staff advocate, or both? Can a volunteer assume direct care responsibilities for a patient, or is that solely within the purview of staff?	Although volunteers felt comfortable working with staff, they were often unsure of their status in the organizational hierarchy They felt that staff should give them more feedback about the quality of their work.	Eight noted that they wanted more information from staff and expected greater staff-initiated communication with them.	The staff most directly in contact with the volunteers were the volunteer coordinator, nurse, and social worker. When asked to name the staff with whom they worked, most volunteers named a nurse.

Supplement 3. Example of Initial Data Extraction Form for One Included Paper

Overgaard (2015) The boundaries of care work: a comparative study of professionals and volunteers in Denmark and Australia

Themes	Participant Quotes (First Order Constructs)	Primary Author Interpretations (Second Order Constructs)
Boundaries/ stepping on toes	"And it's the certainty that there is a razorsharp line between being a professional and being a volunteer. The volunteers must of course not in any way interfere in the care." (Hospice Leader, Denmark) "And there was no clear-cut delineation of what they could and couldn't do. So, they might be feeding patients. Do they know how to assess [if patients] can or cannot swallow?" (Nurse Unit Manager, Australia)	Boundaries between volunteers and staff at the Danish hospice were created and articulated primarily as a means to prevent volunteers from participating in any direct caregiving Observational data revealed that volunteers at the Danish hospice were allocated practical, labour-intensive type jobs. Anything that involved direct care was off-limits to the volunteers; until recently, volunteers were not even allowed to enter the rooms of the patients
Understanding of the role ... them and us/we/ separate but part of whole	"We are the cake, and they are the cream. That is extremely important because they are not taking any piece of the cake. That is the difference between volunteers and professionals." (Hospice Leader, Denmark)	(Australian) The use of volunteers was not understood to pose a risk to paid staff positions the volunteers at the Australian hospice perform work that overlaps with that of nurses and social workers in particular
Access to information/trust	"A volunteer came up to me after dinner and asked, "How old is that patient?" It may seem like an innocent question, (...) but we are not allowed [to tell]." (Nurse, Denmark) "There are times when we have raised concerns that a new patient has arrived and we, as hosts, haven't been informed that the person is almost blind or deaf." (Volunteer, Denmark)	The Danish hospice took a rather strict approach to confidentiality, which consisted of two layers: one between the paid staff and volunteers, and another between the volunteers and the outside world The strict approach to confidentiality sometimes made it difficult for the volunteers to perform their roles. Although confidentiality might be understood as a means of protecting care receivers, it might also be understood to protect paid staff from interference by volunteers. (Australian) The resignation and a change in management saw the volunteers' engagement significantly restricted to include less autonomous roles and required volunteers to work under supervision. Yet, at the time of data collection, volunteers were still trusted with extensive responsibilities and volunteers shared many job functions with the nursing staff and social workers, including work that required high levels of competency.

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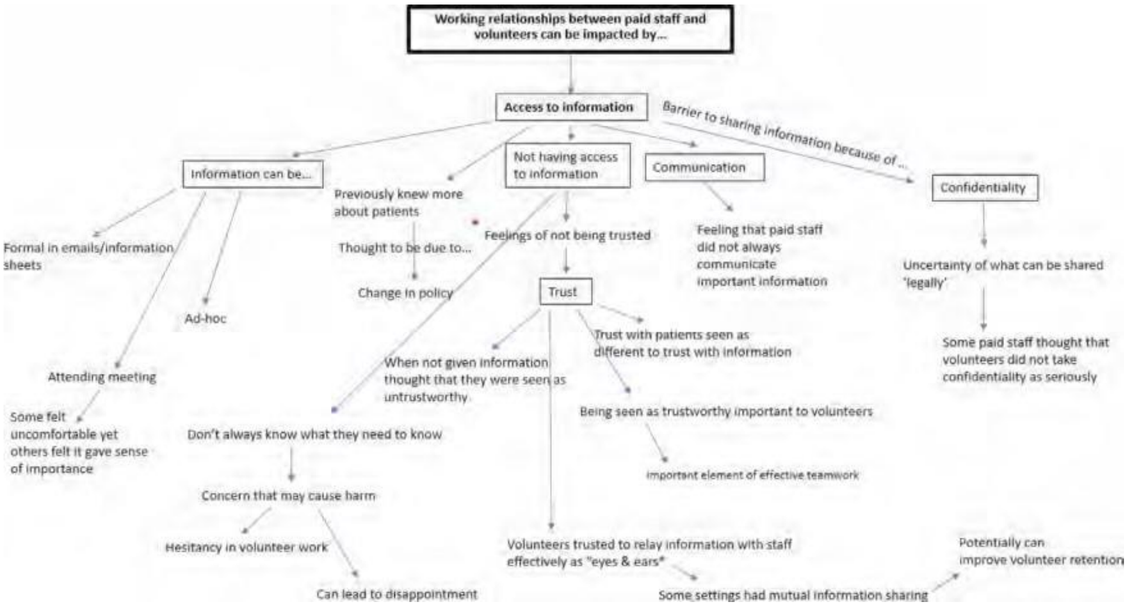
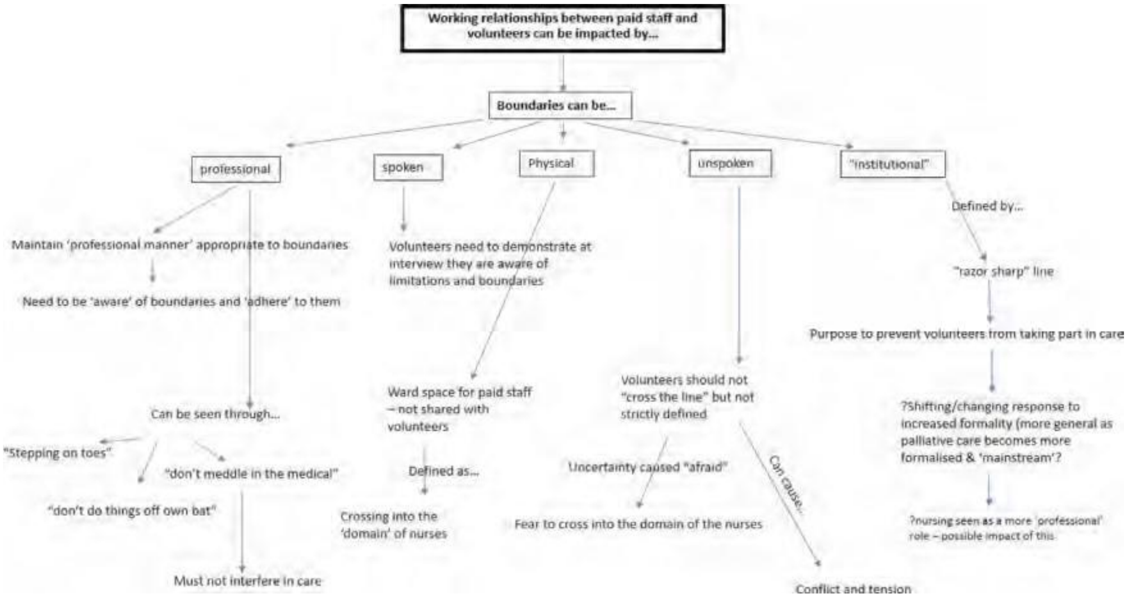
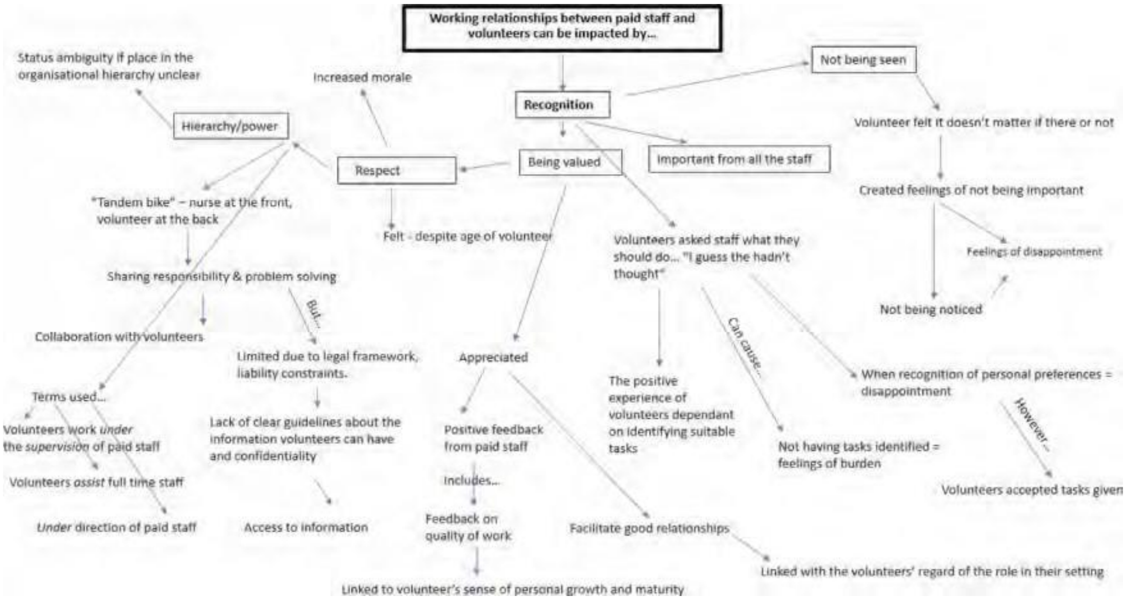
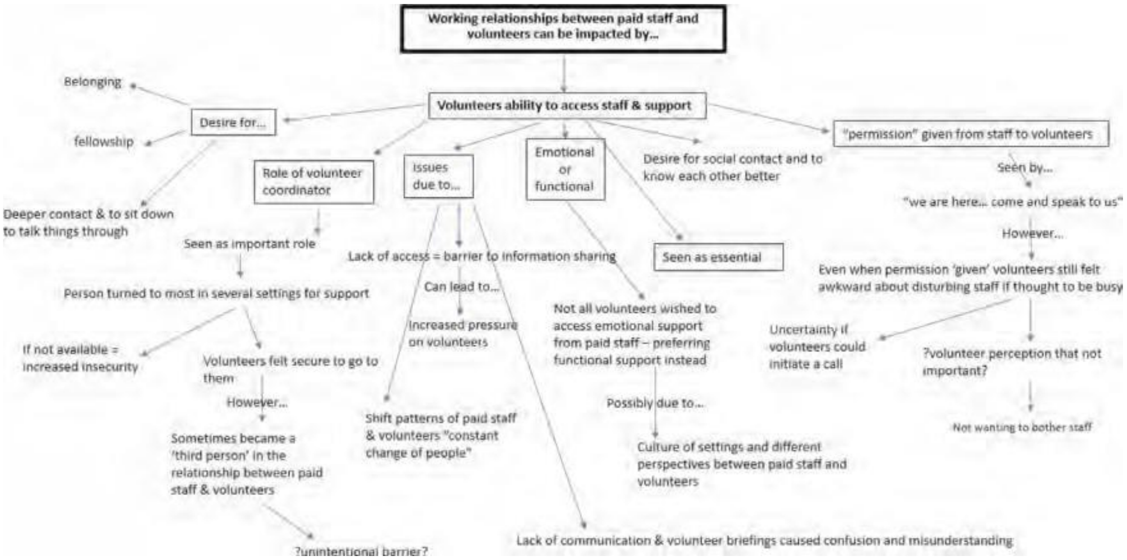
Themes	Participant Quotes (First Order Constructs)	Primary Author Interpretations (Second Order Constructs)
		At the Australian hospice, the concern for confidentiality was addressed in the same way with staff and volunteers, i.e., through education and monitoring. This approach to confidentiality reflected the general hospice culture of volunteers being trusted like other staff.
Hierarchy/ power		Danish professionals have effectively managed to maintain a monopoly over caregiving, which has resulted in a successful professionalisation project

Supplement 4. Concept Maps for Each Stary Line

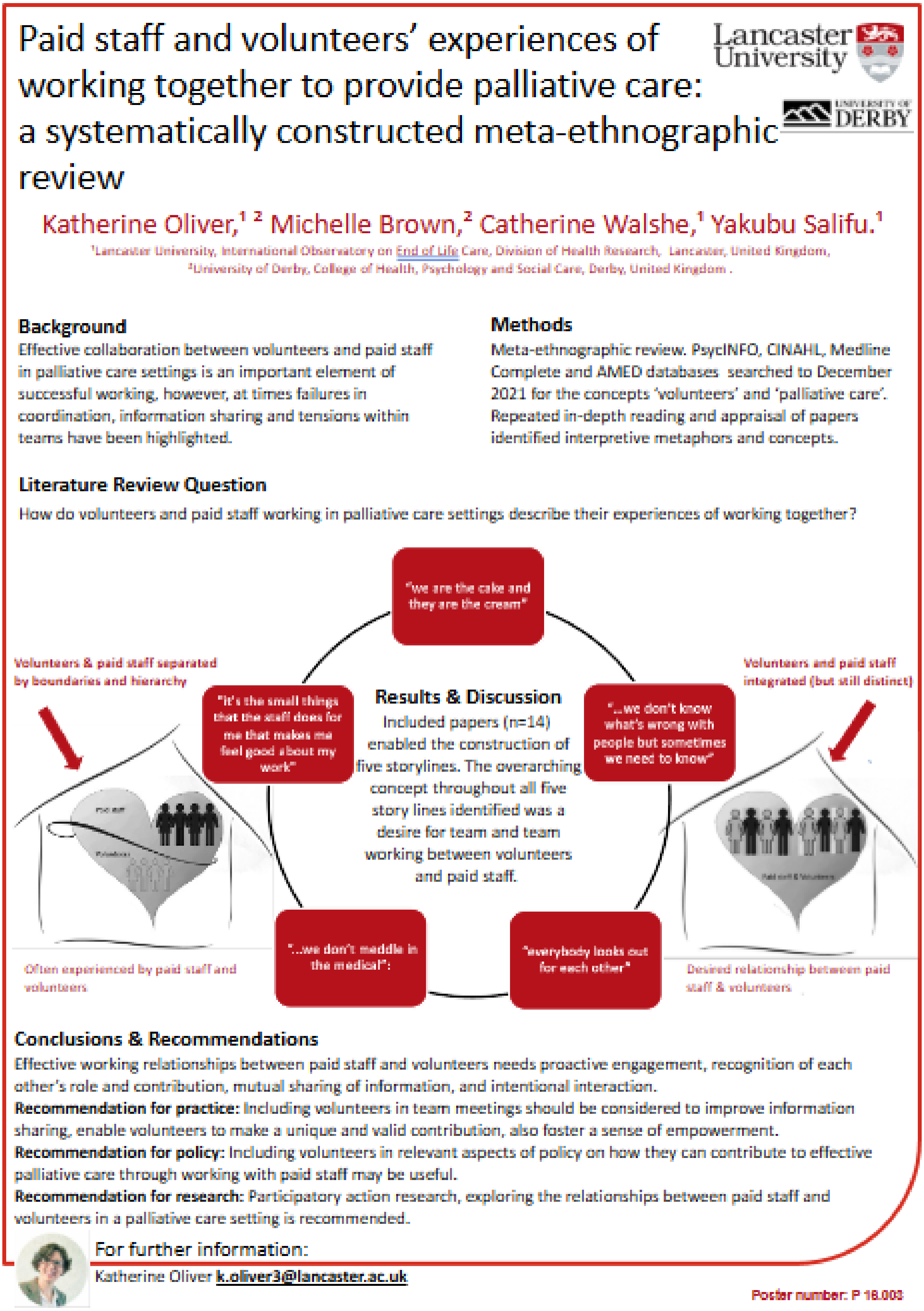





Working relationships between paid staff and volunteers can be impacted by…
Recognition
Not being seen
Volunteer felt it doesn't matter if there or not
Created feelings of not being important
Feelings of disappointment
Not being noticed
Important from all the staff
Being valued
Respect
Increased morale
Hierarchy/power
Status ambiguity if place in the organisational hierarchy unclear
"Tandem bike" – nurse at the front, volunteer at the back
Sharing responsibility & problem solving
But…
Collaboration with volunteers
Limited due to legal framework, liability constraints.
Lack of clear guidelines about the information volunteers can have and confidentiality
Access to information
Terms used…
Volunteers work *under* the *supervision* of paid staff
Volunteers *assist* full time staff
Under direction of paid staff
Felt - despite age of volunteer
Appreciated
Positive feedback from paid staff
Includes…
Feedback on quality of work
Linked to volunteer's sense of personal growth and maturity
Facilitate good relationships
Linked with the volunteers' regard of the role in their setting
Volunteers asked staff what they should do… "I guess the hadn't thought"
The positive experience of volunteers dependant on identifying suitable tasks
Can cause…
Not having tasks identified = feelings of burden
When recognition of personal preferences = disappointment
However…
Volunteers accepted tasks given


Working relationships between paid staff and volunteers can be impacted by…
Volunteers ability to access staff & support
Desire for…
Belonging
fellowship
Deeper contact & to sit down to talk things through
Role of volunteer coordinator
Seen as important role
Person turned to most in several settings for support
If not available = increased insecurity
Volunteers felt secure to go to them
However…
Sometimes became a 'third person' in the relationship between paid staff & volunteers
?unintentional barrier?
Issues due to…
Lack of access = barrier to information sharing
Can lead to…
Increased pressure on volunteers
Shift patterns of paid staff & volunteers "constant change of people"
Lack of communication & volunteer briefings caused confusion and misunderstanding
Emotional or functional
Not all volunteers wished to access emotional support from paid staff – preferring functional support instead
Possibly due to…
Culture of settings and different perspectives between paid staff and volunteers
Desire for social contact and to know each other better
Seen as essential
"permission" given from staff to volunteers
Seen by…
"we are here… come and speak to us"
However…
Even when permission 'given' volunteers still felt awkward about disturbing staff if thought to be busy
Uncertainty if volunteers could initiate a call
?volunteer perception that not important?
Not wanting to bother staff

Appendix B Poster of the meta-ethnographic literature review



Paid staff and volunteers' experiences of working together to provide palliative care: a systematically constructed meta-ethnographic review

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Background

Effective collaboration between volunteers and paid staff in palliative care settings is an important element of successful working, however, at times failures in coordination, information sharing and tensions within teams have been highlighted.

Methods

Meta-ethnographic review. PsycINFO, CINAHL, Medline Complete and AMED databases searched to December 2021 for the concepts 'volunteers' and 'palliative care'. Repeated in-depth reading and appraisal of papers identified interpretive metaphors and concepts.

Literature Review Question

How do volunteers and paid staff working in palliative care settings describe their experiences of working together?

Results & Discussion

Included papers (n=14) enabled the construction of five storylines. The overarching concept throughout all five story lines identified was a desire for team and team working between volunteers and paid staff.

"we are the cake and they are the cream"

"...we don't know what's wrong with people but sometimes we need to know"

"everybody looks out for each other"

"...we don't meddle in the medical":

"It's the small things that the staff does for me that makes me feel good about my work"

Volunteers & paid staff separated by boundaries and hierarchy

Often experienced by paid staff and volunteers

Volunteers and paid staff integrated (but still distinct)

Desired relationship between paid staff & volunteers

Conclusions & Recommendations

Effective working relationships between paid staff and volunteers needs proactive engagement, recognition of each other's role and contribution, mutual sharing of information, and intentional interaction.

Recommendation for practice: Including volunteers in team meetings should be considered to improve information sharing, enable volunteers to make a unique and valid contribution, also foster a sense of empowerment.

Recommendation for policy: Including volunteers in relevant aspects of policy on how they can contribute to effective palliative care through working with paid staff may be useful.

Recommendation for research: Participatory action research, exploring the relationships between paid staff and volunteers in a palliative care setting is recommended.

For further information:

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Poster number: P 18.003

Appendix C The eMERGe meta-ethnography reporting guidance from: France, et al (2019). Improving reporting of meta-ethnography: the eMERGe reporting guidance. *BMC Medical Research Methodology, 19*(1), 25. **https://doi.org/10.1186/s12874-018-0600-0**

No.	Criteria Headings	Reporting Criteria
Phase 1—Selecting meta-ethnography and getting started		
Introduction		
1	Rationale and context for the meta-ethnography	Describe the gap in research or knowledge to be filled by the meta-ethnography, and the wider context of the meta-ethnography
2	Aim(s) of the meta-ethnography	Describe the meta-ethnography aim(s)
3	Focus of the meta-ethnography	Describe the meta-ethnography review question(s) (or objectives)
4	Rationale for using meta-ethnography	Explain why meta-ethnography was considered the most appropriate qualitative synthesis methodology
Phase 2—Deciding what is relevant		
Methods		
5	Search strategy	Describe the rationale for the literature search strategy
6	Search processes	Describe how the literature searching was carried out and by whom
7	Selecting primary studies	Describe the process of study screening and selection, and who was involved
Findings		
8	Outcome of study selection	Describe the results of study searches and screening

Phase 3—Reading included studies		
Methods		
9	Reading and data extraction approach	Describe the reading and data extraction method and processes
Findings		
10	Presenting characteristics of included studies	Describe characteristics of the included studies
Phase 4—Determining how studies are related		
Methods		
11	Process for determining how studies are related	Describe the methods and processes for determining how the included studies are related: - Which aspects of studies were compared AND - How the studies were compared
Findings		
12	Outcome of relating studies	Describe how studies relate to each other
Phase 5—Translating studies into one another		
Methods		
13	Process of translating studies	Describe the methods of translation**:** - Describe steps taken to preserve the context and meaning of the relationships between concepts within and across studies- Describe how the reciprocal and refutational translations were conducted- Describe how potential alternative interpretations or explanations were considered in the translations

Findings		
14	Outcome of translation	Describe the interpretive findings of the translation.
Phase 6—Synthesizing translations		
Methods		
15	Synthesis process	Describe the methods used to develop overarching concepts (“synthesised translations”)Describe how potential alternative interpretations or explanations were considered in the synthesis
Findings		
16	Outcome of synthesis process	Describe the new theory, conceptual framework, model, configuration, or interpretation of data developed from the synthesis
Phase 7—Expressing the synthesis		
Discussion		
17	Summary of findings	Summarize the main interpretive findings of the translation and synthesis and compare them to existing literature
18	Strengths, limitations, and reflexivity	Reflect on and describe the strengths and limitations of the synthesis: - Methodological aspects—for example, describe how the synthesis findings were influenced by the nature of the included studies and how the meta-ethnography was conducted.- Reflexivity—for example, the impact of the research team on the synthesis findings
19	Recommendations and conclusions	Describe the implications of the synthesis

Appendix D Search strategy for meta-ethnographic literature review

Search terms used in AMED

Sequence	Search terms	Limiters	Results
S3	S1 & S2	Peer Reviewed Journal, English	473
S2	Volunteers OR TI (volunteer* OR voluntary OR unpaid) OR AB (volunteer* OR voluntary OR unpaid)	None	6,993
S1	"Palliative Care" OR "Assisted Suicide" OR "Euthanasia" OR "Terminally Ill Patients" OR "Hospice" OR "Bereavement" OR "Grief" OR "Respite Care") OR TI (Palliat* OR Terminal* OR bereave* OR endstage OR "end stage" OR "advanced stage" OR "last stage" OR "late stage" OR "final stage" OR dying OR "end of life" Or end-of-life OR hospice OR "supportive care" OR (death N5 (grief OR mourn* OR loss))) OR AB (Palliat* OR Terminal* OR bereave* OR endstage OR "end stage" OR "advanced stage" OR "last stage" OR "late stage" OR "final stage" OR dying OR "end of life" Or end-of-life OR hospice OR "supportive care" OR (death N5 (grief OR mourn* OR loss))	None	22,322

Search terms used in PsychInfo

Sequence	Search terms	Limiters	Results
S3	S2 & S2	Peer Reviewed Journal, English	1,212
S2	DE "Volunteers" OR TI (volunteer* OR voluntary OR unpaid) OR AB (volunteer* OR voluntary OR unpaid)		70,095
S1	DE "Palliative Care" OR DE "Assisted Suicide" OR DE "Euthanasia" OR DE "Terminally Ill Patients" OR DE "Hospice" OR DE "Bereavement" OR DE "Grief" OR DE "Respite Care") OR TI (Palliat* OR Terminal* OR bereave* OR endstage OR "end stage" OR "advanced stage" OR "last stage" OR "late stage" OR "final stage" OR dying OR "end of life" Or end-of-life OR hospice OR OR "supportive care" OR (death N5 (grief OR mourn* OR loss))) OR AB (Palliat* OR Terminal* OR bereave* OR endstage OR "end stage" OR "advanced stage" OR "last stage" OR "late stage" OR "final stage" OR dying OR "end of life" Or end-of-life OR hospice OR "supportive care" OR (death N5 (grief OR mourn* OR loss))		80,046

