Understanding the experiences of community hospice volunteers – a narrative analysis

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Acknowledgements

Abstract

It is suggested that hospice volunteers could play an important role in providing community support to dying people, but there are conflicting views as to whether volunteers should fulfil a professional role or one of friendship. The use of community volunteers is relatively uncommon in hospices in the United Kingdom, in contrast to their use across the voluntary sector, and there is limited research available about hospice volunteers' experiences. This research addresses this perceived gap in knowledge by exploring how visiting dying people affects community hospice volunteers' experiences, and their attitudes towards death and dying.

The thesis is a qualitative study using audio-recorded interviews with 16 volunteers, recruited from four independent hospices, exploring their stories of visiting dying people. A dialogical narrative analysis is used to interrogate the interview data and explore common storylines. Systems theory is drawn on to explore these storylines and the rules, meanings and belief systems which influence how volunteers manage their relationships with dying people, the hospice and death.

Analysis revealed how volunteers found being with the dying an enriching experience, they developed friendships and learnt to cope with multiple deaths, some drawing on the example of doctors and nurses. However, this thesis has uncovered how a hospice system, which has a preference for applying professional rules rigidly, does not fit with a home visiting service based on friendship. This results in a detrimental impact on volunteers' experiences, often deterring volunteers from sharing their positive stories about death.

This thesis argues that there is a strong case for hospices and other organisations working with volunteers to consider that community volunteering may not require rigid rules and volunteers can learn to manage relationships and loss. This requires organisations to work more responsively with community volunteers in a relationship based on trust and collaboration.

Key Words

Narrative, hospice, volunteer, community, palliative care, experiences, systems theory

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1 Introduction

Volunteers have played a crucial role in the formation and development of hospice care in the UK and across the world (Davis Smith, 2004). Yet the use of volunteers in the community to support people at the end of life is relatively uncommon in the United Kingdom (UK). Burbeck et al.'s (2014b) survey found that only 32% of volunteers involved with patient care visit people at home. This is in contrast to other countries such as America, Australia, Canada, India and Israel where volunteers form an integral part of supporting people in their communities (Bingley and Clark, 2008; Kumar, 2013; McKee et al., 2010).

Recent studies suggest that the need for end of life care in the community will grow as mortality rates increase and people live longer with increasingly debilitating conditions (Calanzani et al., 2013; Etkind et al., 2017). Although many people wish to be cared for and to die at home, 47% of people in England die in hospital (Gomes et al., 2011; Office for National Statistics, 2012). The fact that hospital deaths have become routine, may reflect the change in how death is managed in western society (Garber and Leadbeater, 2010). Death has changed from an event which is a normal part of life, to an event which is increasingly managed by healthcare professionals (Walter, 1999; Zimmermann, 2007). A report by the Commission into the Future of Hospice Care (2013) recommends that volunteers could play a crucial role in helping hospices meet the growing need to support dying people at home.

The encouragement to use more hospice volunteers in the community comes at a time when hospices have shifted from organisations that had little bureaucracy or hierarchy, to organisations that are now said to be heavily regulated (Howarth, 2007). Milligan (2007) and Guirguis-Younger et al. (2005) agree that increasing regulation may drive volunteering to become more professional and less informal, potentially affecting the experience of the volunteer. Morris et al. (2015) suggest that such regulation may also constrain hospice managers from using community volunteers. Some hospices in the UK have started using volunteers to support people in their own homes, mainly providing practical help and companionship (Page, 2011; Richardson, 2012; Walshe et al., 2016). If community volunteers are providing a role which is more related to friendships and companionship, it is not clear how volunteers are then affected by trends of regulation and professionalisation, an area this thesis will explore.