Search terms used in CINAHL			
S3	S1 & S2	English Language; Peer Reviewed	1,882
S2	(MH "Volunteer Experiences") OR (MH "Volunteer Workers")) OR TI (volunteer* OR voluntary OR unpaid) OR AB (volunteer* OR voluntary OR unpaid	none	76,487
S1	(MH “Hospice and Palliative Nursing”) OR (MH “Palliative Medicine”) OR (MH “Palliative Care”) OR (MH “Hospice and Palliative Nurses Association”) OR (MH “Terminal Care”) OR (MH “Hospice Care”)) OR TI (Palliat* OR Terminal* OR bereave* OR endstage OR “end stage” OR “advanced stage” OR “last stage” OR “late stage” OR “final stage” OR dying OR “end of life” Or end-of-life OR hospice OR “supportive care” OR (death N5 (grief OR mourn* OR loss))) OR AB (Palliat* OR Terminal* OR bereave* OR endstage OR “end stage” OR “advanced stage” OR “last stage” OR “late stage” OR “final stage” OR dying OR “end of life” Or end-of-life OR hospice OR “supportive care” OR (death N5 (grief OR mourn* OR loss))	none	149,402

Search terms used in MEDLINE Complete			
Sequence	Search terms	limiters	Results
S4	S1 & S2 & S3	English Language; Scholarly (Peer Reviewed) Journals	1,008
S3	(MH "Qualitative Research+") OR TI (experience OR interview* OR qualitative OR experience* OR “semi-structured” OR semistructured OR unstructured) OR AB (experience OR interview* OR qualitative OR experience* OR “semi-structured” OR semistructured OR unstructured)	none	1,069
S2	(MH "Volunteers+") OR (MH "Hospital Volunteers") OR TI (volunteer* OR voluntary OR unpaid) OR AB (volunteer* OR voluntary OR unpaid)	none	297,492
S1	(MH "Palliative Care") OR (MH "Palliative Medicine") OR (MH "Hospice and Palliative Care Nursing") OR (MH "Hospices")) OR (Palliat* OR Terminal* OR bereave* OR endstage OR "end stage" OR "advanced stage" OR "last stage" OR "late stage" OR "final stage" OR `dying OR "end of life" Or end-of-life OR hospice OR "supportive care" OR (death N5 (grief OR mourn* OR loss)) OR (Palliat* OR Terminal* OR bereave* OR endstage OR "end stage" OR "advanced stage" OR "last stage" OR "late	none	856,435

	stage" OR "final stage" OR dying OR "end of life" Or end-of-life OR hospice OR "supportive care" OR (death N5 (grief OR mourn* OR loss)		

Appendix E Main characteristics of included papers

Author, Year & Country	Aim/s	Setting/Context/Service Description	Sample		Methodology & Method	Themes/Key Findings
Sangild Stølen 2021 Denmark	To explore the challenges experienced in volunteer-professional care-giver cooperation in the general palliative care provided in nursing homes.	Looking at care provision in two nursing homes as part of general palliative care offered in Denmark.	Observations of volunteers (n= 50-60) Interviews with volunteers (n=9) Professional caregivers (n=13)		Participant observations and interviews Sociological phenomenological approach	Symbolic indications of 'them-an us'. Unspoken boundaries. Volunteers do the fun stuff. Meanings and actions regarding residents' best interests. Social activities support the wellbeing c the individual resident. Shielding the residents from excessive activity. The link, which was seen as the activity co-ordinator.
Vanderstichelen et al., 2020 Belgium	To describe volunteer roles across care settings through the perspective of those closely involved in the care of terminally ill people.	Participants were recruited from hospital, home, day care and live-in services	Volunteer (n=28) Palliative care nurse (n=4) Palliative care psychologists (n=6) Family		Focus groups and individual interviews using a phenomenological epistemology.	Volunteers as 'the other face of care', focus on psychological, social and existential care, and building relationships/ The limina space of volunteers. Barriers to and facilitators of volunteer role performance.
Vanderstichelen et al., 2019 Belgium	To explore what constitutes volunteer-professional collaboration around palliative care	Palliative care volunteers in Belgium provide direct patient care. Their contribution comprises of a wide range of tasks, including practical and nursing tasks. Their main contribution is psychological,	Volunteer (n=28) Palliative care nurse (n=4) Palliative care psychologist (n=6)		Semi-structured focus groups and interviews a qualitative descriptive design with 'grounded theory and	Contact with professional caregivers. Support from healthcare professionals. Information sharing and coordination. Barriers to and facilitators of volunteer-professional collaboration.

		existential and signposting care tasks.	Family physician (n=12)		phenomenological overtones’	
Cloyes et al., 2017 USA	To describe how inmate volunteers learn hospice care through formal education and training, supervised practice, guidance from more experienced inmates and support from correctional staff.	The Louisiana State Penitentiary Prison Hospice Program (largest maximum-security prison in the US)	Observational data In-depth interviews with: Correctional officers (n=5) Medical & hospice staff (n=14) Inmate hospice volunteers (n=24)		Ethnographic study including in-depth interviews and observational data	Learning to care: included formal training and education for prospective volunteers, practical experience at the bedside, forma & informal peer mentorship, interactions with medical and correctional staff.
Overgaard 2015 Denmark and Australia	To develop an understanding of the principles and conflicts that shape the division of labour (between volunteer and paid staff).	Two hospices – one located in Denmark and one in Australia	Volunteer co-ordinator (current & former) (n=3) Hospice leader (n=1) Nurse unit manager (n=2) Social worker (n=1) Diversional therapist (n=1) Pastoral care manager (n=1) Nurse (n=5) Volunteers (n=26) Kitchen staff (n=1)		A comparative case study approach involving non-participant observation and unstructured interviews.	Within the Danish hospice the boundaries between volunteers and paid staff were discussed as means of preventing volunteers from participating in direct care-giving. This was in contrast to the Australian hospice, in which direc personal patient care was ‘not of limits to volunteers’.

Elliott & Umeh 2013 UK	To examine the psychological experiences of volunteer carers in a UK hospice.	Participants were from one UK hospice in the Northwest of England	Voluntary carers (n=9)		Qualitative design Unstructured interview format. Data were analysed using a grounded theory protocol.	Motivation to volunteer, which included feeling that they were giving something back. Volunteering skills, including bein aware and adhering to boundarie between their roles and those of paid staff. Psychological support and holistic care. Perceptions of the hospice. Performance hinderances, this theme included relationships between the paid staff and volunteers were occasionally a source of tension.
Field-Richards & Arthur 2012 UK	To explore the nurse – volunteer relationship in a day hospice.	One day care hospice in the East Midlands in England.	Day hospice volunteers (n=12)		Underpinned by a qualitative interpretive approach Semi-structured interviews	Formalization, which included a structured induction, interview process & regulations. Division of labour. Working relationships, including those between volunteers and nurses.
Brown 2011 USA	To examine the coping techniques utilized by hospice volunteers.	Study participants were recruited by a letter invitation sent to 70 volunteer coordinators who were members of the western state Hospice & Palliative Care Association.	Hospice volunteers (n=15)		A combination of Phenomenological & hermeneutic methods semi-structured interviews	Volunteers used problem-focused coping, which included seeking advice from members of the hospice inter-disciplinary team. Emotion-focused coping, meanin making through appraisal and physical techniques. The most significant coping mechanism wa talking with the volunteer coordinator.
McKee et al., 2010	To better understand the role of hospice volunteers in the rural	North-western Ontario	Included hospice volunteers, Family members, members		‘focused ethnography’	Volunteers have time to be there ‘just sit’ and time to listen. Time for a real relationship. Volunteers

Canada	context. Especially in what ways their contribution to end-of-life care is unique or irreplaceable.		of the senior's club, Health professionals, a hospital administrator, members of the clergy, funeral director, police and ambulance personnel.		13 individual 'loosely structured' interviews and 8 focus groups, field notes, photographs.	hold the dying person in community. Between friends and professionals: a unique circle of care.
Duggal et al 2008 USA	To present the unique volunteer roles and experiences at the children's hospice and share ways that volunteers work to support the efforts of the clinical team.	Based at a hospice providing free of charge hospice care to children and their families living with life threatening illness.	Volunteer director (n=1) Volunteers (not stated)		Descriptive design and interviews	Volunteer selection is important ensuring a cohesive workforce. Training equips volunteers to wo with confidence. It is important t ensure volunteer stability and satisfaction.
Anderson & Öhlén 2005 Sweden	To obtain an understanding of what it means to be a hospice volunteer in a country without a tradition of hospice or palliative volunteer care services.	Three hospices in central & western parts of Sweden	Volunteers (n=10)		Phenomenological hermeneutic approach Interviews	Why volunteers get involved in hospices, including their motives for becoming involved in hospice Encountering the hospice, which included subthemes of 'getting t know the atmosphere of the hospice', 'being assigned a constructive task' and 'longing fo fellowship'. Encountering the patient, which included three subthemes of 'wanting to understand the needs of the patient', 'imagining what fills the patient's thoughts and time' and 'retaining the encounter with the dying patient'.

Dein & Abbas 2005 UK	To establish the stresses that volunteers have to cope with in a hospice setting. To examine the ways that volunteers cope with these stresses. To examine the perceptions that volunteers have about the support provided by qualified staff at the hospice.	Volunteers from an 8-bedded in-patient unit and 10 day places.	Volunteers (n=17)		Two focus groups. Data were analysed using thematic analysis. Groups were facilitated by a psychiatrist and two palliative care doctors.	Stressors included losing patients and dealing with disfigurement. Work was generally reported ass satisfying and stress-free. Coping strategies included keeping a distance from clients & religious faith. Support was generally perceived as adequate.
Sadler & Marty 1998 USA	To examine the turning points volunteers found important in their hospice training and volunteer experiences.	The study took place in a small hospice organization with 8 paid staff and approximately 40 volunteers.	Volunteers (n=17)		Semi-structured interviews Turning point analysis	Pre-hospice turning points – personal events, such as persona experiences with death and dying Interpersonal turning points – interpersonal events, including interaction with hospice staff. Group turning points – included small group interactions, structur support, recognition, and status and membership.
Paradis, Miller & Runnion 1987 USA	To explore the primary stressors experienced by volunteers providing direct patient care.	Data collected from 5 research sites in Kentucky and New York	Volunteers (n=17)		In-depth interviews with four open-ended questions.	Volunteer stress found to be in four main areas - role ambiguity, status ambiguity, patients and families, and stress related to the volunteer's personal circumstances.

Appendix F Summary of first and second order constructs for each paper, and the storylines identified.

Example of Participant quotes (First order constructs) indicated in italics

Example of Primary author interpretation (Second order constructs) indicated in normal text

Papers in order of date (newest to oldest)	**Understanding of the role … them and us/we/separate but part of whole**	**Hierarchy/ Power/Recognition/ Feeling 'Qualified'**	**Access to information/ Trust**	**Access to staff/support/role of the volunteer coordinator**	**Boundaries**
Stølen (2021)	*'We can do better. I feel we sometimes look at [the volunteers] as "them" and then there's "us". We do our work and focus on that, but we do not connect it to the volunteers' work. They're a great part of what we can offer' (care assistant)* The analysis identified phenomena encapsulating features of meanings derived from interactions between volunteers and	*I'm afraid of stepping on someone's toes. I do not want my work to come at the cost of professional resources... (volunteer)*	*'They can ask me about things I'm not allowed to tell them about. It is about confidentiality. Then you try to find a way, so the resident does not lose their dignity' (care assistant).* The professional	*(About coordinators) 'It's a barrier when we don't arrange encounters between volunteers and professional caregivers (...) It isn't enough for the activity coordinator to have third-person contact to the volunteers. If they are not on the ward, we do not get to know each other. It is about trust. It is about developing a mutual understanding'. (Care assistant)* For professional caregivers, the activity coordinator role communicated priorities about the primary contact and responsibility for volunteers and cooperating with them about offered social care activities. Some professional	*...I want to respect the boundaries' (volunteer) …* When volunteers went to the ward to pick up a resident to participate in an activity or deliver a resident to their room afterward, they reported feeling that they crossed an institutional boundary, which they understood as entering the professional caregivers' domain. In this space, they felt uncertain about whether they unknowingly crossed pre- established and unspoken boundaries.

	professional caregivers that communicated a ‘them- and- us’ understanding. This made cooperating on care activities for residents more challenging for both groups		obligation of confidentiality was a strong symbol for volunteers and professional caregivers alike, communicating their differing knowledge, roles, and authority, as well as the protection of the residents’ personal integrity. Knowing what information could be given to volunteers was not always easy.	caregivers felt that this role could be a barrier to daily cooperation and mutual under-standing.	
Vanderstichelen, Cohen,	Volunteers were found to represent an ‘other’, more approachable ‘face			*‘I think the problem for us is also, with us the nurses work- two nurses work, er, 2 days in the week, one works 3 days. Er,*	*‘The point is that we don’t meddle in the medical…’ (volunteer)*

Van Wesemael, Deliens, and Chambaere (2020)	of care’ and to occupy a liminal space between and overlapping the professional and the family domains.			*the occupational therapist, er, er, Monday, Wednesday and the week after on Wednesday, Friday. So, it’s a constant change of people. A lot has to be done and settled in between. And then I think that the communication, I feel, falls short…’ (volunteer)* *Lack of support and coordination for the volunteers* impeded their role of ‘being there’ and the development of the relationship with the dying person… However, when support and coordination were present, participants indicated they facilitated volunteer role performance.	Professional care givers indicated that volunteers should not cross the line when providing psychological guidance. However, these boundaries were never strictly defined.
Vanderstichelen, Cohen, Van Wesemael, Deliens, and Chambaere (2019)	Our study shows that volunteers and nurses assume complementary roles, work together cooperatively	*‘You have a tandem bike. The nurse is at the front and the volunteer is at the back because you’re responsible for this together and*	*‘What I have issues with sometimes, but I don’t have that much experience with palliative volunteers, but I think that maybe it applies to*	*‘Just your functioning in the group, what you think is good, what you think is bad, what they think should be improved. That sounds very, very harsh now, right? But it’s brought in a very soft manner and always ends (laughs) on a positive note. (.) But it gives you the chance, I think, to talk openly for once without someone*	

		together you brief each other'. (volunteer) Patients and family carers described the volunteer-nurse relationships as hierarchical, suggesting that volunteers are there to support nurses and that health care professionals provide directions to volunteers Family physicians were unclear about	*volunteering in general - regarding professional confidentiality, I have issues with it. I once met a volunteer who really came into my practice: 'Oh and that patient,' you see. And I was like whoah, whoah. I don't have to tell you all of this. (.) No, regarding professional confidentiality, I sometimes think - Because you can be a palliative volunteer and*	*else present, without stepping on toes' (volunteer)* Participants described two types of support that health care professionals offered volunteers while working together: functional support and emotional support.	

		whether volunteers are allowed to take part in illness trajectory discussions with patients and whether they were qualified for this.	*be involved, but if you start spreading that around to everyone, then I think .. I think it's tough. We're so strictly bound to that, but they're not. At least I think not, legally?' … 'They are in principle. (…) They don't always take it that seriously, yeah' (Family physicians)* volunteer-nurse collaboration was characterized		

			by mutual information-sharing about the patient's condition and its development		
Cloyes et al. (2017)	The inmate hospice volunteer role represents a unique hybrid between the roles of hospice volunteers, nurse assistants and family caregivers found outside the prison in community-based hospice programs.	*'[b]e a resource to them. When they ask questions, answer the questions; give them the best answer that you can; and do the research that you need to do in order to give them that. They're going to suck [the information] up like a sponge. And then they'll be able to use it in the future. They want this to*	The work of becoming a volunteer involves learning to trust; being able to trust not only others, but also trusting oneself and being trustworthy. This sense of trust is foundational to the teamwork and sense of stewardship described by inmates and staff, and to how they represent the hospice program to	Despite the availability of grief counseling offered by the hospice social worker, every volunteer interviewed stated that they preferred to discuss their experiences with their mentors and fellow volunteers.	LSP nurses also stressed the importance of interacting with volunteers in a professional manner, maintaining appropriate boundaries while also recognizing the value of volunteers as the front-line members of the hospice care team.

		work.' (nurse) Volunteers described how an ongoing willingness to learn from their patients and each other was essential to being a "good" volunteer… This ethic of continuous learning is valued; good volunteers continue to educate themselves and each other as they gain more experience. 'They get a very, very close	inmates outside the unit.		

		relationship or rapport with the [patients]… That's why we really respect whenever they say something's wrong with one of the patients, they see those declining health issues.' (nurse)			
Overgaard (2015)	*'We are the cake and they are the cream. That is extremely important because they are not taking any piece of the cake. That is the difference between volunteers and professionals.' (Hospice Leader, Denmark)*	Danish professionals have effectively managed to maintain a monopoly over care-giving, which has resulted in a successful professionali	*'A volunteer came up to me after dinner and asked, 'How old is that patient?' It may seem like an innocent question,(...) but we are not allowed*		*'And it's the certainty that there is a razor-sharp line between being a professional and being a volunteer. The volunteers must of course not in any way interfere in the care'. (Hospice Leader, Denmark)* Boundaries between volunteers and staff at the Danish hospice were created and articulated primarily as a means to prevent volunteers from participating in any direct care-giving

	the volunteers at the Australian hospice perform work that overlaps with that of nurses and social workers in particular	sation project	*[to tell].' (Nurse, Denmark)* The strict approach to confidentiality sometimes made it difficult for the volunteers to perform their roles.		
Elliott and Umeh (2013)	Participants also believed that volunteers may sometimes bridge the gap between the patient and the nursing staff, acting almost as a 'go between', thereby providing another form of psychological support to the patient	*'She said basically the hospice would grind to a halt without the volunteers… and I think that's made it worthwhile' (volunteer)* *'And you've got to make sure that*	*'We used to know more about the patients but it was intruding on their privacy and so…it's a question of need-to-know, and we don't always know what we need to know' (volunteer)*	Some participants mentioned having good relationships with other volunteers and the paid staff as essential for team working. This was considered an important asset for a good volunteer.	It is important that hospice volunteers are aware of and adhere to the boundaries between their roles and those of the paid staff.

		[you] speak to the staff, not do something off your own bat, that's the thing' (volunteer) Feeling appreciated by the paid staff not only facilitated good relationships between the volunteers and paid staff, but also helped the volunteers to regard their role within the hospice as valuable.	The lack of patient information provided to volunteers also seemed to promote the feeling among some of the participants that they were untrustworthy despite having signed a confidentiality agreement.		
Field-Richards and	*'Maybe they felt a bit kind of threatened if you like, I don't know why they would because I*	*'the nurses treat us with great respect and they're*	*'so I [wasn't] meant to give her digestive biscuits but I*		There was a perception among volunteers that these boundaries were shifting in response to increasing formality and a changing interface between paid and

Arthur (2012)	*mean we're not professional and you know we're not nurses…I mean we're only here to help you know…we're not looking to take their jobs off them' (Volunteer)* there was consensus among volunteers that the current flexible and informal status of their role augmented the quality of nursing care provided	*very glad of us and you know we're glad of them…they're wonderful with us' (volunteer)* The nature of relationships between volunteers and nurses within the hospice was variable. Those reporting positive relationships with nurses felt that they worked well as a team, were appreciated, and were well supported in their role.	*didn't know that…we don't know what's wrong with people but sometimes we need to know' (volunteer)* There was a perception among volunteers that staff did not always communicate important information required to work effectively within the broadening sphere of hospice volunteering.		unpaid work. These changes impacted directly on working relationships.

Brown (2011)			Volunteer coordinators should immediately notify volunteers regarding the death of a patient. In addition, providing information about funeral services and allowing volunteers to participate in such grief-related rituals may provide a sense of closure and emotional comfort.	*'That is my main coping skill is to talk with out with my volunteer coordinator. When those things happen (stressful experiences) I try to get more information. If the information is something I don't want to hear, I again, talk it out and that to me has usually been the best way to deal with the stress that I feel from these experiences that I have'.* In addition to seeking assistance from the volunteer coordinator, participants sought assistance and advice from a variety of hospice workers including social workers, nurses, and clergy. One participant said she used the interdisciplinary team for assistance	
McKee, Kelley, Guirguis-Younger, MacLean, and Nadin (2010)	*'The nurses, they go into the home and it's like, 'Okay, I got to get this done and I've got to get that done...' It's very task-oriented...[But] I've seen [volunteers] just being there, that is what*		They know how to relay the needs of the dying and their family members in a way that nurses trust		

	they do: they are being there; they sit, they listen.' (nurse) It was a significant theme in these interviews that volunteers found it difficult to describe their work in a way that they felt has credibility with formal providers of care, and they were not sure if their role was understood by formal providers.		("They are like our eyes and ears"; "They are very observant and they help us"), and they know how to interpret and manage the formal system in a way that families trust		
Duggal, Farah, Straatman, Freeman, and Dickson (2008)	The hospice has a large pool of active volunteers with diverse talents, skills, and abilities that supplement the work of the professional staff	*'At Canuck Place Children's Hospice, I am respected, even though I am a younger member of the team.' (volunteer)* The morning family volunteer		*'You have a close relationship with the nurses, a one-on-one interaction, which you may not experience in other healthcare settings' (volunteer)* forming stronger relationships between staff and volunteers so volunteers feel engaged as part of the overall team.	Evidence must be provided throughout the interview of the following examples of qualities and attributes: Self-awareness and ability to set personal limits and boundaries

		works under the supervision of the school teacher. The study suggests that hospice volunteers benefit from personal growth, as well as improved self-esteem and self-worth from their interactions with patients and staff			
Andersson and Ohlen (2005)	Being assigned a constructive task. Volunteers contributed by performing a variety of tasks that were additional to or an enhancement of the work performed by the regular staff, including the inter-professional healthcare team. How	*She described feeling not important, ‘because nobody takes any notice what I think about the*	*‘That’s right. You don’t have to know that. But all the time those questions are there in the sick person and within me. I wonder*	The social contact with the hospice, the security of being familiar with staff, and the opportunity of contributing something to compensate for the support that their own relative had been given, were important reasons.	Volunteers may feel uncertainty about what is expected of them and they are afraid to ‘cross over into the domain of the nurses’.

	positive the experience of being a volunteer was largely depended on how the staff and the volunteer mutually succeeded in identifying suitable tasks and if the volunteer was given clear guidelines on how to perform the tasks. Simply coming to a ward without having a defined task can be experienced as a burden.	*situation' (volunteer)* One volunteer related how uncertain she felt about whether staff noticed that she was there or not. Positive encounters with the hospice are closely related to personal growth.	*what is wrong with him or her. It may be someone you see a lot, others you never see. I haven't felt OK to ask either, since somehow, we have got to know that we don't need to know what's up with people. I have been careful not to ask. It's as if it's none of my business' (volunteer)* The volunteers from another hospice recounted how staff clearly told them that it		

			was not that important for the volunteers to know what sickness the patients were afflicted with because the volunteer could still do a good job.		
Dein and Abbas (2005)	Several pointed out how their roles were different from or complementary to those of professional staff and they perceived little competition between the groups.	Much of this satisfaction might derive from the ideology of the hospice movement which involves three core ideas: … the delivery of such care by non-hierarchical multidisciplinary teams which values the skills and contribution	In relation to this there is a need for volunteers who will be working with patients to be given more information about the disease processes they will encounter and the issues of disfigurement that they will encounter in their jobs.	*'Also, the Day hospice nurses. They are always there and say repeatedly that 'we are here, if there are any problems please come and speak to us'. We have a very good relationship'. (volunteer)* Generally, volunteers reported good working relationships with professional staff	One source of stress derives from 'boundary conflicts' - tensions between paid staff and volunteers over the work done by volunteers and the information (often deemed confidential) about patients that they wanted…

		s of individual team members rather than their status or qualifications in our study volunteers generally reported feeling valued and morale was perceived to be high in the hospice generally. A number of factors might relate to this high level of satisfaction and morale: … positive feedback from professional staff	Specifically, they should be taught the basic presentations of cancer, the common treatment modalities, cure versus palliation and alternative therapies. However, issues of confidentiality prohibit volunteers having direct access to patients' medical records.		

Sadler and Marty (1998)	The use of the pronoun "we" when referring to hospice was common among all those interviewed.	*'As a member of the team I feel that my reports are just as important as any of the other members. I can honestly say that no team member carries any more weight than anyone else. Each member has his or her area of expertise and then it is put on the table and we make a decision based on that information.' (volunteer)*		*'Although (the coordinator and director] do a good job of setting us up for the realities of volunteering, I think they should spend some time with us at the end of training and discuss our needs. I think it would be very beneficial to me and to other volunteers if we could sit down one-to-one with (them] and discuss how we can meet both hospice's needs as well as my needs'. (volunteer)* All of the interpersonal turning points emphasized the importance of interacting with hospice staff, volunteers, patients, and patients' families. Of these, the most important turning point, mentioned by all 17 volunteers, was the quality of interaction they had with hospice staff during training. In this study, the two main people involved regularly in training were the training coordinator and the executive director.	

		the executive director, despite her hierarchical role in the organization, made the volunteers feel like an important part of the organization. *‘it's the small things that the staff does for me that makes me feel good about my work’ (volunteer)* … In short, while people expressed different levels of desire for recognition, many of the volunteers			

		admitted that the informal and formal recognition they received was an important part of their desire to be volunteers. *‘ .. as long as hospice allows me to grow and helps me to understand myself as an individual, I will continue my relationship with the organization.’ (volunteer)* it is important to make sure that volunteers attending team			

		meetings arc made to feel comfortable, given advice on how to contribute to the meetings, and made to feel as much of an "expert" as the others at the meeting.			
Paradis, Miller, and Runnion (1987)	Role ambiguity refers to conflicting obligations and responsibilities experienced by volunteers. For example, is the volunteer a patient advocate, a staff advocate, or both? Can a volunteer assume direct care responsibilities for a patient, or is that solely within the purview of staff?	Although volunteers felt comfortable working with staff, they were often unsure of their status in the organizational hierarchy They felt that staff should give them more feedback about the	Eight noted that they wanted more information from staff and expected greater staff-initiated communication with them.	The staff most directly in contact with the volunteers were the volunteer coordinator, nurse, and social worker. When asked to name the staff with whom they worked, most volunteers named a nurse.	

		quality of their work.			

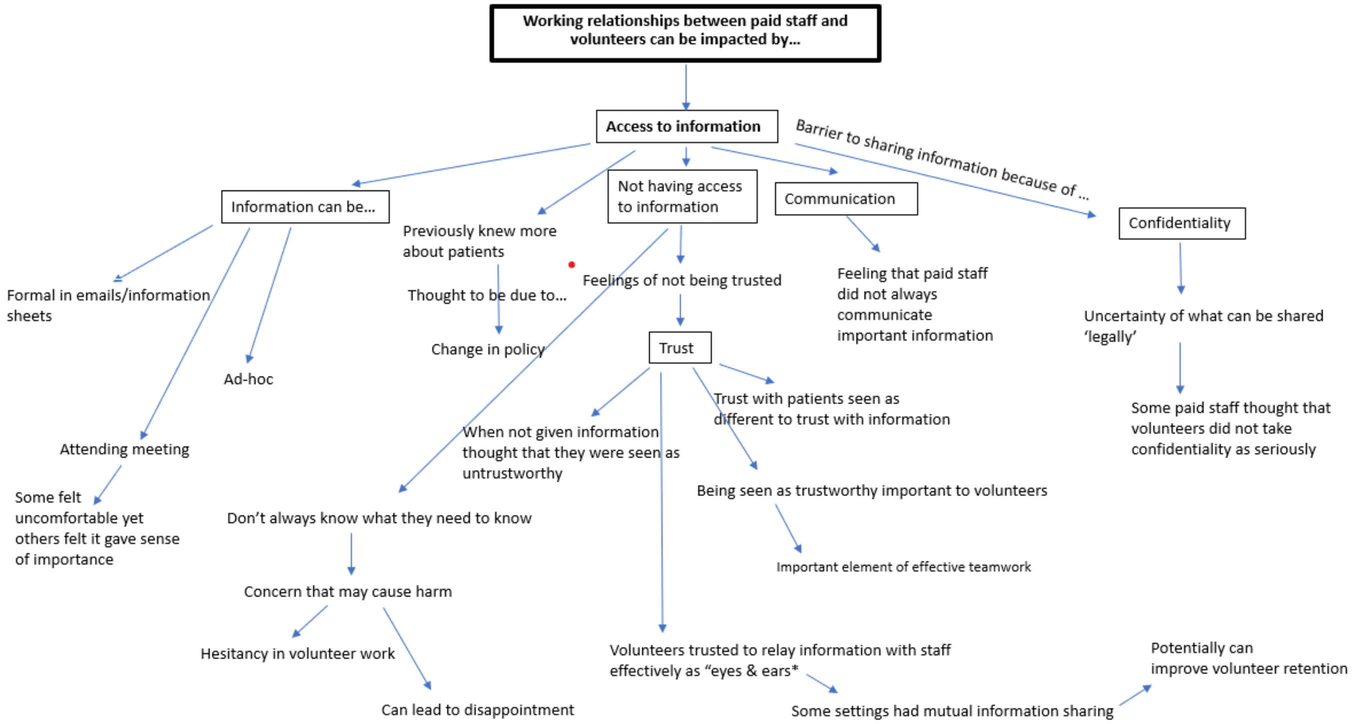
Appendix G Data extraction form

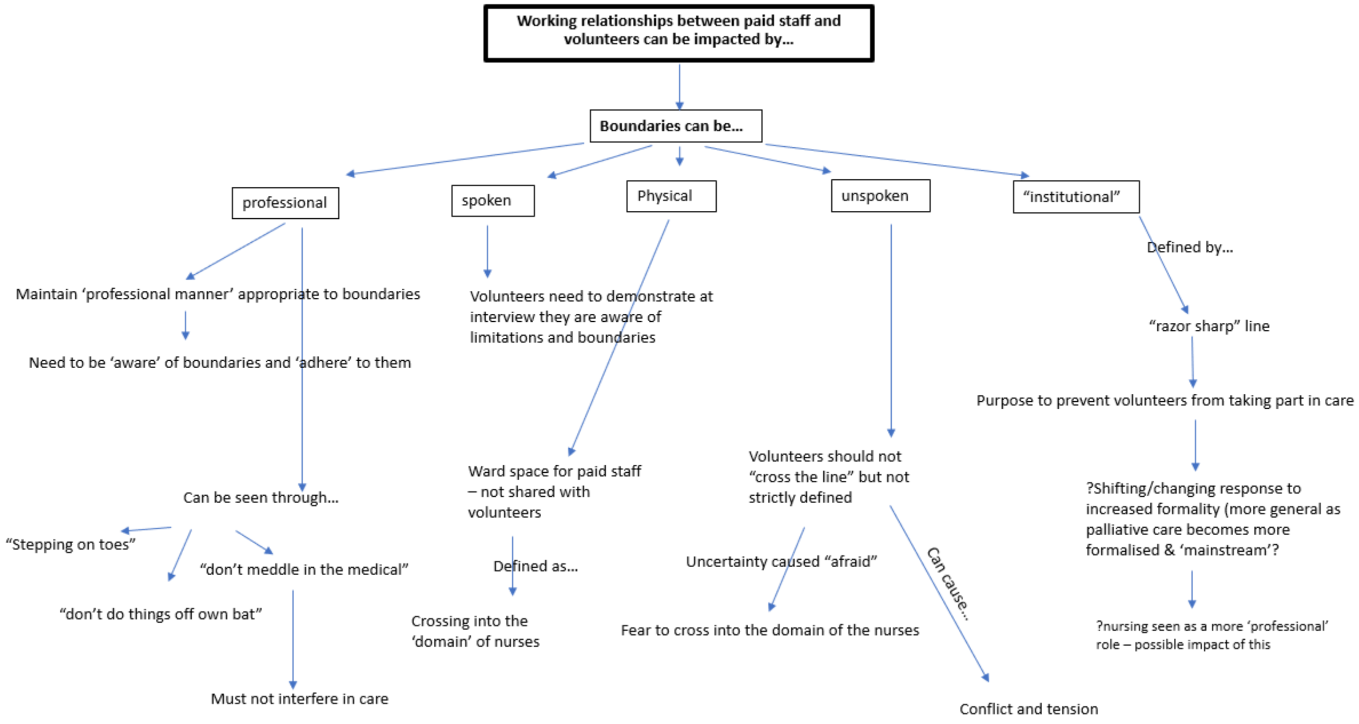
Overgaard (2015) The boundaries of care work: a comparative study of professionals and volunteers in Denmark and Australia

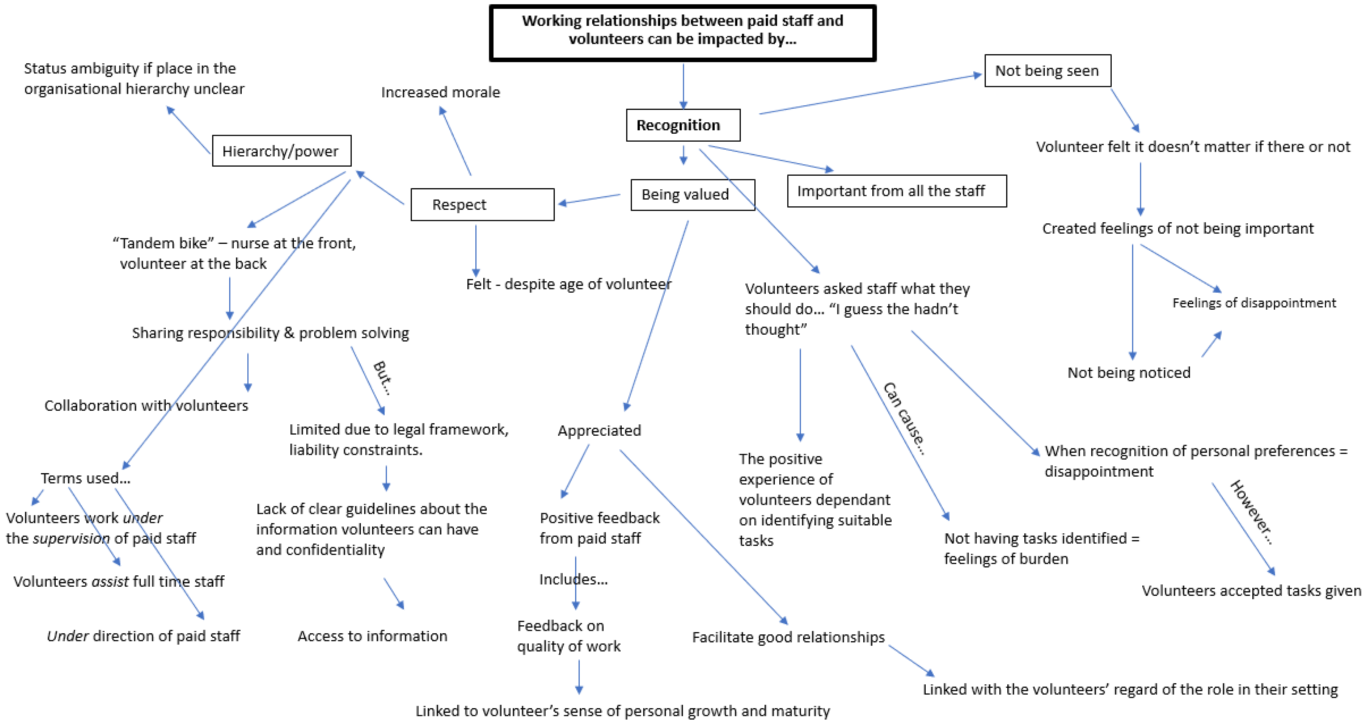
Themes	Participant quotes (first order constructs)	Primary author interpretations (second order constructs)
Boundaries/ stepping on toes	'And it's the certainty that there is a razor-sharp line between being a professional and being a volunteer. The volunteers must of course not in any way interfere in the care'. (Hospice Leader, Denmark) 'And there was no clear-cut delineation of what they could and couldn't do. So, they might be feeding patients. Do they know how to assess [if patients] can or cannot swallow?' (Nurse Unit Manager, Australia)	Boundaries between volunteers and staff at the Danish hospice were created and articulated primarily as a means to prevent volunteers from participating in any direct care-giving Observational data revealed that volunteers at the Danish hospice were allocated practical, labour-intensive type jobs. Anything that involved direct care was off-limits to the volunteers; until recently, volunteers were not even allowed to enter the rooms of the patients
Understanding of the role … them and us/we/separate but part of whole	'We are the cake and they are the cream. That is extremely important because they are not taking any piece of the cake. That is the difference between volunteers and professionals.' (Hospice Leader, Denmark)	(Australian) The use of volunteers was not understood to pose a risk to paid staff positions the volunteers at the Australian hospice perform work that overlaps with that of nurses and social workers in particular
Access to information/Trust	'A volunteer came up to me after dinner and asked, 'How old is that patient?' It may seem like an innocent question,(...) but we are not allowed [to tell].' (Nurse, Denmark) 'There are times when we have raised concerns that a new patient has arrived and we, as hosts, haven't	The Danish hospice took a rather strict approach to confidentiality, which consisted of two layers: one between the paid staff and volunteers, and another between the volunteers and the outside world

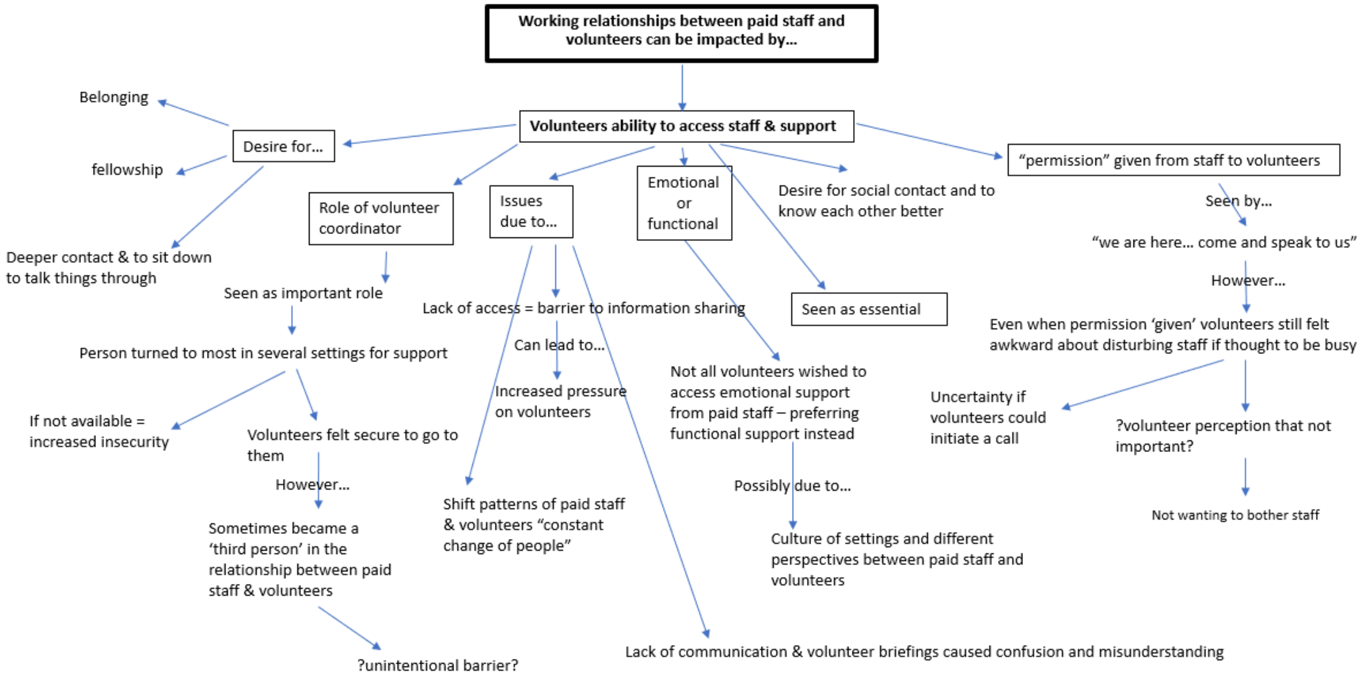
	been informed that the person is almost blind or deaf.’ (Volunteer, Denmark)	The strict approach to confidentiality sometimes made it difficult for the volunteers to perform their roles. Although confidentiality might be understood as a means of protecting care receivers, it might also be understood as a way to protect paid staff from interference by volunteers. (Australian) The resignation and a change in management saw the volunteers’ engagement significantly restricted to include less autonomous roles and required volunteers to work under supervision. Yet, at the time of data collection, volunteers were still trusted with extensive responsibilities and volunteers shared many job functions with the nursing staff and social workers, including work that required high levels of competency. At the Australian hospice, the concern for confidentiality was addressed in the same way with staff and volunteers, i.e. through education and monitoring. This approach to confidentiality reflected the general hospice culture of volunteers being trusted like other staff.
Hierarchy/ Power		Danish professionals have effectively managed to maintain a monopoly over care-giving, which has resulted in a successful professionalisation project

Appendix H Concept maps

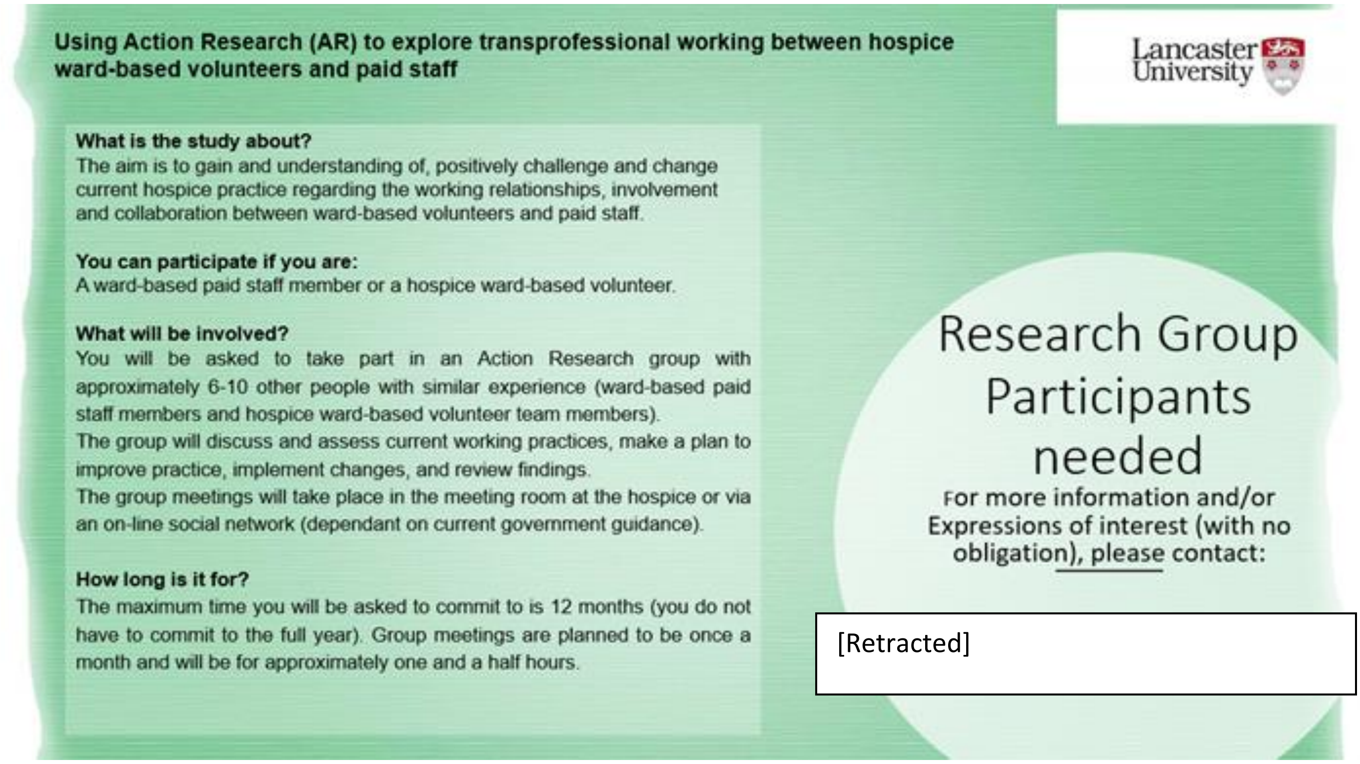





Working relationships between paid staff and volunteers can be impacted by…
Recognition
Not being seen
Volunteer felt it doesn't matter if there or not
Created feelings of not being important
Feelings of disappointment
Not being noticed
Important from all the staff
Being valued
Respect
Increased morale
Hierarchy/power
Status ambiguity if place in the organisational hierarchy unclear
"Tandem bike" – nurse at the front, volunteer at the back
Sharing responsibility & problem solving
Collaboration with volunteers
But…
Limited due to legal framework, liability constraints.
Lack of clear guidelines about the information volunteers can have and confidentiality
Access to information
Terms used…
Volunteers work under the supervision of paid staff
Volunteers assist full time staff
Under direction of paid staff
Felt - despite age of volunteer
Appreciated
Positive feedback from paid staff
Includes…
Feedback on quality of work
Linked to volunteer's sense of personal growth and maturity
Facilitate good relationships
Linked with the volunteers' regard of the role in their setting
Volunteers asked staff what they should do… "I guess the hadn't thought"
The positive experience of volunteers dependant on identifying suitable tasks
Can cause…
Not having tasks identified = feelings of burden
When recognition of personal preferences = disappointment
However…
Volunteers accepted tasks given


Working relationships between paid staff and volunteers can be impacted by…
Volunteers ability to access staff & support
Desire for…
Belonging
fellowship
Deeper contact & to sit down to talk things through
Role of volunteer coordinator
Seen as important role
Person turned to most in several settings for support
If not available = increased insecurity
Volunteers felt secure to go to them
However…
Sometimes became a 'third person' in the relationship between paid staff & volunteers
?unintentional barrier?
Issues due to…
Lack of access = barrier to information sharing
Can lead to…
Increased pressure on volunteers
Shift patterns of paid staff & volunteers "constant change of people"
Lack of communication & volunteer briefings caused confusion and misunderstanding
Emotional or functional
Not all volunteers wished to access emotional support from paid staff – preferring functional support instead
Possibly due to…
Culture of settings and different perspectives between paid staff and volunteers
Desire for social contact and to know each other better
Seen as essential
"permission" given from staff to volunteers
Seen by…
"we are here… come and speak to us"
However…
Even when permission 'given' volunteers still felt awkward about disturbing staff if thought to be busy
Uncertainty if volunteers could initiate a call
?volunteer perception that not important?
Not wanting to bother staff

Appendix I Recruitment posters



Using Action Research (AR) to explore transprofessional working between hospice ward-based volunteers and paid staff

Lancaster University

What is the study about?
The aim is to gain and understanding of, positively challenge and change current hospice practice regarding the working relationships, involvement and collaboration between ward-based volunteers and paid staff.

You can participate if you are:
A ward-based paid staff member or a hospice ward-based volunteer.

What will be involved?
You will be asked to take part in an Action Research group with approximately 6-10 other people with similar experience (ward-based paid staff members and hospice ward-based volunteer team members).
The group will discuss and assess current working practices, make a plan to improve practice, implement changes, and review findings.
The group meetings will take place in the meeting room at the hospice or via an on-line social network (dependant on current government guidance).

How long is it for?
The maximum time you will be asked to commit to is 12 months (you do not have to commit to the full year). Group meetings are planned to be once a month and will be for approximately one and a half hours.