Previous literature reviews have identified little research about the experiences and perspectives of community hospice volunteers visiting dying people at home (Burbeck et al., 2014a; Morris et al., 2012; Wilson et al., 2005). This thesis focuses on that deficit and contributes to new knowledge about community hospice volunteering. My research aims to understand what it is like for hospice volunteers to visit dying people at home and asks the question "how does community hospice volunteering with people at the end of life impact on volunteers, in relation to their experiences and their attitudes to death and dying?" My qualitative research reported here, invited 16 adult volunteers to share the stories of their experiences. The volunteers were recruited from independent hospices which provide community volunteer support.

This thesis is underpinned by a critical realist paradigm, explained in Chapter 4, using a social constructionist epistemology to understand what people say as a version of reality, that has been jointly constructed by the participants involved and the cultural context that surrounds them (Gergen, 1999). I chose a narrative methodology to generate and analyse the stories the volunteers told about their experiences, as storytelling is part of social life and people are said to use stories to make sense of their experiences and help them create meaning (Riessman, 2008). A narrative approach encourages readers, not only to see how people's stories are put together, but the 'reality' that is then created by that story (Frank, 2010; Smith, 2013). People tell stories for a reason, therefore I use a dialogical analytic approach to explore why the story is being told and the influences on the story, including my own influence as researcher and listener (Frank, 1995).

To understand the stories that are generated, a theoretical framework is required in order to examine the social nature of the volunteers' experiences within the contexts of societal and regulatory influences. Therefore this thesis draws on the theoretical framework of systems theory developed by Bateson (1972). Systems theory has been used as a way of understanding how people behave in social groups, such as families and organisations (Dallos and Draper, 2000; Senge and Sterman, 1992); it shifts the emphasis from understanding how people behave because of their emotional and cognitive states, to understanding their behaviour in terms of their relationships with others (Bateson, 1972). Systems theory proposes that how we behave is influenced by rules and belief systems and relationships, and needs to be viewed in the context of wider systems of family, community and society. This has particular relevance to this thesis because of the interpersonal relationships that volunteers may form with dying patients, and the belief systems that affect those relationships, as well as the contextual influences of rules and regulations on their experiences.

1.1 **My motivations for this thesis**

I have been working within palliative care for over 37 years, and in the last 10 years have become more interested in the role of volunteers and how regulation and professionalisation may be affecting volunteers. During my early years as a specialist palliative care nurse, I believed that hospice volunteers only helped with things that paid staff did not have time to do, 'extras' like arranging flowers, and spending time with patients and families. My view has changed over the years and I now believe that volunteers have the capacity to be a crucial part of the support for dying people, especially in the community.

As a Hospice CEO I was inspired by the work of Dr Suresh Kumar (2009), who developed the Neighbourhood Network in Palliative Care in Kerala, India, to develop something similar in the UK. In 2011, I started Hospice Neighbours, a scheme which uses local volunteers to give practical and companionship support to people at home. Hearing Hospice Neighbours tell of their experiences motivated me to undertake research in this area. I wanted to promote the voice of the volunteer and what it was like for them to visit dying people at home.

My training as a family therapist introduced me to systems theory and I became interested in what influenced people's behaviour and relationships. Systems theory reminds me that I need to acknowledge the perspectives I bring to this research. As a CEO, readers might expect me to hold the view that rules in an organisation need to be upheld, rules that may see the development of close relationships as breaking boundaries. However, over the years with Hospice Neighbours I have witnessed how a close relationship may be valued by the volunteer and the dying person, yet I have also experienced how some professionals often express concerns about such relationships. Therefore, I am interested in how organisational rules and beliefs may affect the volunteers' experiences as they manage their relationships with the people they are visiting. I have kept a diary of reflections throughout the research process, which informs the thesis.

1.2 **Structure of the thesis**

Chapter 1 introduces the research and explains the rationale, research framework and how the research was designed, implemented and analysed.