Research Group Participants needed

For more information and/or Expressions of interest (with no obligation), please contact:

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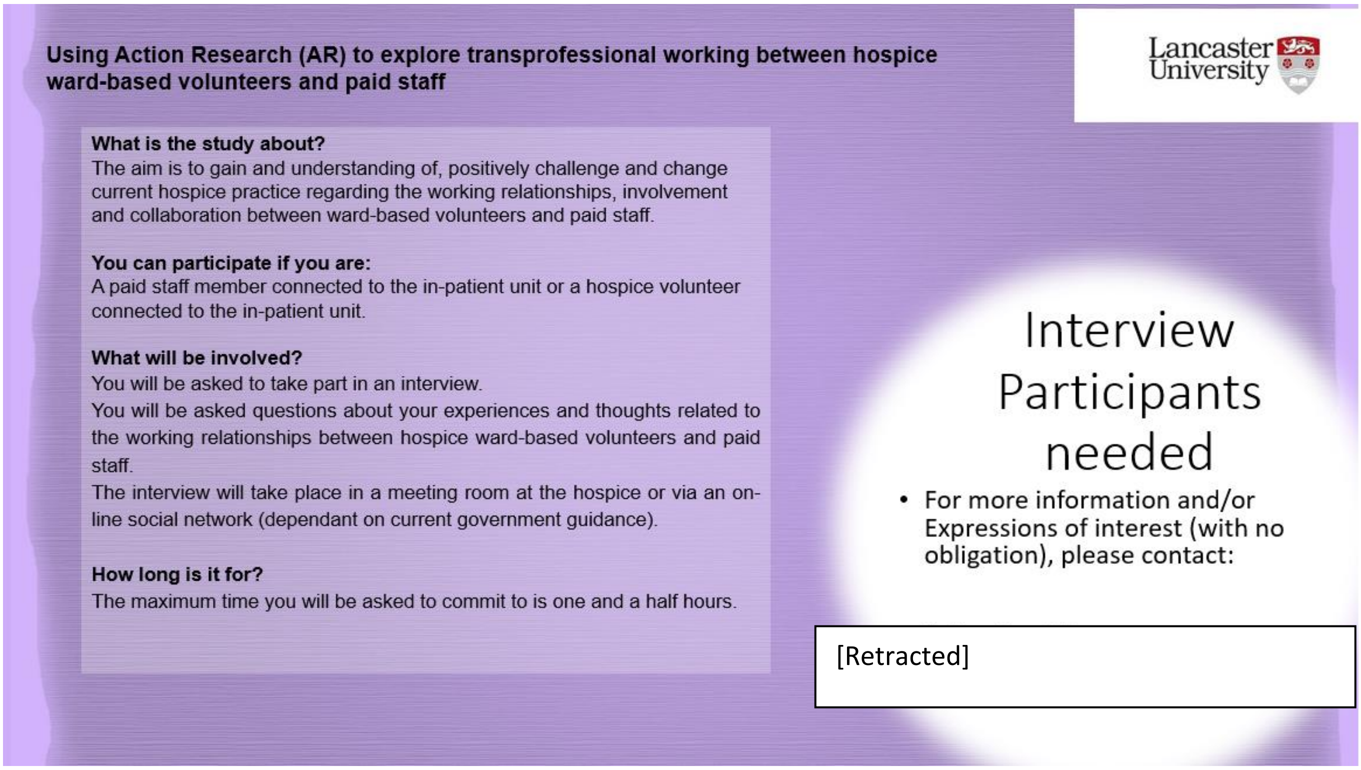

Using Action Research (AR) to explore transprofessional working between hospice ward-based volunteers and paid staff

Lancaster University

What is the study about?
The aim is to gain and understanding of, positively challenge and change current hospice practice regarding the working relationships, involvement and collaboration between ward-based volunteers and paid staff.

You can participate if you are:
A paid staff member connected to the in-patient unit or a hospice volunteer connected to the in-patient unit.

What will be involved?
You will be asked to take part in an interview.
You will be asked questions about your experiences and thoughts related to the working relationships between hospice ward-based volunteers and paid staff.
The interview will take place in a meeting room at the hospice or via an on-line social network (dependant on current government guidance).

How long is it for?
The maximum time you will be asked to commit to is one and a half hours.

Interview Participants needed

- For more information and/or Expressions of interest (with no obligation), please contact:

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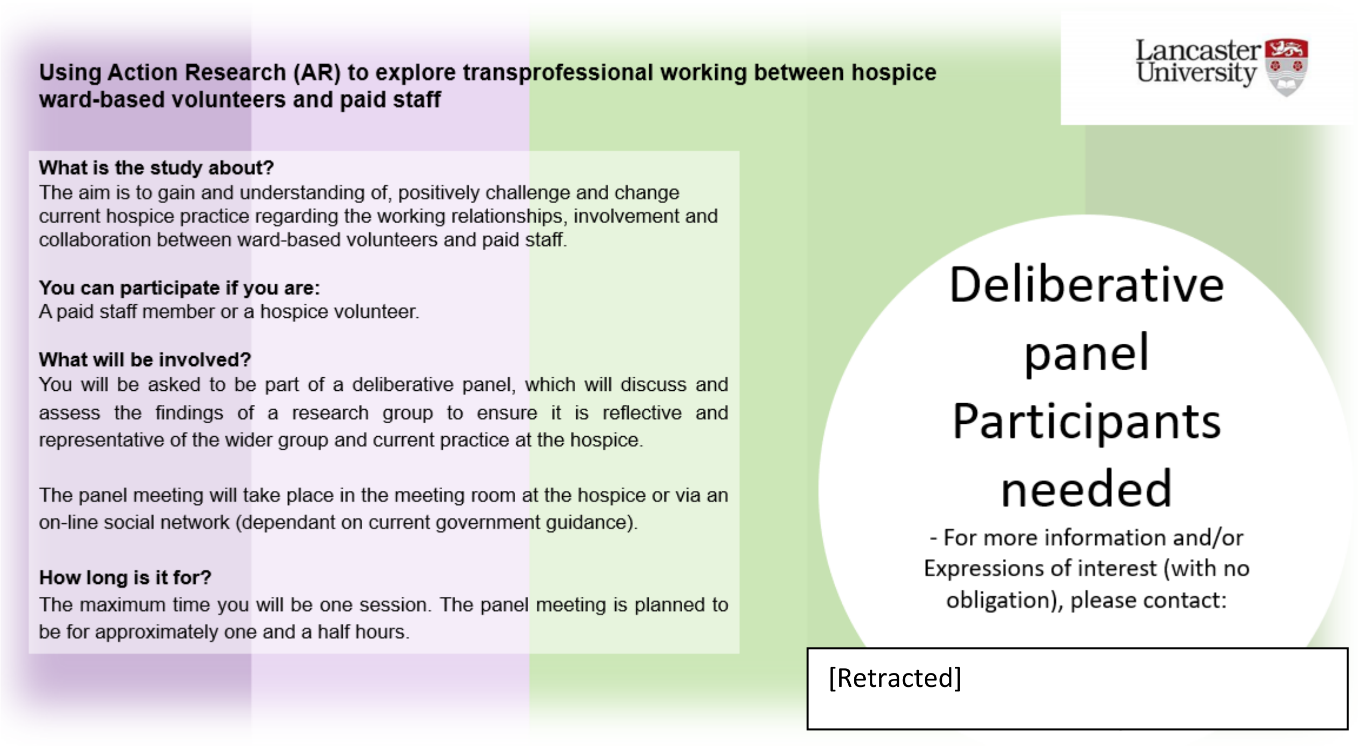


Lancaster University

Using Action Research (AR) to explore transprofessional working between hospice ward-based volunteers and paid staff

What is the study about?
The aim is to gain and understanding of, positively challenge and change current hospice practice regarding the working relationships, involvement and collaboration between ward-based volunteers and paid staff.

You can participate if you are:
A paid staff member or a hospice volunteer.

What will be involved?
You will be asked to be part of a deliberative panel, which will discuss and assess the findings of a research group to ensure it is reflective and representative of the wider group and current practice at the hospice.

The panel meeting will take place in the meeting room at the hospice or via an on-line social network (dependant on current government guidance).

How long is it for?
The maximum time you will be one session. The panel meeting is planned to be for approximately one and a half hours.

Deliberative panel Participants needed

- For more information and/or Expressions of interest (with no obligation), please contact:

[Retracted]

Appendix J Semi-structured interview topic guide

1 – General introductions and encourage the participant to relax and feel at ease. Clarify the consent form and ensure they are willing to proceed. Give opportunity for questions.

2 – Ask about their history with the hospice and how they came to be in their role (either paid or voluntary).

3 – Explore their experiences as an employed team member/member of the volunteer team of the current volunteer-professional collaboration at the hospice in-patient unit.

4 - Explore any examples of positive/negative volunteer-professional collaboration on the ward that they would be willing to discuss.

5 - Explore suggestions of how volunteer-professional collaboration could be improved.

6 – Give opportunity to discuss any other relevant thoughts.

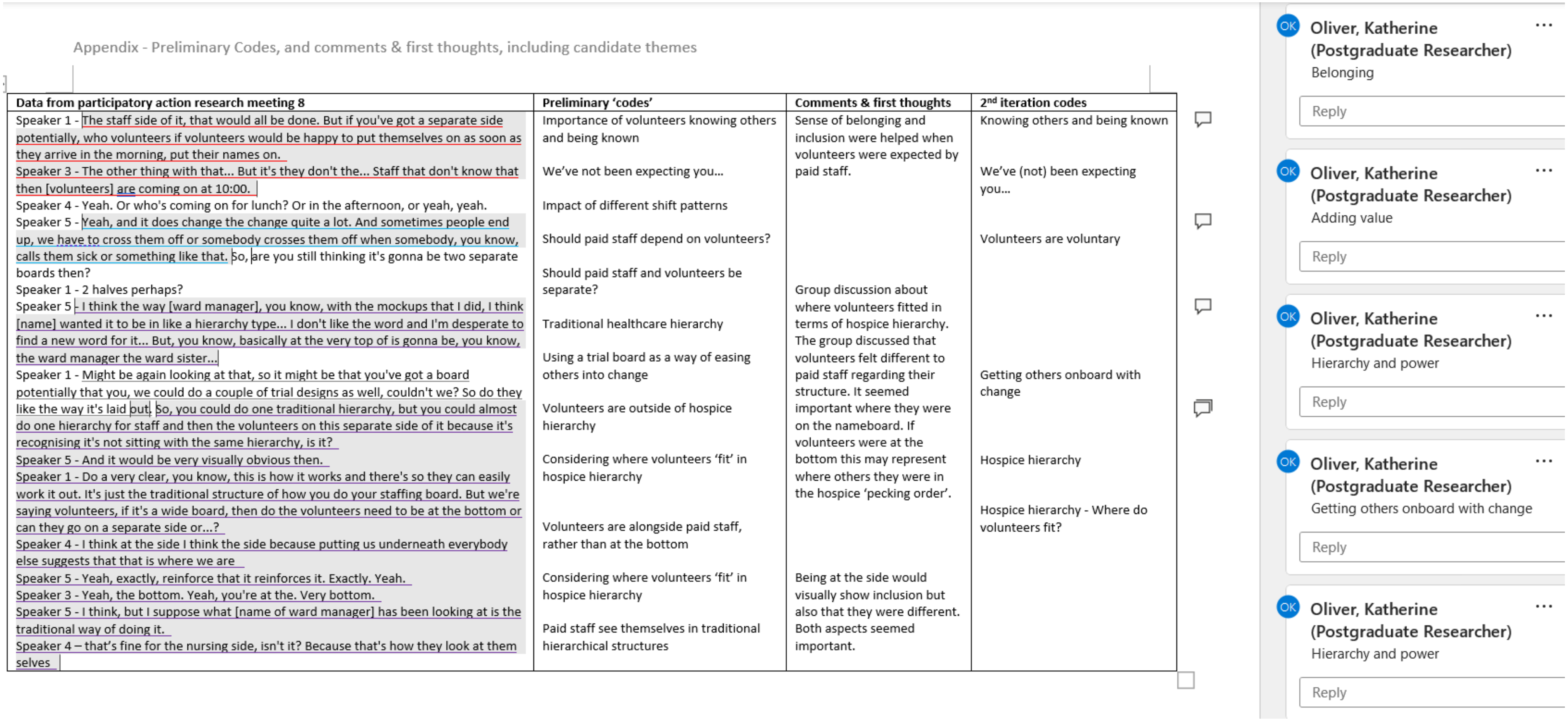
7 – Conclusions and draw the interview gradually to a close. Ensure that the participant is comfortable with what has taken place. Give them the opportunity to ask further questions.

Appendix K Journal entry

Pre meeting notes on 4/3/24 (considering the lack of response to the name board)

A challenge would be to try to encourage others - how to do the PAR approach on a bigger scale? How to communicate a message of intent to a bigger group without being thought of as ‘banging on’ or appearing to be on a soap box? It would be important that any change is group lead. This reminds me of research about how many people it takes to change a culture (lower than many people often think! It has been said that a committed minority of 25% can be a good target for ‘cultural shifts’ within an organisation). But all involved need to be willing/wanting to have an *active* part. Again, knowledge and empowerment are important aspects – ensuring all have the right tools, skills, knowledge… to be a change agent.

Appendix L Preliminary codes, comments, first thoughts and second codes



Appendix - Preliminary Codes, and comments & first thoughts, including candidate themes

Data from participatory action research meeting 8	Preliminary 'codes'	Comments & first thoughts	2nd iteration codes
Speaker 1 - The staff side of it, that would all be done. But if you've got a separate side potentially, who volunteers if volunteers would be happy to put themselves on as soon as they arrive in the morning, put their names on.	Importance of volunteers knowing others and being known	Sense of belonging and inclusion were helped when volunteers were expected by paid staff.	Knowing others and being known
Speaker 3 - The other thing with that... But it's they don't the... Staff that don't know that then [volunteers] are coming on at 10:00.	We've not been expecting you…		We've (not) been expecting you…
Speaker 4 - Yeah. Or who's coming on for lunch? Or in the afternoon, or yeah, yeah.	Impact of different shift patterns		
Speaker 5 - Yeah, and it does change the change quite a lot. And sometimes people end up, we have to cross them off or somebody crosses them off when somebody, you know, calls them sick or something like that. So, are you still thinking it's gonna be two separate boards then?	Should paid staff depend on volunteers?		Volunteers are voluntary
Speaker 1 - 2 halves perhaps?	Should paid staff and volunteers be separate?	Group discussion about where volunteers fitted in terms of hospice hierarchy. The group discussed that volunteers felt different to paid staff regarding their structure. It seemed important where they were on the nameboard. If volunteers were at the bottom this may represent where others they were in the hospice 'pecking order'.	
Speaker 5 - I think the way [ward manager], you know, with the mockups that I did, I think [name] wanted it to be in like a hierarchy type... I don't like the word and I'm desperate to find a new word for it... But, you know, basically at the very top of is gonna be, you know, the ward manager the ward sister...	Traditional healthcare hierarchy		
Speaker 1 - Might be again looking at that, so it might be that you've got a board potentially that you, we could do a couple of trial designs as well, couldn't we? So do they like the way it's laid out. So, you could do one traditional hierarchy, but you could almost do one hierarchy for staff and then the volunteers on this separate side of it because it's recognising it's not sitting with the same hierarchy, is it?	Using a trial board as a way of easing others into change Volunteers are outside of hospice hierarchy		Getting others onboard with change
Speaker 5 - And it would be very visually obvious then.	Considering where volunteers 'fit' in hospice hierarchy		Hospice hierarchy
Speaker 1 - Do a very clear, you know, this is how it works and there's so they can easily work it out. It's just the traditional structure of how you do your staffing board. But we're saying volunteers, if it's a wide board, then do the volunteers need to be at the bottom or can they go on a separate side or...?			Hospice hierarchy - Where do volunteers fit?
Speaker 4 - I think at the side I think the side because putting us underneath everybody else suggests that that is where we are	Volunteers are alongside paid staff, rather than at the bottom		
Speaker 5 - Yeah, exactly, reinforce that it reinforces it. Exactly. Yeah.	Considering where volunteers 'fit' in hospice hierarchy	Being at the side would visually show inclusion but also that they were different. Both aspects seemed important.	
Speaker 3 - Yeah, the bottom. Yeah, you're at the. Very bottom.			
Speaker 5 - I think, but I suppose what [name of ward manager] has been looking at is the traditional way of doing it.	Paid staff see themselves in traditional hierarchical structures		
Speaker 4 – that's fine for the nursing side, isn't it? Because that's how they look at them selves			

OK **Oliver, Katherine (Postgraduate Researcher)**
Belonging
Reply

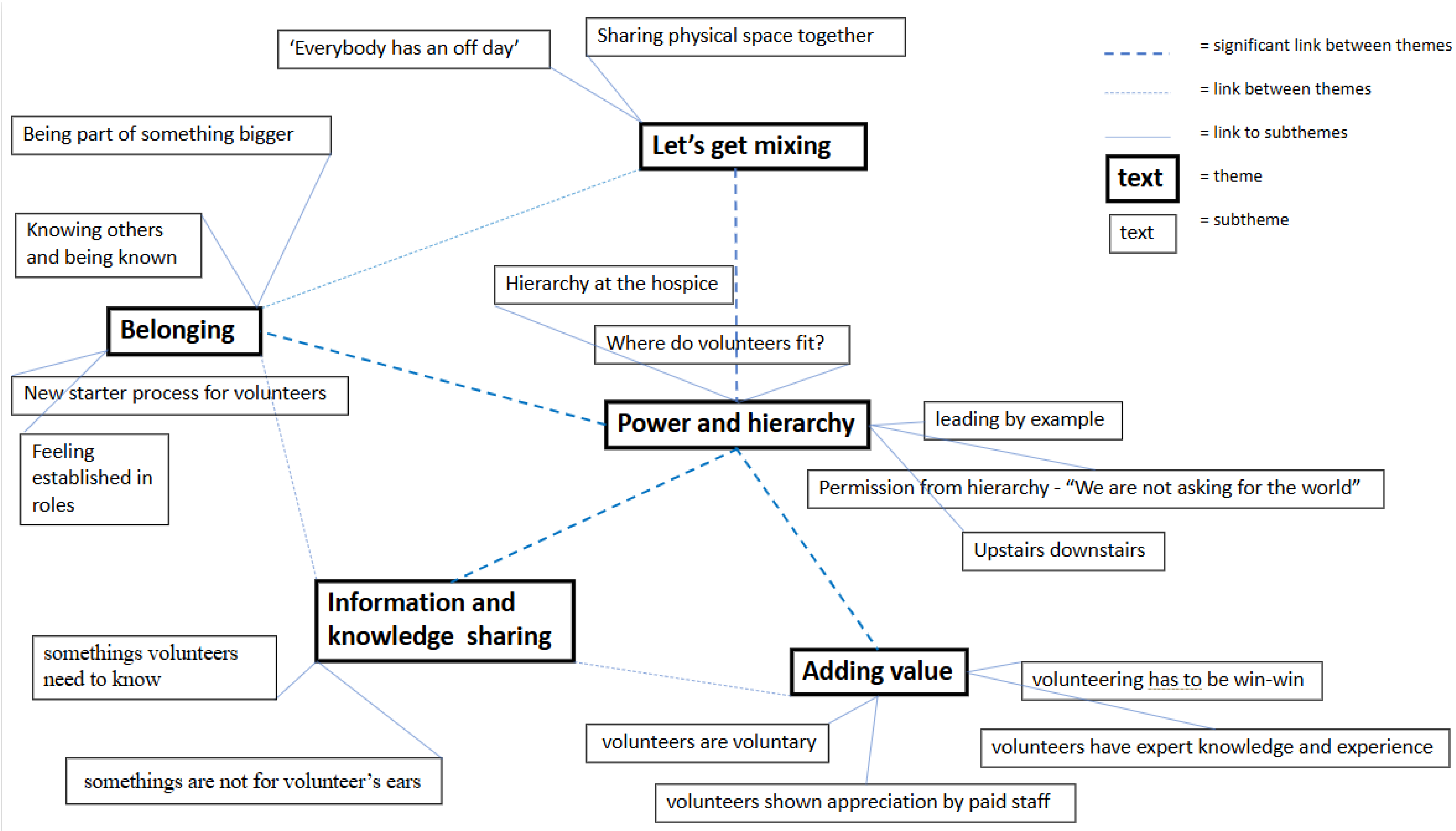
OK **Oliver, Katherine (Postgraduate Researcher)**
Adding value
Reply

OK **Oliver, Katherine (Postgraduate Researcher)**
Hierarchy and power
Reply

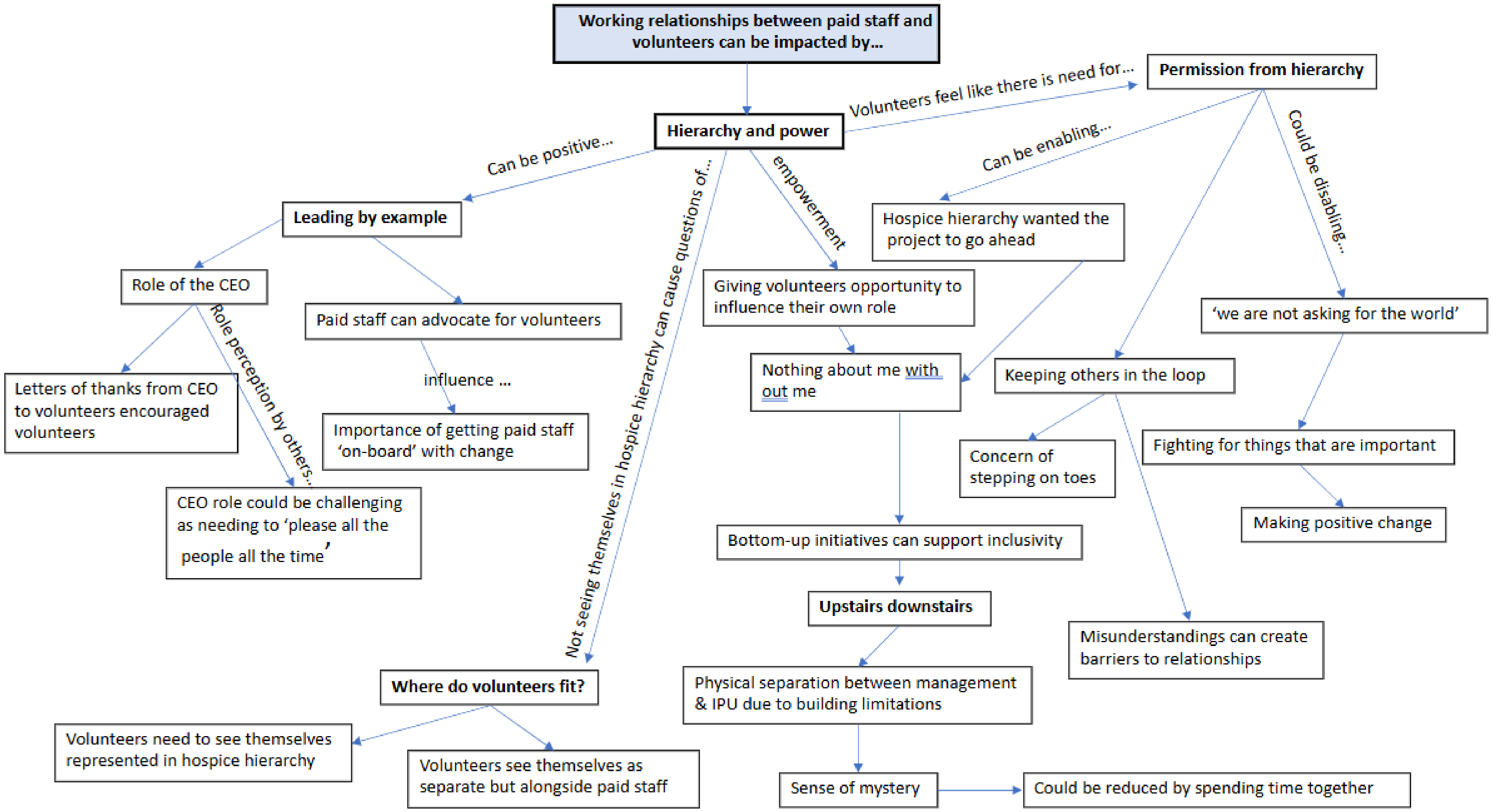
OK **Oliver, Katherine (Postgraduate Researcher)**
Getting others onboard with change
Reply

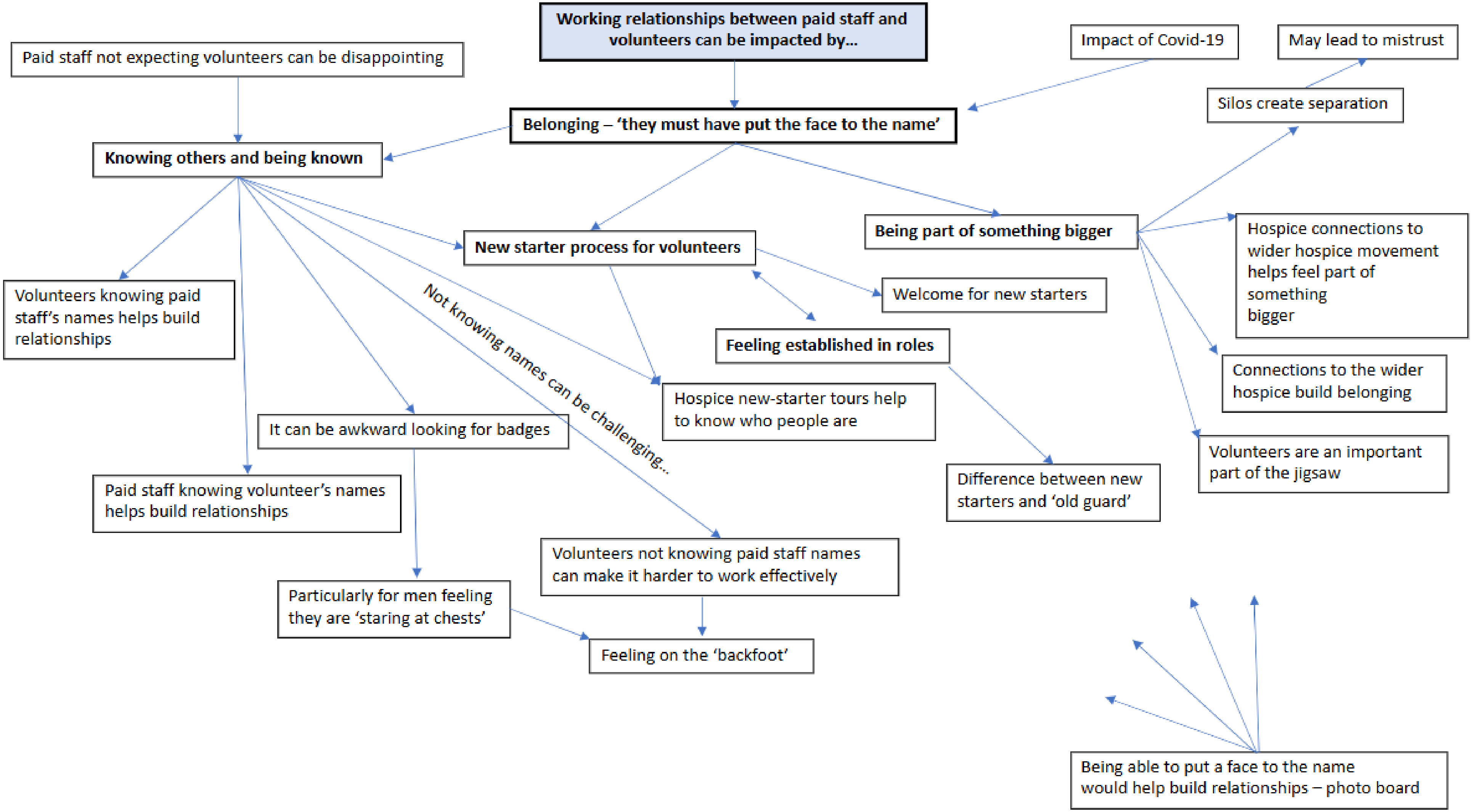
OK **Oliver, Katherine (Postgraduate Researcher)**
Hierarchy and power
Reply

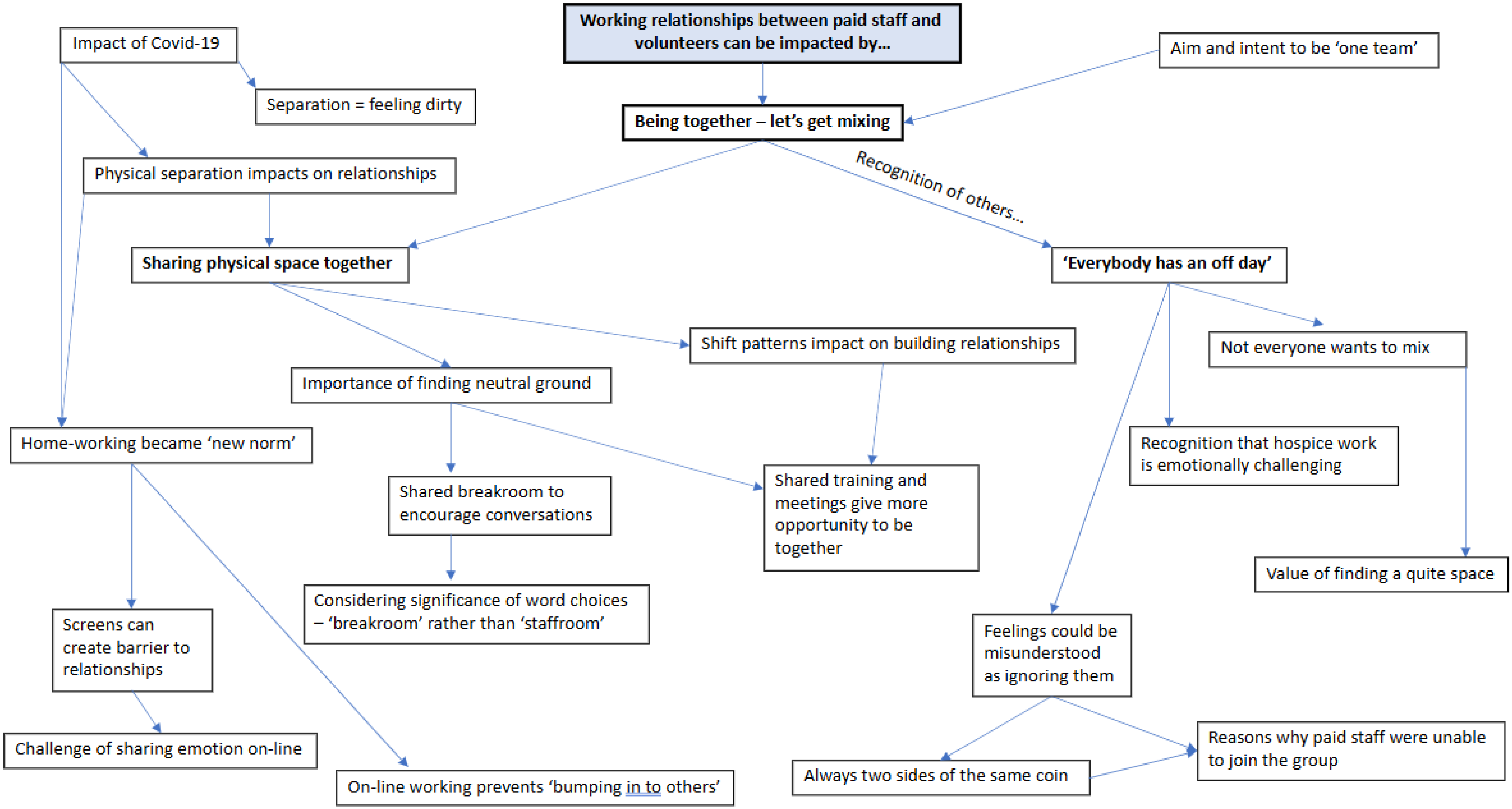
Appendix M Codes and themes links

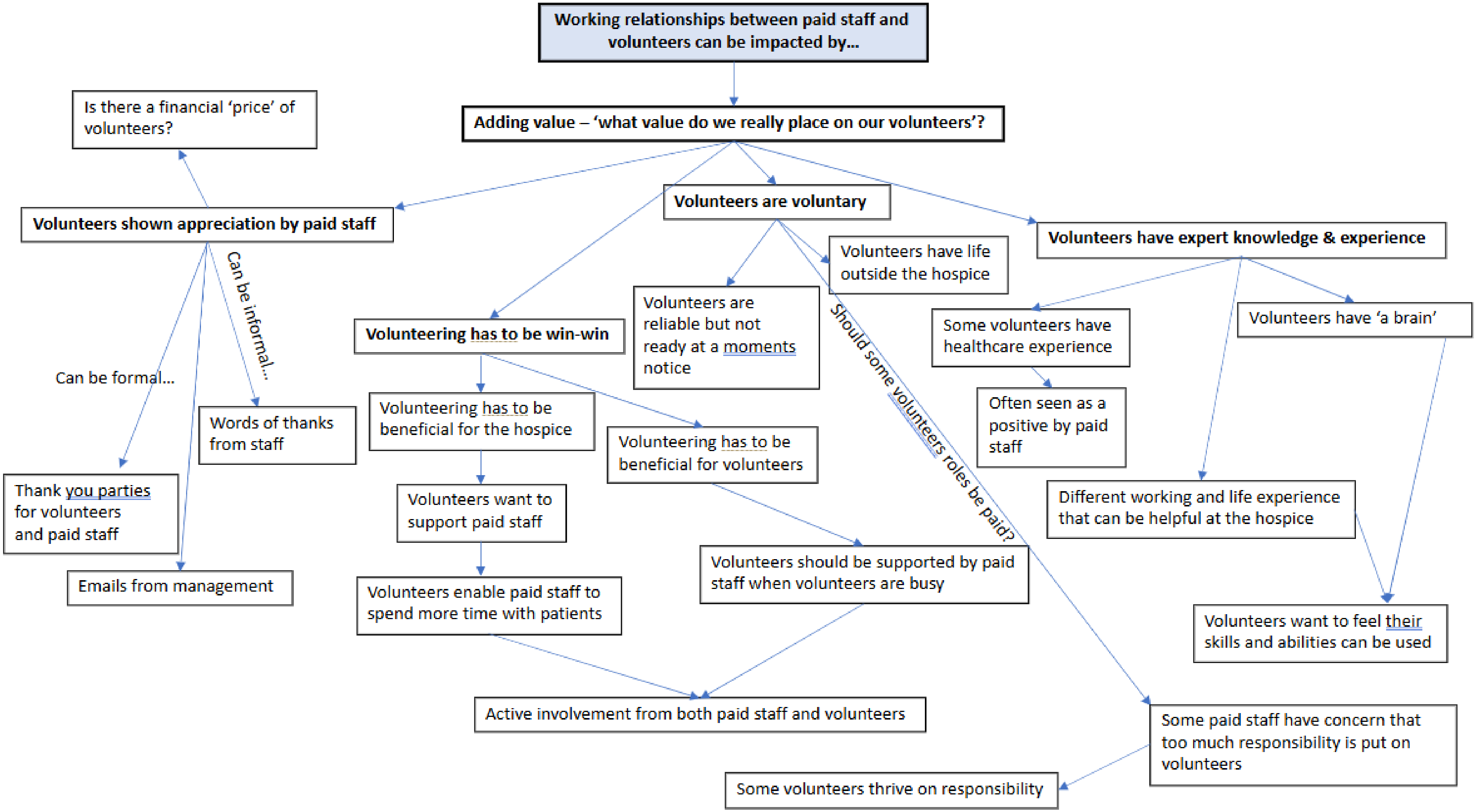


Appendix N Final themes concept maps




Working relationships between paid staff and volunteers can be impacted by…
Paid staff not expecting volunteers can be disappointing
Impact of Covid-19
May lead to mistrust
Belonging – 'they must have put the face to the name'
Silos create separation
Knowing others and being known
Being part of something bigger
New starter process for volunteers
Hospice connections to wider hospice movement helps feel part of something bigger
Volunteers knowing paid staff's names helps build relationships
Not knowing names can be challenging…
Welcome for new starters
Feeling established in roles
Connections to the wider hospice build belonging
Hospice new-starter tours help to know who people are
It can be awkward looking for badges
Volunteers are an important part of the jigsaw
Paid staff knowing volunteer's names helps build relationships
Difference between new starters and 'old guard'
Volunteers not knowing paid staff names can make it harder to work effectively
Particularly for men feeling they are 'staring at chests'
Feeling on the 'backfoot'
Being able to put a face to the name would help build relationships – photo board


Working relationships between paid staff and volunteers can be impacted by…
Being together – let's get mixing
Aim and intent to be 'one team'
Impact of Covid-19
Separation = feeling dirty
Physical separation impacts on relationships
Sharing physical space together
Recognition of others…
'Everybody has an off day'
Shift patterns impact on building relationships
Not everyone wants to mix
Importance of finding neutral ground
Home-working became 'new norm'
Recognition that hospice work is emotionally challenging
Shared breakroom to encourage conversations
Shared training and meetings give more opportunity to be together
Value of finding a quite space
Considering significance of word choices – 'breakroom' rather than 'staffroom'
Screens can create barrier to relationships
Feelings could be misunderstood as ignoring them
Challenge of sharing emotion on-line
Reasons why paid staff were unable to join the group
On-line working prevents 'bumping in to others'
Always two sides of the same coin



Working relationships between paid staff and volunteers can be impacted by…

Adding value – 'what value do we really place on our volunteers'?

Volunteers shown appreciation by paid staff

Is there a financial 'price' of volunteers?

Can be formal…

Can be informal…

Thank you parties for volunteers and paid staff

Emails from management

Words of thanks from staff

Volunteering has to be win-win

Volunteering has to be beneficial for the hospice

Volunteers want to support paid staff

Volunteers enable paid staff to spend more time with patients

Volunteering has to be beneficial for volunteers

Volunteers should be supported by paid staff when volunteers are busy

Active involvement from both paid staff and volunteers

Volunteers are voluntary

Volunteers are reliable but not ready at a moments notice

Volunteers have life outside the hospice

Should some volunteers roles be paid?

Some paid staff have concern that too much responsibility is put on volunteers

Some volunteers thrive on responsibility

Volunteers have expert knowledge & experience

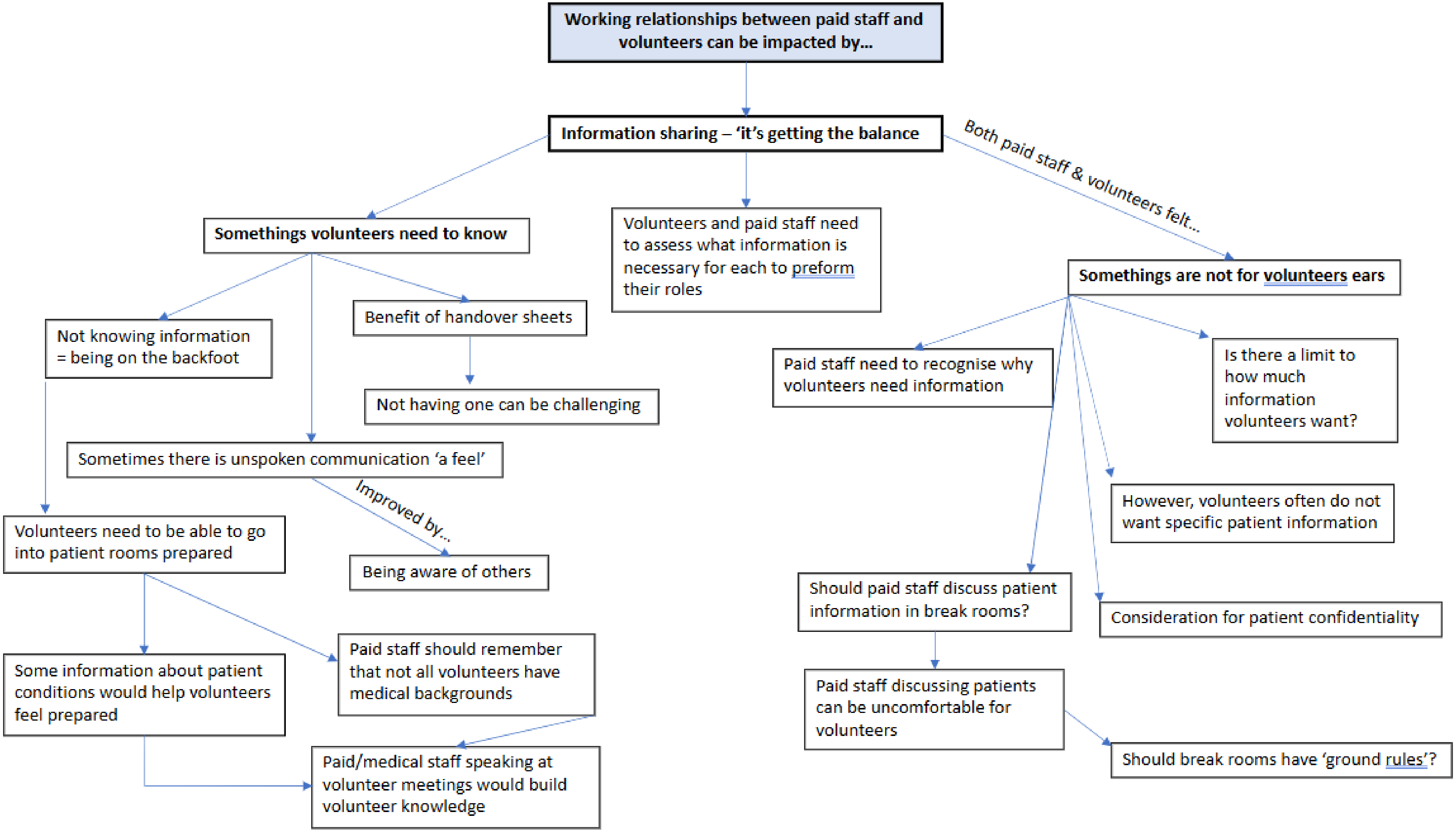
Some volunteers have healthcare experience

Often seen as a positive by paid staff

Volunteers have 'a brain'

Different working and life experience that can be helpful at the hospice

Volunteers want to feel their skills and abilities can be used



Working relationships between paid staff and volunteers can be impacted by…

Information sharing – 'it's getting the balance

Somethings volunteers need to know

Not knowing information = being on the backfoot

Benefit of handover sheets

Not having one can be challenging

Sometimes there is unspoken communication 'a feel'

Improved by…

Being aware of others

Volunteers need to be able to go into patient rooms prepared

Some information about patient conditions would help volunteers feel prepared

Paid staff should remember that not all volunteers have medical backgrounds

Paid/medical staff speaking at volunteer meetings would build volunteer knowledge

Volunteers and paid staff need to assess what information is necessary for each to preform their roles

Both paid staff & volunteers felt…

Somethings are not for volunteers ears

Paid staff need to recognise why volunteers need information

Is there a limit to how much information volunteers want?

However, volunteers often do not want specific patient information

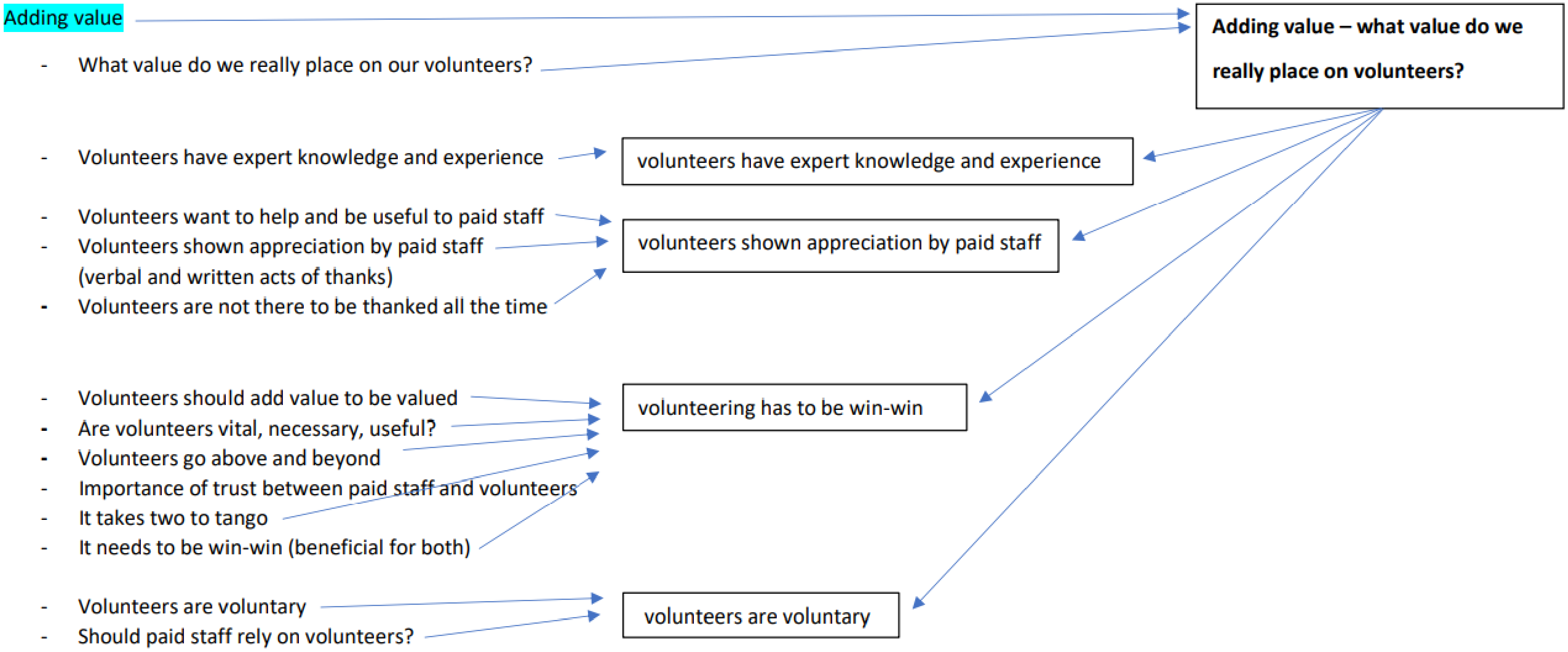
Should paid staff discuss patient information in break rooms?

Paid staff discussing patients can be uncomfortable for volunteers

Should break rooms have 'ground rules'?

Consideration for patient confidentiality

Appendix O Code books and themes



Adding value

- What value do we really place on our volunteers?

- Volunteers have expert knowledge and experience

- Volunteers want to help and be useful to paid staff
- Volunteers shown appreciation by paid staff (verbal and written acts of thanks)
- Volunteers are not there to be thanked all the time

- Volunteers should add value to be valued
- Are volunteers vital, necessary, useful?
- Volunteers go above and beyond
- Importance of trust between paid staff and volunteers
- It takes two to tango
- It needs to be win-win (beneficial for both)

- Volunteers are voluntary
- Should paid staff rely on volunteers?

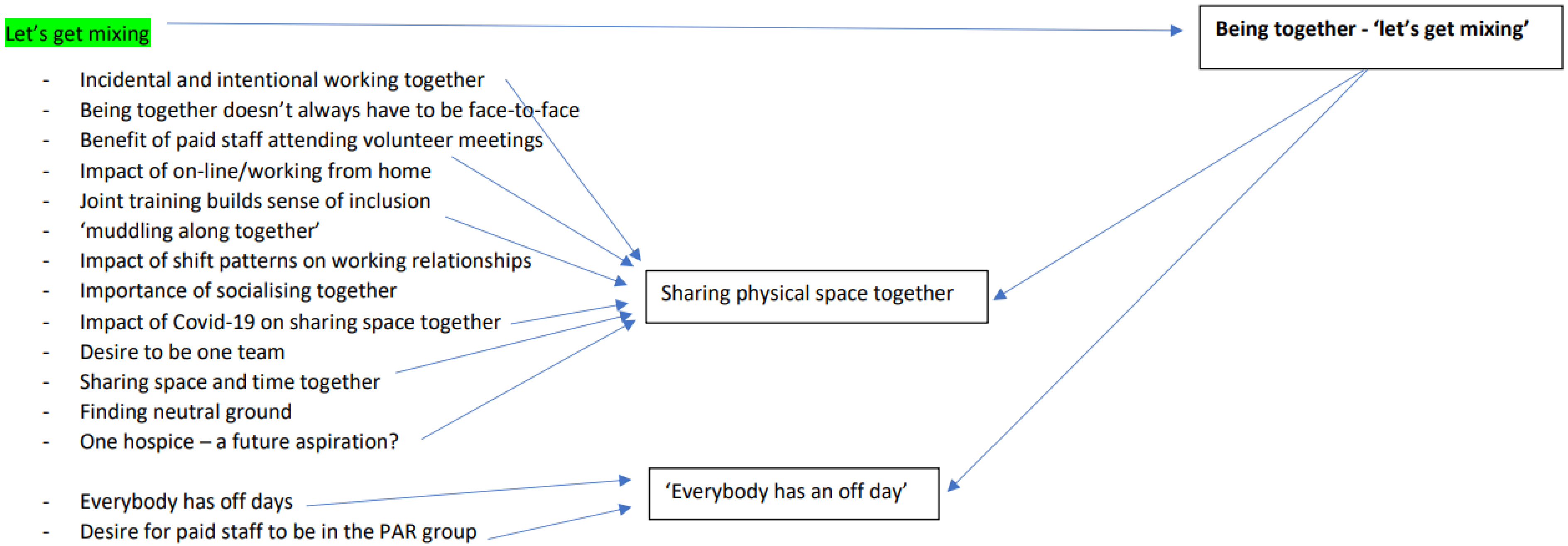
Adding value – what value do we really place on volunteers?

volunteers have expert knowledge and experience

volunteers shown appreciation by paid staff

volunteering has to be win-win

volunteers are voluntary



Let’s get mixing

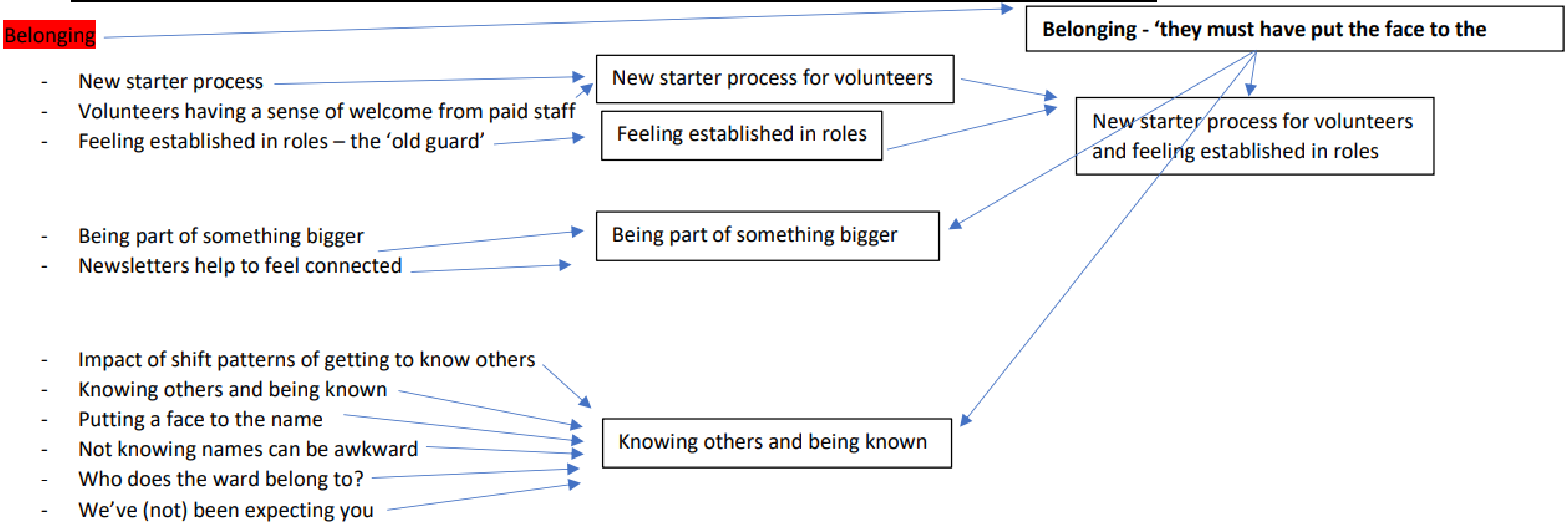
- Incidental and intentional working together
- Being together doesn’t always have to be face-to-face
- Benefit of paid staff attending volunteer meetings
- Impact of on-line/working from home
- Joint training builds sense of inclusion
- ‘muddling along together’
- Impact of shift patterns on working relationships
- Importance of socialising together
- Impact of Covid-19 on sharing space together
- Desire to be one team
- Sharing space and time together
- Finding neutral ground
- One hospice – a future aspiration?