Chapter 2 reviews the background, which provides the context to the thesis, exploring how increasing demand on hospices could be met by more community hospice volunteers and a health promotion approach to palliative care. I discuss how community hospice volunteering has developed differently to similar schemes, both in the UK and internationally. I explore the increasing regulation affecting UK hospices, and I examine discourses about professionalising care and how this affects volunteers' roles and relationships with dying people. I consider how death in Western society has become medicalised and how hospices are being encouraged to provide a health promotion approach to palliative care.

Chapter 3 examines literature from across the world which explores community hospice volunteers' experiences, identified from a systematic literature review.

In Chapter 4, I introduce the philosophical paradigm and methodology selected to answer the research question and explain the justification for using systems theory to understand the experiences of the volunteers.

Chapter 5 describes the research methods and how the data is generated using interviews with community hospice volunteers. I describe how I use narrative dialogical analysis to analyse the data.

Chapter 6 explores the findings and narrative threads identified from the 16 interviews. Systems theory is used to understand the different belief systems that influence how the volunteers behave, particularly in relation to rules and the boundaries of relationships. I also explore how their experiences have affected how they think about life and death, discuss my own reflections on the research process and summarise the key findings.

Chapter 7 discusses the findings in relation to the reviewed literature, examining new insights into the volunteers' experiences. This chapter uses concepts from systems theory to examine the impact of different belief systems and the role of feedback on the volunteers' experiences. I conclude by discussing how the knowledge generated from this thesis could inform an alternative model for community hospice visiting.

Chapter 8 draws together the main points of the thesis and reviews the strengths and limitations of this research. I discuss the implications of this research for hospices and other organisations using volunteers in the community and conclude with recommendations for further research.

2 Background and Context

This chapter explores the background and context for this research about community hospice volunteering. I examine the changing contexts for UK hospices, which include increasing demand, new commissioning arrangements and regulation. I discuss the different solutions that are suggested to meet increasing demand which include the increasing the use of community hospice volunteers and a health promotion model of palliative care (Kellehear, 1999; The Commission into the Future of Hospice Care, 2013).

I explore how community hospice volunteering fits within the context of healthcare volunteering in the UK and consider why community hospice volunteering has not developed in the same way as other community volunteer schemes in the UK and in other parts of the world. I go on to discuss how the influence of regulation and professionalisation may affect the community volunteer role and volunteers' relationships with professionals and patients.

I conclude by exploring how societal attitudes to death and dying, as Western society is said to be less familiar with death and death is said to have been 'medicalised' (Clark, 2002; Zimmermann, 2007). I also examine how discourses about professionalising volunteers may be in conflict with a drive to engage volunteers to be part of the solution to support more dying people and their families.

2.1 Changing contexts for hospices

The number of hospices in the UK has grown significantly since the inception of the modern hospice movement in 1967. 186 of the 220 hospices are independent charities and form part of the 165,801 UK charities identified in 2017 (HospiceUK, 2016; The National Council for Voluntary Organisations, 2017). It is recognised that even before a growth in population, hospices are not meeting current demand: Dixon et al. (2015) estimate there are approximately 92,000 people in England who could benefit from hospice care, but are not receiving it. Calanzani et al. (2013) warn that the need for end of life care will grow in the UK as people live longer and suffer from increasingly debilitating conditions; for example, those with long term conditions could rise to 18 million by 2025, with an additional 2.1 million people over 85 having increasing care needs. Etkind et al.'s (2017) study estimating future population needs, suggests that deaths in England and Wales will rise by 25.4% by 2040 with up to 47% more people requiring palliative care.

The importance of community care is highlighted by several authors and is a core component of England's End of Life Care Strategy (Department of Health, 2008). Gomes et al. (2011) and Hunt et al. (2014) show that most people who express a preference, would prefer to be cared for and to die at home, yet the majority of people still die within an institution (see Table 2.1). The low number of home deaths may reflect people's capacity to cope with and support home deaths, as in Western society death is increasingly managed by healthcare professionals, a theme I discuss later.