- Everybody has off days
- Desire for paid staff to be in the PAR group

Being together - ‘let’s get mixing’

Sharing physical space together

‘Everybody has an off day’



Belonging

- New starter process
- Volunteers having a sense of welcome from paid staff
- Feeling established in roles – the 'old guard'

- Being part of something bigger
- Newsletters help to feel connected

- Impact of shift patterns of getting to know others
- Knowing others and being known
- Putting a face to the name
- Not knowing names can be awkward
- Who does the ward belong to?
- We've (not) been expecting you

New starter process for volunteers

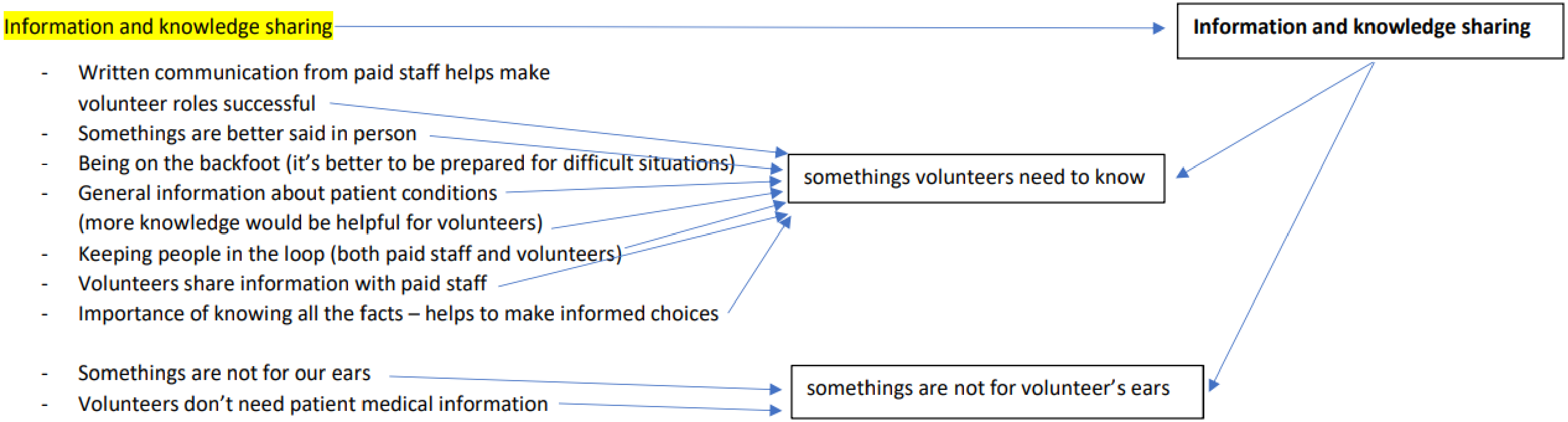
Feeling established in roles

Being part of something bigger

Knowing others and being known

Belonging - 'they must have put the face to the

New starter process for volunteers and feeling established in roles



Information and knowledge sharing

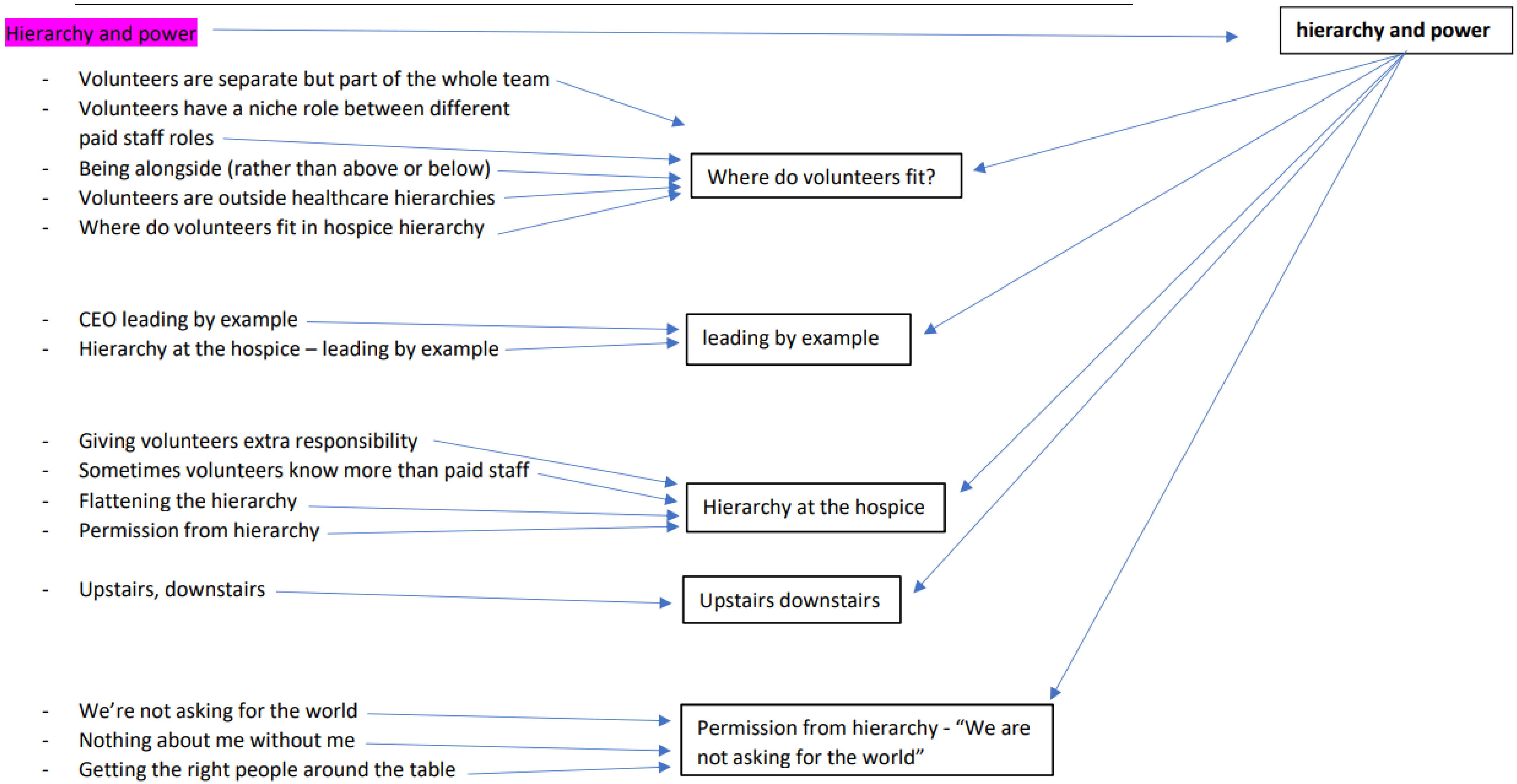
- Written communication from paid staff helps make volunteer roles successful
- Somethings are better said in person
- Being on the backfoot (it's better to be prepared for difficult situations)
- General information about patient conditions (more knowledge would be helpful for volunteers)
- Keeping people in the loop (both paid staff and volunteers)
- Volunteers share information with paid staff
- Importance of knowing all the facts – helps to make informed choices

- Somethings are not for our ears
- Volunteers don't need patient medical information

Information and knowledge sharing

somethings volunteers need to know

somethings are not for volunteer's ears



Hierarchy and power

- Volunteers are separate but part of the whole team
- Volunteers have a niche role between different paid staff roles
- Being alongside (rather than above or below)
- Volunteers are outside healthcare hierarchies
- Where do volunteers fit in hospice hierarchy

- CEO leading by example
- Hierarchy at the hospice – leading by example

- Giving volunteers extra responsibility
- Sometimes volunteers know more than paid staff
- Flattening the hierarchy
- Permission from hierarchy

- Upstairs, downstairs

- We're not asking for the world
- Nothing about me without me
- Getting the right people around the table

hierarchy and power

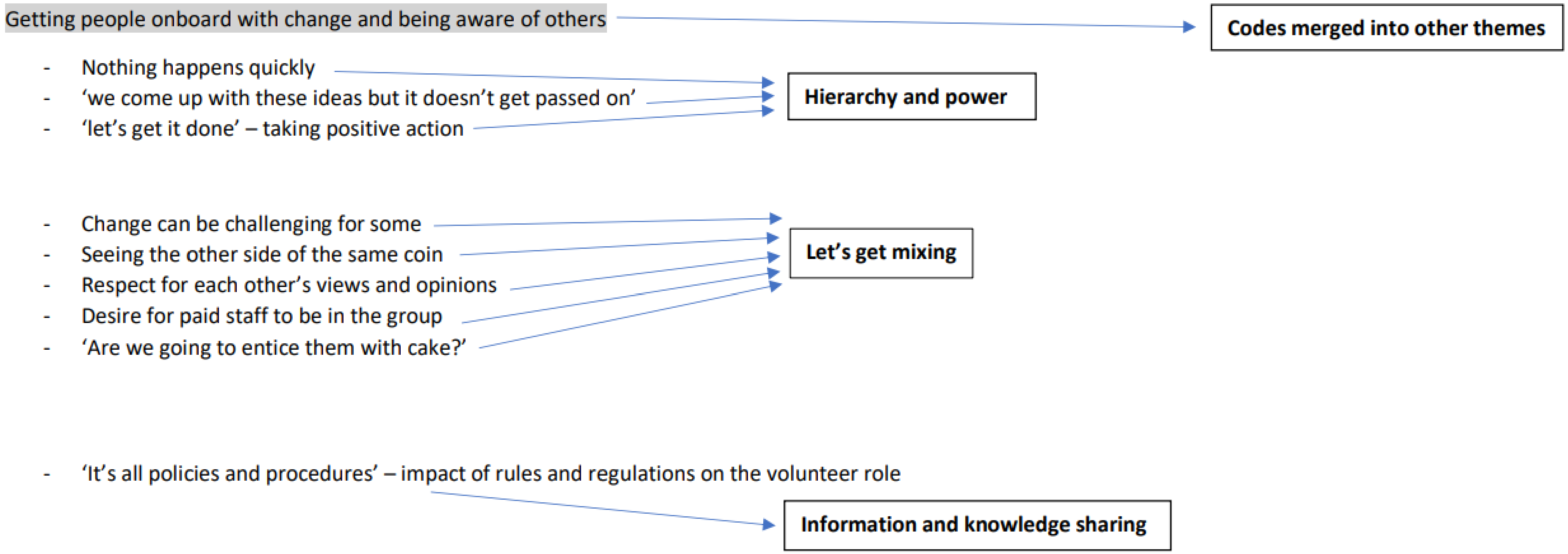
Where do volunteers fit?

leading by example

Hierarchy at the hospice

Upstairs downstairs

Permission from hierarchy - "We are not asking for the world"



Getting people onboard with change and being aware of others

Codes merged into other themes

- Nothing happens quickly
- ‘we come up with these ideas but it doesn’t get passed on’
- ‘let’s get it done’ – taking positive action

Hierarchy and power

- Change can be challenging for some
- Seeing the other side of the same coin
- Respect for each other’s views and opinions
- Desire for paid staff to be in the group
- ‘Are we going to entice them with cake?’

Let’s get mixing

- ‘It’s all policies and procedures’ – impact of rules and regulations on the volunteer role

Information and knowledge sharing

Appendix P Data sources from phase of research

Data source from different phases of the participatory action research

Theme	Hospice documents	Interview Volunteer 1	Interview Volunteer 2	Interview Volunteer 3	Interview Paid staff 1	Interview paid staff 2	PAR 1	PAR 2	PAR 3	PAR 4	PAR 5	PAR 6	PAR 7	PAR 8	PAR 9	PAR 10	Questionnaires	Deliberative panel
Hierarchy and power			🟦		🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦
Belonging		🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	
Let's get mixing		🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦
'What value do we really place on our volunteers?'	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦			🟦	🟦	🟦
Information and knowledge sharing		🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦		🟦	🟦	🟦

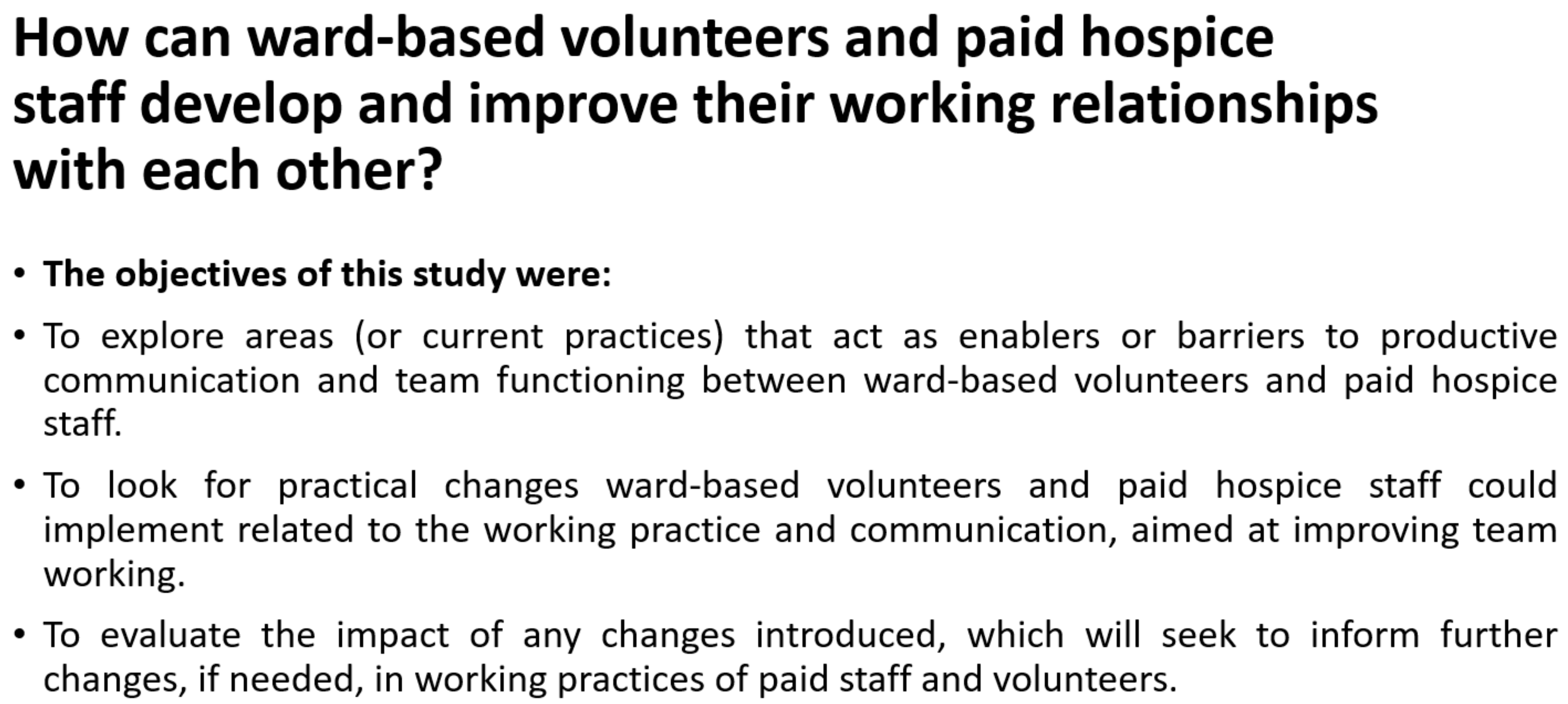
Theme/subtheme	Hospice documents	Interview Volunteer 1	Interview Volunteer 2	Interview Volunteer 3	Interview Paid staff 1	Interview paid staff 2	PAR 1	PAR 2	PAR 3	PAR 4	PAR 5	PAR 6	PAR 7	PAR 8	PAR 9	PAR 10	Questionnaires	Deliberative panel
Belonging		🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	
Knowing others & being known		▨	▨	▨		▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	
New starter process for volunteers & feeling established in roles		▨	▨		▨			▨	▨	▨	▨	▨				▨	▨	
Being part of something bigger		▨	▨			▨	▨	▨		▨				▨				

Theme/subtheme	Hospice documents	Interview Volunteer 1	Interview Volunteer 2	Interview Volunteer 3	Interview Paid staff 1	Interview paid staff 2	PAR 1	PAR 2	PAR 3	PAR 4	PAR 5	PAR 6	PAR 7	PAR 8	PAR 9	PAR 10	Questionnaires	Deliberative panel
Let's get mixing		🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦
Sharing physical space together		▨	▨	▨	▨	▨	▨	▨	▨	▨	▨		▨	▨		▨	▨	▨
Everybody has an off day			▨				▨			▨		▨	▨	▨	▨		▨	

Theme/subtheme	Hospice documents	Interview Volunteer 1	Interview Volunteer 2	Interview Volunteer 3	Interview Paid staff 1	Interview paid staff 2	PAR 1	PAR 2	PAR 3	PAR 4	PAR 5	PAR 6	PAR 7	PAR 8	PAR 9	PAR 10	Questionnaires	Deliberative panel
'What value do we really place on our volunteers?'	■	■	■	■	■	■	■	■	■	■	■	■	■			■	■	■
Volunteers shown appreciation by paid staff		▨	▨	▨		▨		▨		▨	▨							
Volunteering has to be win-win		▨	▨			▨						▨	▨			▨	▨	
Volunteers have expert knowledge & experience		▨	▨	▨	▨	▨	▨									▨		▨
Volunteers are voluntary			▨		▨				▨			▨					▨	▨

Theme/subtheme	Hospice documents	Interview Volunteer 1	Interview Volunteer 2	Interview Volunteer 3	Interview Paid staff 1	Interview paid staff 2	PAR 1	PAR 2	PAR 3	PAR 4	PAR 5	PAR 6	PAR 7	PAR 8	PAR 9	PAR 10	Questionnaires	Deliberative panel
Information and knowledge sharing		■	■	■	■	■	■	■	■	■	■	■	■	■		■	■	■
Somethings volunteers need to know		▨	▨	▨		▨	▨	▨	▨	▨						▨	▨	▨
Somethings are not for volunteer ears		▨	▨	▨	▨						▨		▨	▨				▨

Appendix Q PowerPoint for the deliberative panel



How can ward-based volunteers and paid hospice staff develop and improve their working relationships with each other?

- **The objectives of this study were:**
- To explore areas (or current practices) that act as enablers or barriers to productive communication and team functioning between ward-based volunteers and paid hospice staff.
- To look for practical changes ward-based volunteers and paid hospice staff could implement related to the working practice and communication, aimed at improving team working.
- To evaluate the impact of any changes introduced, which will seek to inform further changes, if needed, in working practices of paid staff and volunteers.

How was this explored?

- **Phase one: Understanding the context**. The purpose of phase one was to better understand the context and culture of the organisation within which the participatory action research group would operate. Phase one consisted of semi-structured interviews with patient paid staff and ward-based volunteers based at a single hospice. The initial findings of the semi-structured interviews and the findings of the literature review then helped to build a SWOT (Strengths, Weaknesses, Opportunities and Threats) analysis at the start of phase two to create a starting point for the participatory research group.
- **Phase two: Action cycles**. The purpose of phase two was to conduct iterative action research cycles directed by a participatory research group. The aim was to collaboratively plan, action, observe and reflect on current practice and the impact of suggested changes.
- **Phase three: Considering the evidence.** The intention of the final phase of the research is to include a deliberative panel formed of members of the wider hospice team to help refine findings and results through discussions...

How was this explored? - Phase 1, literature review

Abstract

Context. Volunteers in palliative care settings are an essential part of care provision for patients and those important to them. Effective collaboration between volunteers and paid staff has been regarded as an important element of successful working, however, at times failures in coordination, information sharing and tensions within teams have been highlighted.

Objectives. To explore the views expressed by volunteers and paid staff about their experiences of working together in palliative care settings.

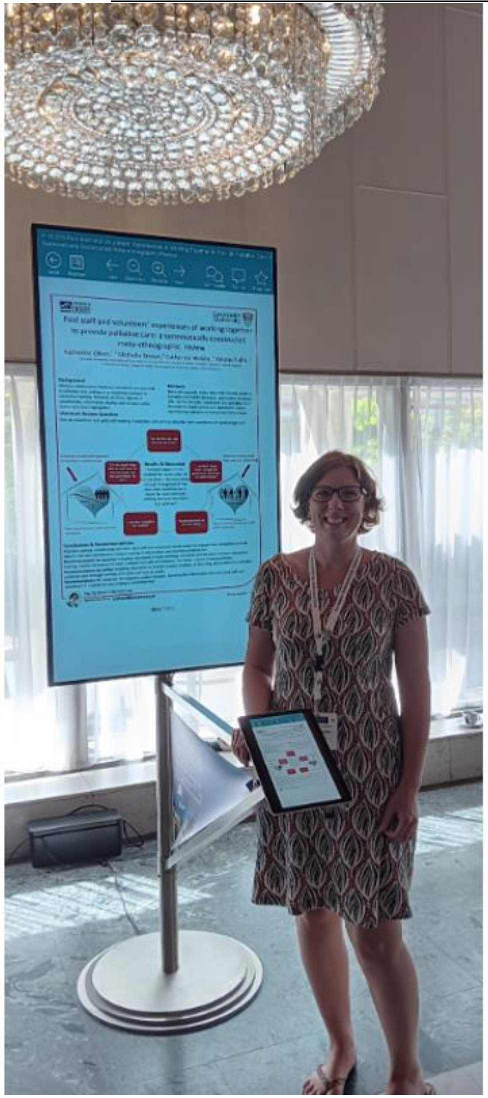
Methods. A systematic exploration of qualitative research using a meta-ethnographic approach. PsycINFO, CINAHL, Medline Complete, and AMED databases were searched from inception to December 2021 for the concepts “volunteers” and “palliative care.” Repeated in-depth reading and appraisal of papers identified metaphors and concepts, providing new interpretations.

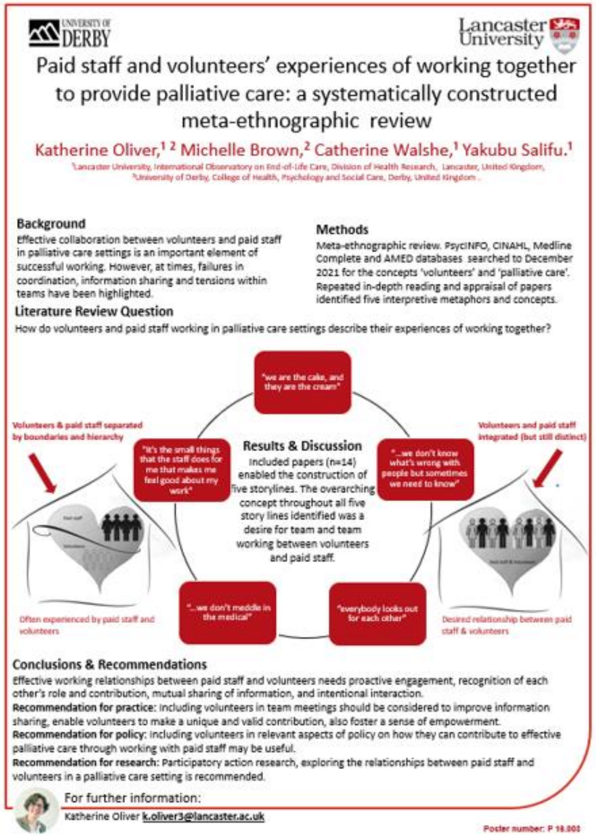
Results. Included papers (n = 14) enabled the construction of five storylines: 1) “we are the cake, and they are the cream”: understanding the volunteer role—separate, but part of a whole. 2) “...we don’t know what’s wrong with people but sometimes we need to know”: access to information and importance of trust. 3) “everybody looks out for each other”: access to paid staff and their support. 4) “...we don’t meddle in the medical”: boundaries. 5) "it’s the small things that the staff does for me that makes me feel good about my work": sense of value and significance.

Conclusions. For effective working relationships between paid staff and volunteers, proactive engagement, recognition of each other’s role and contribution, mutual sharing of information, and intentional interaction between both groups is needed.

- Oliver K, Brown M, Walshe C, Salifu Y. (2023) 'A Meta-Ethnographic Review of Paid Staff and Volunteers Working together in Palliative Care'. *Journal of Pain and Symptom Management.* 66(6): pp 656-670.doi: 10.1016/j.jpainsymman.2023.08.004

European Association for Palliative Care (2023 – Rotterdam)





Paid staff and volunteers' experiences of working together to provide palliative care: a systematically constructed meta-ethnographic review

Katherine Oliver,[1 2] Michelle Brown,[2] Catherine Walshe,[1] Yakubu Salifu.[1]

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[2]University of Derby, College of Health, Psychology and Social Care, Derby, United Kingdom .

Background

Effective collaboration between volunteers and paid staff in palliative care settings is an important element of successful working. However, at times, failures in coordination, information sharing and tensions within teams have been highlighted.

Methods

Meta-ethnographic review. PsycINFO, CINAHL, Medline Complete and AMED databases searched to December 2021 for the concepts 'volunteers' and 'palliative care'. Repeated in-depth reading and appraisal of papers identified five interpretive metaphors and concepts.

Literature Review Question

How do volunteers and paid staff working in palliative care settings describe their experiences of working together?

"we are the cake, and they are the cream"

"It's the small things that the staff does for me that makes me feel good about my work"

"…we don't know what's wrong with people but sometimes we need to know"

"…we don't meddle in the medical"

"everybody looks out for each other"

Results & Discussion

Included papers (n=14) enabled the construction of five storylines. The overarching concept throughout all five story lines identified was a desire for team and team working between volunteers and paid staff.

Volunteers & paid staff separated by boundaries and hierarchy

Often experienced by paid staff and volunteers

Volunteers and paid staff integrated (but still distinct)

Desired relationship between paid staff & volunteers

Conclusions & Recommendations

Effective working relationships between paid staff and volunteers needs proactive engagement, recognition of each other's role and contribution, mutual sharing of information, and intentional interaction.

Recommendation for practice: Including volunteers in team meetings should be considered to improve information sharing, enable volunteers to make a unique and valid contribution, also foster a sense of empowerment.

Recommendation for policy: Including volunteers in relevant aspects of policy on how they can contribute to effective palliative care through working with paid staff may be useful.

Recommendation for research: Participatory action research, exploring the relationships between paid staff and volunteers in a palliative care setting is recommended.

For further information:
Katherine Oliver k.oliver3@lancaster.ac.uk

Poster number: P 18.003

How was this explored? - Phase 1, semi-structured interviews

- 5 interviews were carried out between 8/12/21 and 20/5/22. They consisted of 2 paid staff members and 3 volunteers. 4 interviews were face-to-face and 1 was via Microsoft Teams. All interviewees appeared to be white, female and between 50 – 70. They were all based on or had frequent contact with the In-patient unit at the hospice. First thoughts:

One team (including support, joint training) - This was almost the 'umbrella theme' that threaded through the interviews, reports, and policies. It often reflected how people saw the working relationship between paid staff and volunteers. There was a desire to be one team rather than two separate teams.

Appreciation (including vital/necessary/useful, trust and responsibility) - Words including 'amazing' and 'fantastic' were used by paid staff to describe volunteers at the hospice. Their contribution was said to be immeasurable within a hospice annual report, as it was noted that without them the hospice would struggle without their 'time, skills and commitment', which appreciated, along with the contribution of the paid staff.

Communication and collaboration (including hand over sheets and role of the volunteer co-ordinator) - Some collaboration between paid staff and volunteers was thought to direct, whereas at times it was also described as indirect, or incidental collaboration.

Recognition of volunteer roles (including new roles, backgrounds) - This helped some to feel comfortable in the in-patient setting and with the kind of tasks they were doing, as well as having previous experience with people and communication – helping to make them useful. Life experience was also recognised as a way of helping volunteers to relate to issues at the hospice.

Recognition of each other (including names and sharing news) - White boards with names on were discussed by both paid staff and volunteers

Impact of covid - Covid had an impact on many aspects of the working relationship and how people worked together. Many of the points and themes discussed were influenced or overshadowed by covid and what people had experienced.

SWOT analysis

Strengths:

-Mutual aims and concerns, which is the wellbeing of patients
-ability to recognise strength & weakness of people, and then give support
-able to adapt to each other's needs
-self-confidence to speak up (allowed freedom to speak)
-recognition of 'off days'
-being able to volunteer/work at hospice
-attracts people with certain personalities
-sense of trust between paid staff & volunteers
-sense of appreciation & welcome
-hand over from kitchen staff

Weakness:

-not always being aware of what you are walking into (patient rooms)
-shift patterns
-communication can be both a strength & weakness
-not knowing 'who is who'
-not knowing each other's roles

Opportunities:

-lots of volunteers come wanting to gain experience
-different students that come wanting to build confidence
-able to free up paid staff to care for patients
-diversity of paid staff & volunteers (gender, age, personalities etc)
-team work
-commitment from the hospice that they want this study to go ahead
-volunteer meetings

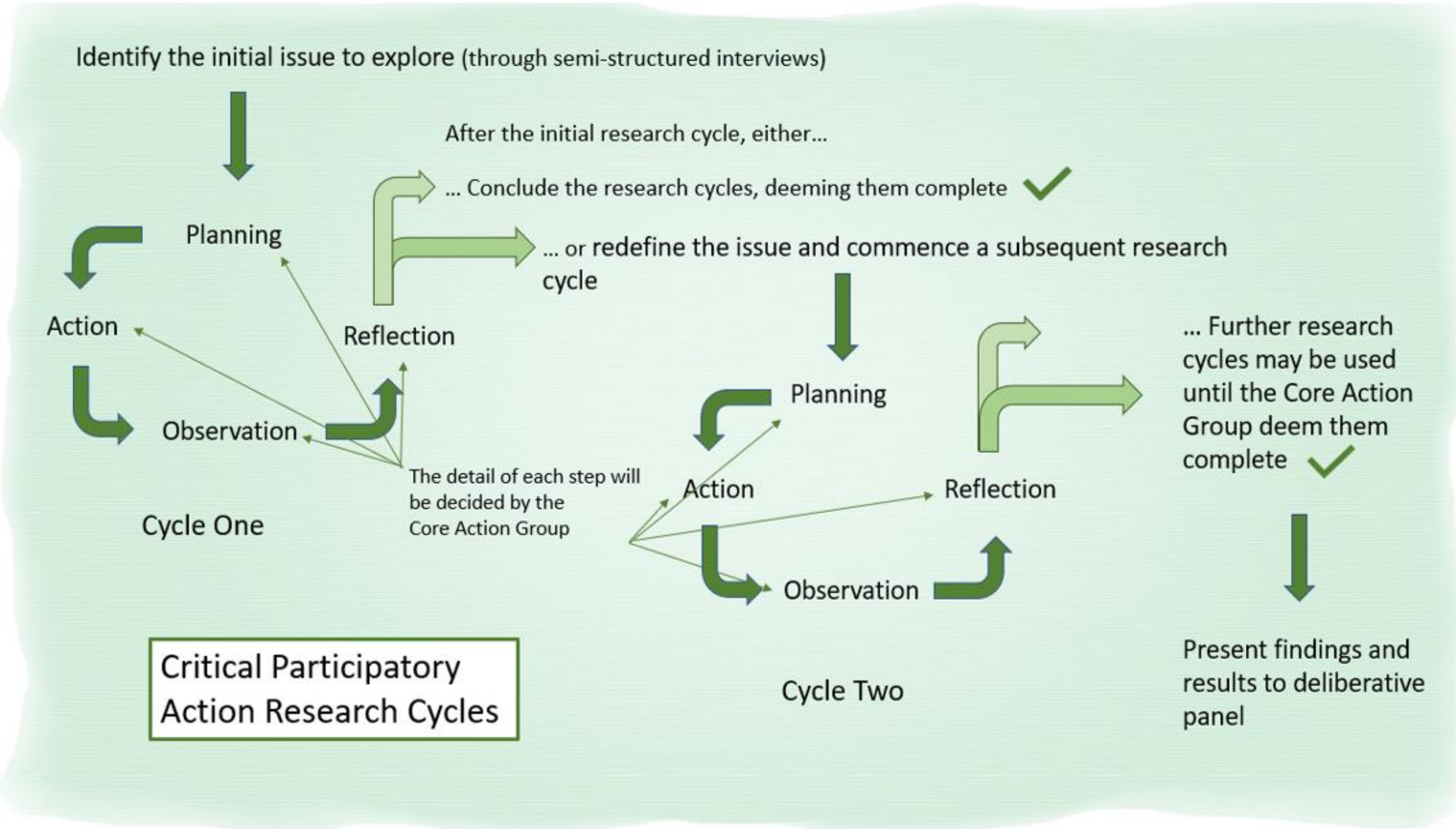
Threats:

- 'them upstairs', higher up
-if the group decide they want to change things they may need to 'go through hoops'
-time scales
-worry of potential coercion in to doing things at hospice don't want to do
-other commitments & how to manage these
-wider cultural issues

How was this explored? - Phase 2, Participatory Action Research Group (PAR)

- The group started with eleven participants (3 paid staff and 8 volunteers) and over time the group changed due to some leaving and others joining. The core group was aged between 35 – 75, 1 male 5 female. I was also a part of the group and attended all but one group meeting.
- Data collection
- meetings were conducted between 6th March 2023 and 25th March 2024. They were approximately once a month and were approximately one to one and a half hours long. The meetings took place in different meeting rooms at the hospice during normal working hours. Meetings were digitally audio recorded with consent, which was stored in a locked cupboard. Recordings were uploaded to a password-protected computer, transcribed verbatim and anonymised. Two meetings were not recorded due to technical issues with the Dictaphone and because I did not attend one of the meetings. Notes were also made before, during and after meetings in a personal reflective journal, which contained anonymised reflections on the group's progress.
- The group decided to conduct questionnaires as part of their evidence gathering. This was sent with an email of explanation by the hospice volunteer lead with a link to a Google Form which participants could complete anonymously. Data analysis
- Transcripts from each of the meetings were (and are being at the moment!) analysed, employing reflective thematic analysis approach. Comments were added to this which were taken from the reflective diary of comments before, during and after the meetings to add personal reflexivity.

What was thought would happen...



Identify the initial issue to explore (through semi-structured interviews)

Planning

Action

Observation

Reflection

Cycle One

After the initial research cycle, either...

... Conclude the research cycles, deeming them complete ✓

... or redefine the issue and commence a subsequent research cycle

The detail of each step will be decided by the Core Action Group

Planning

Action

Observation

Reflection

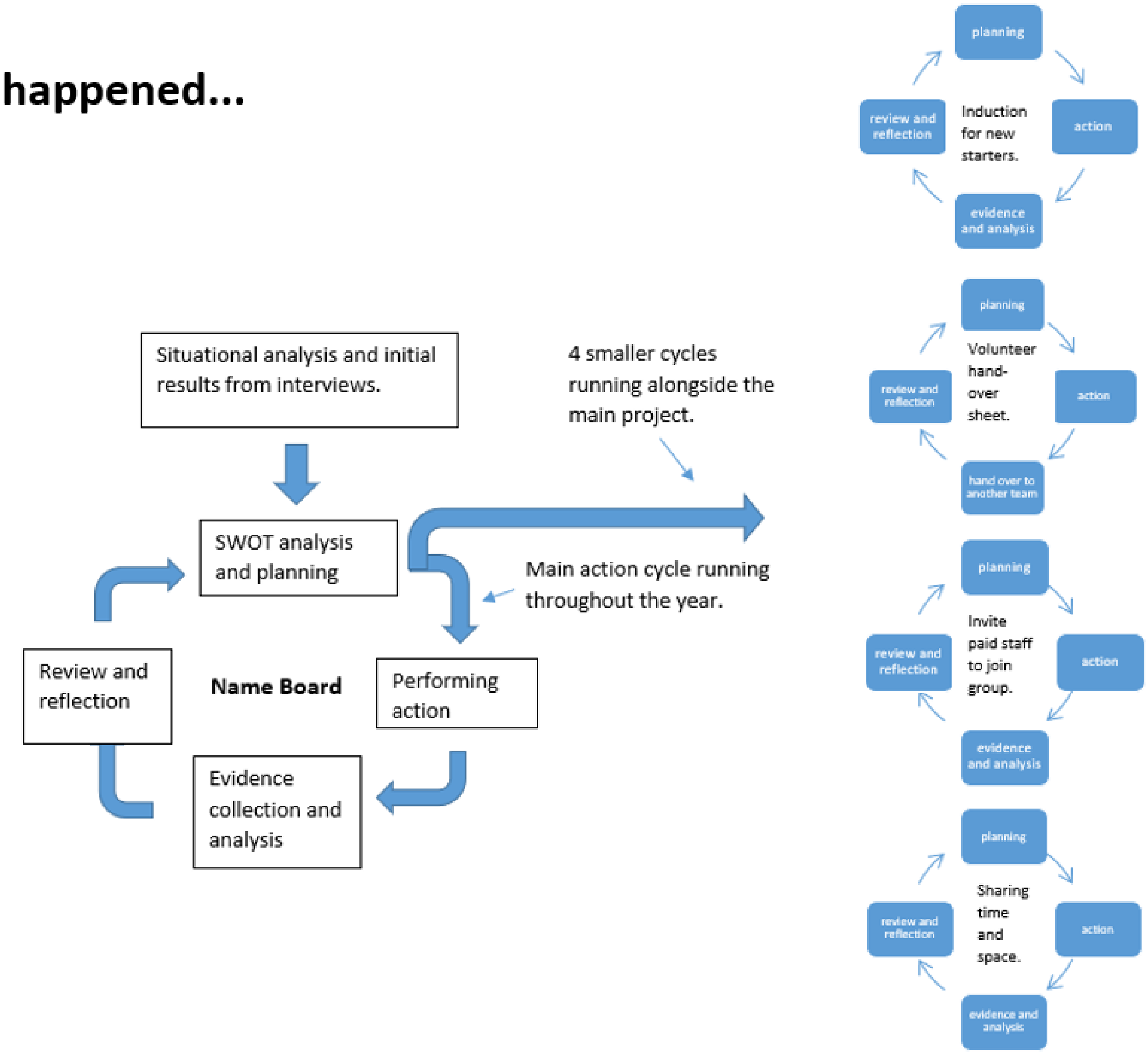
Cycle Two

... Further research cycles may be used until the Core Action Group deem them complete ✓

Present findings and results to deliberative panel

Critical Participatory Action Research Cycles

What actually happened...



Situational analysis and initial results from interviews.

SWOT analysis and planning

Performing action

Evidence collection and analysis

Review and reflection

Name Board

Main action cycle running throughout the year.

4 smaller cycles running alongside the main project.

Induction for new starters.

Volunteer hand-over sheet.

Invite paid staff to join group.

Sharing time and space.

Belonging

- Importance of knowing others and being known

When discussing the current name board one participant said:

"...I walked past that whiteboard, and sometimes there's something about a particular patient that you want to say, so I look on the Whiteboard to see who was dealing with that patient and I have no idea who the person is. I do have to go around, I go to the nurse's station and sit there, looking at everybody's chest to see if that's [name of nurse] or [name of HCA] or whoever it is. I don't know how you can improve that, but maybe if we had more interaction with each other, we wouldn't be so lost as to who is who..." PAR1

Another area that was mentioned for knowing each other's names was the use of name badges that were easier to see were seen as a positive:

“those are really good! I mean my eyesight is not brilliant, but it is very easy. You know 'cause if you're trying to read the name and see is that (name of nurse)? You know in the past, you've got to peer right at their chest, but these yellow ones you can see, so I, I think that's that's really good.” Int

“when we first started... we didn’t have badges to start with, which made it awkward, so as soon as we got badges, we could say ‘well this is what I am’ and we got the lanyards and everything like that”. Int

- Part of something bigger – importance of connections

Shifts and home working had an impact on having a sense of belonging:

"...I've sometimes seen somebody and they said ‘Ohh and I said, gosh, I thought you left’ ‘Oh, no - I've been on three weeks of nights. Yeah, I've been on for a couple of weeks’ and you know because. OK, you know, shifts". PAR 1

Towards the end of the project the name board was having an impact on being aware of others:

"And some of the HCAs have said they had a look at the board and they had a look, they went through all the photos and I heard them say wow, we did not realise we've got this many volunteers. And he said, oh, it's really good to see all the photos, we never realised it.". PAR 9

Adding value

Overall, there was a common experience by those that had and were volunteering that they felt valued by paid staff. This was often expressed verbally, with paid staff saying ‘thank you so much’, which often made volunteers feel useful and that they were doing something worthwhile.

At times volunteers noted that whilst they were appreciated by staff they were unsure how to verbalise the significance of their role. Also, finding difficulty to describe it:

- Vital/necessary/useful...

"...necessary... is necessary too strong a word? Coz it's not necessary, it's not a vital part coz other people can do what we do..., but I think it’s a very, we are a very useful part of the team... So, it's, yeah, we’re not vital, are we? I don’t think anybody is vital coz you would have someone else on the ward to do it..., but I think we have a good... no, we’re not... vitals’ not the right word, I think we’re useful...”

- It takes two to tango

Effective communication and working together was thought to be a two-way responsibility between paid staff and volunteers.

One volunteer explained how they didn’t sit back and wait for paid staff to make the first move:

"...but at the end of the day it was up to us to go and find somebody to say ‘right we are here, what do you want, you know, this is what we will be doing – what else do you want us to do?’, coz it’s a two-way thing as well..." Int

This was also described by both paid staff and volunteers as being win-win, which was both good for the paid staff and hospice, but also beneficial to the volunteer

Information sharing

- Somethings we need to know

One volunteer described a situation when they went into a room of a patient with [redacted] disfigurement and how unprepared they were for this. Adding:

"I came out and I actually mentioned to a senior member of staff at the time of it ‘that was a shock, I wish I'd been aware of this’ and they said ‘Well, we're all professionals and we're all medics’ I went well I'm a volunteer. I'm not a medic ... I said I think you need to be aware there's a lot of volunteers with all different backgrounds... and then they said ‘oh, yeah, that's probably a point’." PAR 1

Another volunteer positively added:

"when we do the hand over with the kitchen staff they explained to us and warned us, you know, if it's a difficult situation, yes." PAR1

Hand over was seen as an important part of knowing how they could and should be doing during their time at the hospice:

"... Any rooms that we can't go into, that you would prefer us not to go into? Anything that you need fetching or doing? Or anything like that’ and generally now that’s, ‘oh, right’, so you’ll then get your feedback as to what you can and can't do, where you can and can't go." Int

Hand over sheets were thought to be helpful. However, there seemed to be some volunteers who had access to a hand over sheet and others that did not depending on which team they were connected to.

- Somethings are not for our ears

There was concern that at times volunteers may want too much information about patients or try to tell paid staff what to do.

However, many volunteers recognised that they did not need 'clinical information' on their hand over sheets

Some volunteers said they felt uncomfortable at times if doctors were discussion medical information about patients in the break room as they did not feel that this was for their ears. However, it was also discussed that volunteers had GDPR training and would be expected by others to hold this information in confidence, showing trust.

Sharing space and time ("Let's get mixing")

Some volunteers discussed partnership:

"...Between paid staff and volunteers, it's not a them and us, it's we're all we're all partnership and we all work together". PAR 1

However, this was not always seen as the case:

"...Most remember most of the names, but then you get down on the ward and the nursing staff have got jobs to do and we just kind of are in the background. So, you don't want to interfere and you don't build up a rapport because everybody's at work, they do it, they've got a job to do. So it's it is a bit them and us... [it] always will be. But they just get along and the more you see the same people, the more you build a rapport with those people". PAR 1

During Covid staff and volunteers did not interact in the same way as they did not always attend the same physical areas due to an attempt to reduce foot fall. One participant reflected that:

"So even our kitchen staff didn't come on to the ward... they would stand in that line, between obviously from the kitchen to the ward – they wouldn't go over that – so we had to do all the running about, then after probably a year they decided that they were coming on to the ward and then we sort of gradually had the volunteers back, but they stopped all volunteers." Int

Generally, there was a desire to join paid staff and volunteers together more:

"let's get mixing you know... we need to get back to one team they keep saying '[redacted]' - so let's be '[redacted]'..." Int

One way it was thought that being one team could be supported was through joint training days where both paid staff and volunteers needed to do the same training, such as moving and handling, as a way of mixing more between the two groups. Int

The group explored the break room as a neutral, shared space to get groups mixing more and ways this could be achieved.

- **We all have off days**

It was also acknowledged that there is a human factor involved, which would also impact on communication and working together:

"I mean in any environment you are going to get people who speak to people first in the morning and some who don't coz that's the nature of people..."

Hierarchy and power

- **Upstairs downstairs**

The phrase 'them upstairs' was mentioned frequently in relation to the hospice leadership and also the physical space. It appeared that not seeing upstairs in the building created a sense of mystery about what happened and who was up there. This reminded me of the 'wizard of Oz' - the man behind the screen. Building tours for new starters (and those that had been there for longer, but not seen upstairs) was one way the group thought this could be improved.

- **We don't want the world...**

Phrases like 'going through the hoops' and 'things take a long time' were further highlighted in a comment that the group didn't want the world they only wanted a name board. This implied a sense of disempowerment at times within the Participatory Research group and comments about other projects in the past.

- **Recognition of previous experience**

"I think a lot of our volunteers come from nursing backgrounds anyway so, I think that they know don't they, they know what nursing is about so, I think yeah, I think that's the biggest strength, I think." Int

However, there was concern that at times volunteers may want too much information about patients.

- **Volunteers are 'alongside' paid staff**

Paid staff initially discussed that they wanted volunteers included on the name board:

"we have sort of tried to look at different ways of involving the volunteers, but we, which was sort of like – I would like to see their names on the white board alongside us". Int

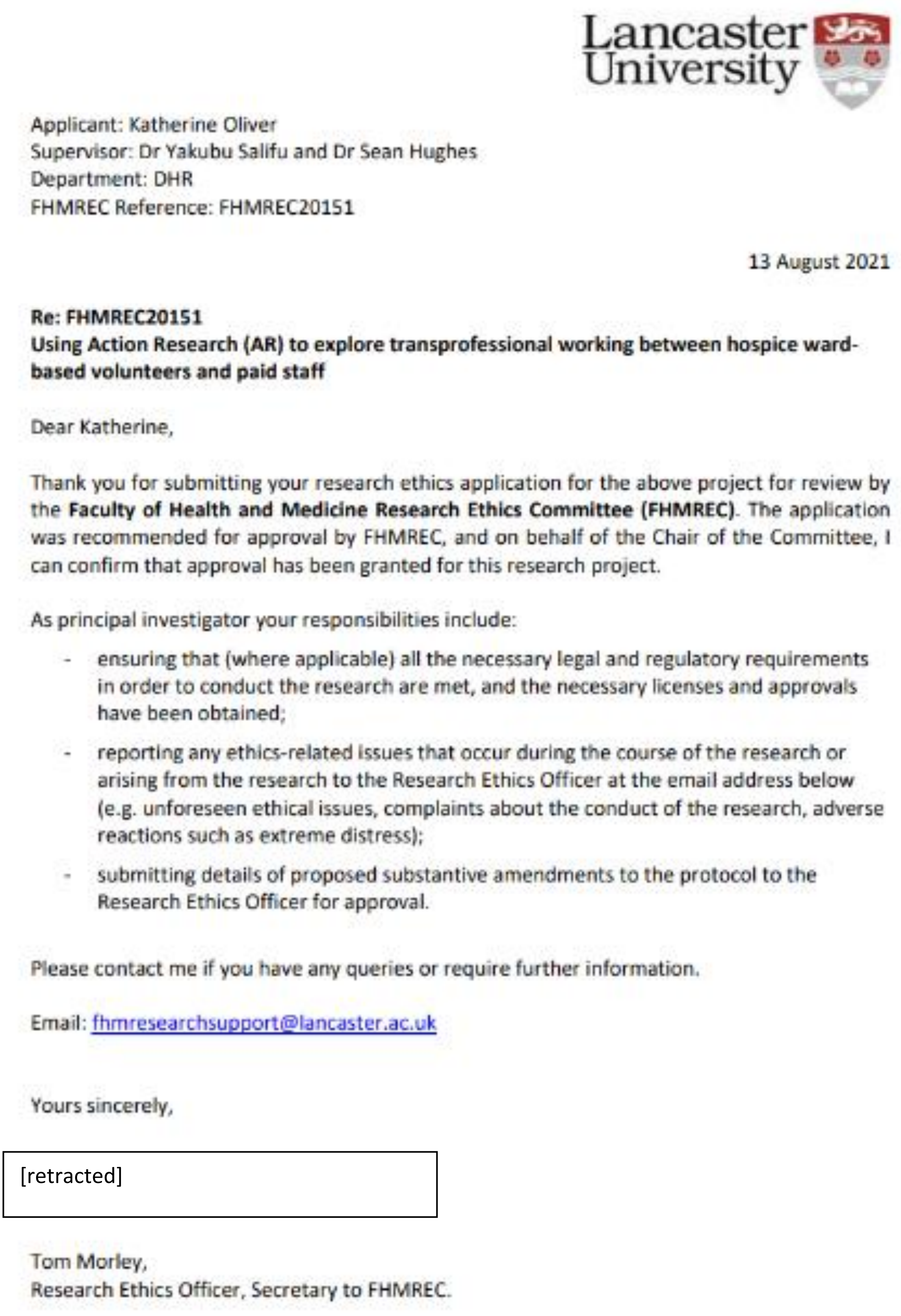
Where volunteer names should go on the board was discussed, one group member said it was interesting seeing where their names were placed on the board each time they were in:

"where are we going to be today – oh, we are up there at the top. Yeah... So that's somebody who's done that are volunteer champions maybe and then others put us at the bottom - and somebody's thought oh shove them on anywhere [laughs]". PAR

It was recognised that health care teams like to remain in traditional hierarchical formats on the name board:

"I mean, the nursing hierarchy does like to be a hierarchy. So, they have the ward sister or whatever you start with the manager and go down. I mean they do that, that happens now... written up on the board. " PAR 10

Appendix R Ethical approval



Lancaster University

Applicant: Katherine Oliver
Supervisor: Dr Yakubu Salifu and Dr Sean Hughes
Department: DHR
FHMREC Reference: FHMREC20151

13 August 2021

Re: FHMREC20151
Using Action Research (AR) to explore transprofessional working between hospice ward-based volunteers and paid staff

Dear Katherine,

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Email: fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

[retracted]

Tom Morley,
Research Ethics Officer, Secretary to FHMREC.

Appendix S Consent and information sheets for phases

Participant Information Sheet for the Action Research Group

Title of the study: Using Action Research (AR) to explore transprofessional working between hospice ward-based volunteers and paid staff

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

Name of Principal Investigator: Katherine Oliver (PhD Student at Lancaster University)

Contact details:

[redacted]

Introduction

My name is Katherine Oliver and I am a PhD student at Lancaster University. This is an invitation to take part in research as part of my study. The purpose of the study is to involve an Action Research Group, consisting of ward-based paid staff and members of the hospice in-patient volunteer team to gain an understanding of, identify and build on existing strengths. Also challenging and changing current hospice practice to improve the volunteer-professional working relationships and collaboration.

You may wish talk to anyone you feel comfortable talking with about the research at this point and time to reflect on whether you want to participate or not. If you do not understand any of the content, concepts, or what will be expected of you, please get in-touch with me for further information (without any obligation to commit to take part).

Purpose of the research

This Action Research will seek to gather and use information so that it has a direct and immediate impact on those affected. This will be used to explore the way the hospice volunteer-professional teams collaborate and support each other, seeking to make build on and/or make positive changes where needed.

Type of Research Intervention

If you choose to join, this research will involve your participation in Core Action Group (CAG) discussions that will take about one and a half hours, once a month for approximately one year (maximum commitment anticipated).

The CAG will be expected to direct the research process, making decisions (in consultation with the main researcher) on how they think identified issues could be best explored and improved. Action research follows a circular format of planning, action, observation, reflection, and problem-solving. This is referred to as an 'action cycle' in the remainder of this information sheet.

Participant Selection

You are being invited to take part in this research because your experience as an employed member of the hospice in-patient unit or as a member of the hospice in-patient volunteer team can contribute much to the group in gaining understanding and knowledge of team working between the volunteer and employed staff.

Voluntary Participation

Your participation in this research study is entirely voluntary. It is your choice whether to participate or not. The choice that you make will have no bearing on your job (employed or voluntary) or on any work-related evaluations. You may also change your mind later and stop participating at any point by informing the principal investigator of your decision.

Procedures

The group will discuss current working and experiences of volunteer-professional collaboration. This discussion (or assessment) will be used by the group to formulate an appropriate plan of action to explore the subject further, plan changes to care provision if needed, allocate tasks as a group to implement changes, and then review their findings. You will not be asked to share any knowledge or experiences that you are not comfortable sharing. You will be expected to participate in the group and take a share of conducting the interventions. However, if there are specific interventions you do not want to participate in, you can choose not to (for any reason, which you do not have to disclose).

The group meetings will take place in the meeting room at the hospice, and no one else but the people who take part in the discussion or myself will be present during this discussion. Please be aware that there is a possibility that the sessions will need to take place on a social networking site, due to covid. The entire discussion (face-to-face or online) will be digitally-audio recorded. The recordings will be transferred as soon as possible to a secure and encrypted computer and the original recording will be stored on a digital voice recorder in a locked cupboard for the duration of the study. The information recorded will be held confidentially, and no one else except me will have access to the recordings. The transferred recordings will be destroyed as soon as the PhD research has been completed.

Each of the sessions will focus on one aspect of the Action Research cycle (Assess, Plan, Implementation, and review). Therefore, each complete cycle is expected to take approximately four months. At the end of each of these cycles you will be asked if you would like to carry on with the research process and will be asked to verbally consent if you wish to proceed. It is anticipated that there will be up to three full Action Research cycles.

Duration

It is anticipated that the research will take place over 12 months (maximum length of time you will be asked to commit to). Group meetings will be on the first Monday of each month and will be one and a half hours.

Risks

This study will explore a challenging area of study, as it will work with those providing care and support to patients approaching the end of life. It is recognised that participants may find aspects of the process emotionally challenging. It is also possible that participants may find it difficult discussing aspects of previous practice that they had been involved in. There is risk that discussing sensitive topics may raise difficult and traumatic memories for participants. Therefore, psychological support will be available for all participants via members of the counselling team that are not connected to the research project. If participants do not wish to discuss issues within the hospice, then they will be signposted to external support.

Benefits

There will be no direct benefit to you, but your participation is likely to help improve the collaboration between employed and volunteer teams, and as such improve your working practice.

Reimbursements

You will not be provided any incentive to take part in the research. Refreshments will be provided at the group meetings (if face-to-face).

Confidentiality

The research being done in the hospice building may draw attention and if you participate you may be asked questions by other people in the hospice setting. Also, due to the changes that will be made to practice, it is anticipated that individuals will be aware that you are part of the Action Research group. I will not be sharing information about you to anyone outside of the research team (which includes my two University Supervisors). The information that I collect from this research project will be kept confidential. Any information about you will have a number and job role on it instead of your name (e.g. nurse 1, or volunteer 2). Only I will know what your number is and I will lock that information up in a secure cupboard and on an encrypted computer.

Please note that if information is disclosed of a criminal nature or that harm to self or another has or could be caused, this will be managed in line with local Hospice policy.

I will ask you and others in the group not to talk to people outside the group about what was said in the group. I will, ask each of you to keep what was said in the group confidential. You should know, however, that I cannot stop or prevent participants who were in the group from sharing things that should be confidential. Also, please maintain the confidentiality of any other participants that take part in the research process (including those involved in interviews).

There is a possibility that you will be asked to gather data, if this is the case you will need to store this safely and appropriately. For example, information on paper or memory stick will need to be locked in fireproof cabinets. Also, data will be gathered in an anonymous way so that individuals cannot be identified.

Sharing the Results

It is expected that I would publish in a peer-reviewed journal also by presenting at relevant conferences. The final thesis will be kept in the Lancaster University library and therefore will be publicly available. Consequently, again, specific details of where the hospice is in England and the identity of participants will be concealed for confidentiality.

Right to Refuse or Withdraw

You may stop participating in the Action Research group at any time that you wish without your job being affected. However, it is important that you are aware that you will only be able to withdraw your data and inclusion in the final report up to the point of commencing the Action Research groups, as it will be challenging to separate your comments, the responses to them, and your contribution to the group study.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

Katherine Oliver (PhD student at Lancaster University)

Contact details:

[redacted]

Dr Yakubu Salifu (main supervisor), contact email address: y.salifu@lancaster.ac.uk

Dr Sean Hughes (supervisor), contact email address: sean.huges@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Catherine Walshe, Tel: [retracted]

Head of Division of Health Research

Email: c.walshe@lancaster.ac.uk

Division of Health Research

Lancaster University

Lancaster

LA1 4AT

If you wish to speak to someone outside of the palliative care Doctorate Programme, you may also contact:

Dr Laura Machin Tel: +44 (0)1524 594973

Chair of FHM REC Email: l.machin@lancaster.ac.uk

Faculty of Health and Medicine

(Lancaster Medical School)

Lancaster University

Lancaster

LA1 4YG

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

Counselling & bereavement support team,

[redacted]

If you do not wish to discuss issues within the hospice, then I will be able to signpost you to other external support – for example:

- The Samaritans: Telephone 116 123 (free from any phone). Email jo@samaritans.org

- British Association for Counselling and Psychotherapy (BACP): BACP House 15 St John's Business Park Lutterworth LE17 4HB tel: 01455 883300. Email: bacp@bacp.co.uk text 01455 560606

Form adapted from: Lancaster University (2020). *Research ethics - Sample participant information sheet*. https://www.lancaster.ac.uk/health-and-medicine/research/ethics/#tabs-397981-3

Informed Consent Form for the Action Research group

Study Title: Using Action Research (AR) to explore transprofessional working between hospice ward-based volunteers and paid staff

Name of Principal Investigator: Katherine Oliver (PhD Student at Lancaster University)

Contact details:

[retracted]

You will be given a copy of the full Informed Consent Form

I am asking if you would like to take part in a research project looking at ways that ward-based hospice employed staff and volunteers can improve their collaboration.

Before you consent to participating in the study, I ask that you read the participant information sheet and mark after each statement with your initials in the box if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Katherine Oliver.

1. ☐ I confirm that I have read the participant information sheet (version 1) and fully understand what is expected of me within this study.
2. ☐ I confirm that I have had the opportunity to ask any questions and to have them answered.
3. ☐ I understand that my interview will be audio recorded and then made into an anonymised written transcript.
4. ☐ I understand that audio recordings will be kept until the research project has been examined.
5. ☐ I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my future working relationship (employed or voluntary) with the hospice being affected.
6. ☐ I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn.
7. ☐ I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published; all reasonable steps will be taken to protect the anonymity of the participants involved in this project.
8. ☐ I consent to information and quotations from my interview being used in reports, conferences and training events.

9. ☐ I understand that the researcher will discuss data with their supervisors as needed.
10. ☐ I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case I will need to follow the guidance at the local hospice.
11. ☐ I consent to Lancaster University keeping written transcriptions of the interview for up to 10 years after the study has finished.
12. ☐ I consent to take part in the above study.

Name of Participant______________ Signature__________________ Date ___________

Name of Researcher ______________Signature __________________Date ___________

Participant Information Sheet for the Semi-structured interviews

Title of the study: Using Action Research (AR) to explore transprofessional working between hospice ward-based volunteers and paid staff

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

Name of Principal Investigator: Katherine Oliver (PhD Student at Lancaster University)

Contact details:

[retracted]

My name is Katherine Oliver and I am conducting this research as a student in the PhD in palliative care programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

This study will explore the way the hospice volunteer-professional teams collaborate and work together, seeking to make positive changes where needed.

Why have I been approached?

You have been approached because the study requires information from people who have experienced being a member or either the employed or volunteer team working on the in-patient unit at the hospice to gain insight into your individual experiences and perspectives.

Do I have to take part?

No. It is completely up to you to decide whether or not you take part. If you choose not to join it will have no impact on your future work (employed or voluntary) and relationship with the hospice.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to be interviewed in one of the hospice private counselling rooms (located away from the ward area) by myself. However, if covid restrictions are in place at the time of the planed interview, this may take place via a social networking site such as zoom. The interview will be audio recorded, so it is easier to accurately document what you have said. The recordings will be transferred as soon as possible to a secure and encrypted computer and the original recording will be stored in a secure locked cupboard and will be deleted once the research is competed. The information recorded is confidential, and no one else except me will have access to the recordings. The transferred recordings will be destroyed as soon as the PhD research process has been fully completed.

Will my data be Identifiable?

Data collected for this study will be stored securely and only the main researcher conducting this study will have identifiable access to this data. Other group members (individuals who are employed by the hospice or members of the hospice volunteer team) will be the only other individuals to be informed of your anonymised data for discussion.

- Audio recordings will be destroyed and/or deleted once the project has been submitted for publication/examined.
- The files on the computer will be encrypted (that no-one other than the main researcher will be able to access them) and the computer itself password protected.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or in publications from the study, so your name will not be attached to them. Please be aware that there is a small risk that full anonymity may not be fully possible due to the small sample size of volunteers and employed workers attached to one hospice. The hospice will be referred to as a 'hospice in England'. All reasonable steps will be taken to protect the anonymity of the participants involved in this project.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and follow hospice policy of disclosure. If possible, I will tell you if I have to do this.

What will happen to the results?

The results will be summarised and reported in a thesis and may be submitted for publication in an academic or professional journal, also may be presented at relevant conferences. The final thesis will be kept in the Lancaster University library and therefore will be publicly available.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation due to discussing difficult and sensitive issues you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

Although it is anticipated that the research will improve volunteer-employed collaboration, there are no direct benefits in taking part.

Right to Refuse or Withdraw

You may stop participating in the interview at any time that you wish without your job being affected. However, it is important that you are aware that you will only be able to withdraw your data and inclusion in the final report up to 4 weeks after the interview, after this time this will no longer be possible.

Who has reviewed the project?

This study has been reviewed and approved by the Health Research Authority (HRA) and the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

Katherine Oliver (PhD student at Lancaster University)

Contact details:

[retracted]

Dr Yakubu Salifu (main supervisor), contact email address: y.salifu@lancaster.ac.uk

Dr Sean Hughes (supervisor), contact email address: sean.huges@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Catherine Walshe, Tel: [retracted]

Head of Division of Health Research

Email: c.walshe@lancaster.ac.uk

Division of Health Research

Lancaster University

Lancaster

LA1 4AT

If you wish to speak to someone outside of the palliative care Doctorate Programme, you may also contact:

Dr Laura Machin Tel: +44 (0)1524 594973

Chair of FHM REC Email: l.machin@lancaster.ac.uk

Faculty of Health and Medicine

(Lancaster Medical School)

Lancaster University

Lancaster

LA1 4YG

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

Counselling & bereavement support team,

[retracted]

If you do not wish to discuss issues within the hospice, then I will be able to signpost you to other external support – for example:

- The Samaritans: Telephone 116 123 (free from any phone). Email jo@samaritans.org

- British Association for Counselling and Psychotherapy (BACP): BACP House 15 St John's Business Park Lutterworth LE17 4HB tel: 01455 883300. Email: bacp@bacp.co.uk text 01455 560606

Form adapted from: Lancaster University (2020). *Research ethics - Sample participant information sheet*. https://www.lancaster.ac.uk/health-and-medicine/research/ethics/#tabs-397981-3

Informed Consent Form for the Semi-structured interviews

Study Title: Using Action Research (AR) to explore transprofessional working between hospice ward-based volunteers and paid staff

Name of Principal Investigator: Katherine Oliver (PhD Student at Lancaster University)

Contact details:

[retracted]

You will be given a copy of the full Informed Consent Form

I am asking if you would like to take part in a research project look at ways that ward-based hospice employed staff and volunteers can improve their collaboration.

Before you consent to participating in the study, I ask that you read the participant information sheet and mark after each statement in the box with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Katherine Oliver.

1. ☐ I confirm that I have read the participant information sheet (version 1) and fully understand what is expected of me within this study.
2. ☐ I confirm that I have had the opportunity to ask any questions and to have them answered.
3. ☐ I understand that my interview will be audio recorded and then made into an anonymised written transcript.
4. ☐ I understand that audio recordings will be kept until the research project has been examined.

5. ☐ I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my future working relationship (employed or voluntary) with the hospice being affected.
6. ☐ I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn. I understand that I will be unable to withdraw my data after 4 weeks after the interview.
7. ☐ I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published; all reasonable steps will be taken to protect the anonymity of the participants involved in this project.
8. ☐ I consent to information and quotations from my interview being used in reports, conferences and training events.
9. ☐ I understand that the researcher will discuss data with their supervisor as needed.
10. ☐ I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case I will need to share this information with their research supervisor and follow guidance at the local hospice.
11. ☐ I consent to Lancaster University keeping written transcriptions of the interview for up to 10 years after the study has finished.
12. ☐ I consent to take part in the above study.

Name of Participant_______________ Signature___________________ Date ____________

Name of Researcher _______________Signature ___________________Date ____________

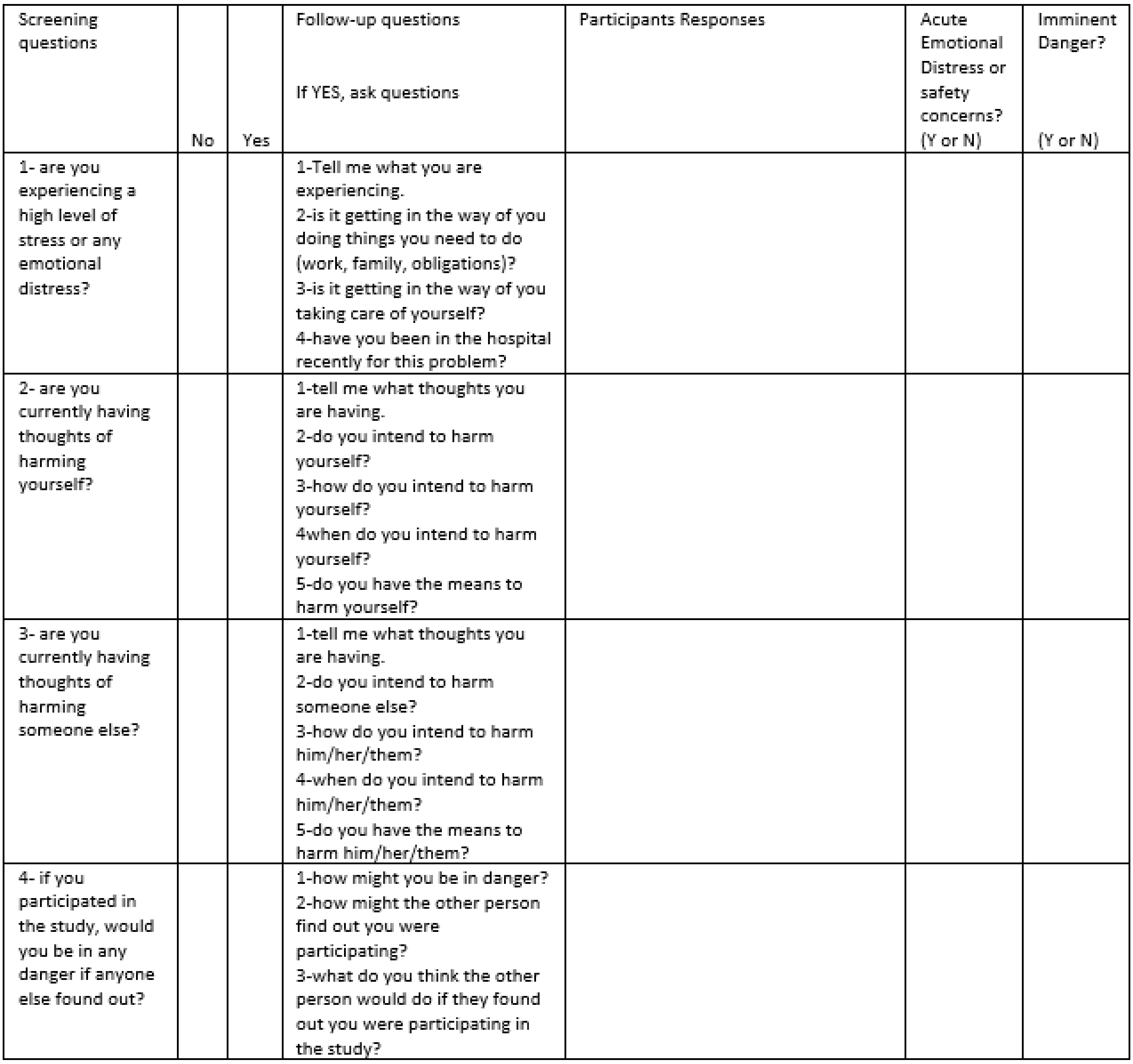
Appendix T Distress protocol

Adapted from Burke Draucker, Martsolf & Poole (2009).

All screening will be conducted by the principal researcher. The screening will take place prior to the interview or commencing involvement in the CAG

Questions:

Do you have any questions about the study? (if yes, answer questions. If no, proceed)



Screening questions	No	Yes	Follow-up questions If YES, ask questions	Participants Responses	Acute Emotional Distress or safety concerns? (Y or N)	Imminent Danger? (Y or N)
1- are you experiencing a high level of stress or any emotional distress?			1-Tell me what you are experiencing. 2-is it getting in the way of you doing things you need to do (work, family, obligations)? 3-is it getting in the way of you taking care of yourself? 4-have you been in the hospital recently for this problem?			
2- are you currently having thoughts of harming yourself?			1-tell me what thoughts you are having. 2-do you intend to harm yourself? 3-how do you intend to harm yourself? 4when do you intend to harm yourself? 5-do you have the means to harm yourself?			
3- are you currently having thoughts of harming someone else?			1-tell me what thoughts you are having. 2-do you intend to harm someone else? 3-how do you intend to harm him/her/them? 4-when do you intend to harm him/her/them? 5-do you have the means to harm him/her/them?			
4- if you participated in the study, would you be in any danger if anyone else found out?			1-how might you be in danger? 2-how might the other person find out you were participating? 3-what do you think the other person would do if they found out you were participating in the study?			

Actions for the principal researcher:

1: If answers to the screening questions are all NO, then read the confidentially statement below again and schedule an interview or invite them to participate in the CAG.

Confidentially statement:

All answers that you give will be kept private. But under law, I must appropriately report in line with hospice policy any suspected cases of child abuse or if you tell me that you are planning serious harm to yourself or others.

2: if a participant's response reflect acute distress or safety concerns but NOT imminent danger, take the following actions:

a, do not schedule an interview

b, recommend that the individual contacts the hospice psychological team or Healthcare provider (eg – GP) for follow up.

c, indicate that with their permission, that the hospice psychological support team will call them the following day to check that they are Okay

d, follow hospice incident reporting policy, informing of the result of the screening tool

3: if the participant's responses to the screening tool indicate imminent danger:

a, do not schedule an interview

b, immediately contact local law authorities

c, indicate that with their permission, that the hospice psychological support team will call them the following day to check they are Okay

d, follow hospice incident reporting policy, informing of the result of the screening tool immediately

Burke Draucker, C., Martsolf, D., & Poole, C. (2009). Developing Distress Protocols for Research on Sensitive Topics, *Archives of Psychiatric Nursing*, 23(5) 343-350.