Table 2.1 Preferred and actual place of death

Age	45-64		65-74		75+	
Place of death	Preferred	Actual	Preferred	Actual	Preferred	Actual
Home	63%	32%	56%	28%	45%	17%
Hospice	32%	11%	37%	9%	41%	3%
Hospital	1%	50%	4%	54%	6%	54%
Care home	1%	3%	2%	7%	5%	25%

Source (Gomes et al., 2011, p.16).

In the UK, hospices started to develop in the 1960s, to provide a new way of caring for dying people, who were marginalised by the healthcare system at that time (Clark et al., 2005). However, in recent years hospices have been criticised for delivering "a bit of heaven for the few" (Clark et al., 2005). Garber and Leadbeater (2010) argue that hospices have, for too long, specialised in cancer-related younger deaths rather than deaths associated with old age and frailty. To respond to such challenges, in 2011 Help the Hospices established the Commission into the Future of Hospice Care (2013) to explore how hospices in the UK might address these problems.

The Commission's report (2013) supports the recommendations of a report by Garber and Leadbeater (2010) and recommends that hospices should move away from giving a high quality service for the few towards providing more care to larger sections of the dying community. The guidance that volunteers need high quality training, support and guidance about boundaries could be seen as contributing to a discourse that volunteers need to be more professional (The Commission into the Future of Hospice Care, 2013). This suggestion that volunteers should be more professional could be said to be in conflict with the Department of Health's (2011) own vision that sees volunteering as connected to social action and reciprocity which can strengthen community resilience.

Milligan and Conradson (2006) explain how since the 1980s, UK governments have been increasingly influencing the voluntary sector to undertake the delivery of services previously provided by the State. For hospices, this has meant they have moved from being regarded as complementary to mainstream healthcare, to being part of that healthcare system and commissioned to provide end of life care for the UK National Health Service (NHS) and therefore subject to specific regulations and standards (Care Quality Commission, 2014). However, this new relationship with government is not without its difficulties. Milligan and Fyfe (2006) suggest that funding mechanisms and regulations mean that voluntary organisations now have to deal with increasing bureaucracy; requiring them to be more 'professional'.

Garber and Leadbeater (2010) propose that this shift to being part of the healthcare system has dangers for hospices as, instead of being disruptive innovators and challenging the medicalisation of death, "they are in danger of becoming incorporated as niche providers of specialist services within the system they set out to change" (Garber and Leadbeater, 2010, p.53). This opinion is in contrast to the report by The Commission into the Future of Hospice Care (2013) which suggests that hospices should collaborate and integrate with NHS services, rather than work separately.

Kellehear (1999) and Abel et al. (2011) propose that, to improve access to palliative care, hospices should move away from a medical model and instead use a health promotion approach to palliative care. Horsfall et al.'s (2012) study demonstrates how caring for the dying builds social capital and compassionate communities. Sallnow et al. (2016) suggest that when communities are engaged with supporting the dying and bereaved, they may not be limited by the constraints of professional boundaries. Evidence of this is seen in Chapter 3 in the study by McKee et al. (2007). Kellehear and O'Connor (2008) note that health promotion models should become self-sustaining and not reliant on continued input and support from healthcare services. This might then contra-indicate the use of hospice community volunteers as a way to develop a health promotion model of palliative care, as hospice volunteers might be reliant on hospices for training and support.

2.2 **Volunteering in healthcare**

It is suggested there are approximated three million people volunteering in health and social care with the public and sector in England with 1.9 million working with older people (Naylor et al., 2013). A survey about community life in England found that 63% of people had volunteered either formally or informally in the last year (Department for Digital Culture Media and Sport, 2017). In the UK, volunteering, which may be formal or informal, is defined as:

> "an activity that involves spending time, unpaid, doing something that aims to benefit the environment or individuals or groups other than (or in addition to) close relatives" (Volunteering England, 2013, p.1).

Informal volunteering would include giving help to people who are not relatives, whereas formal volunteering relates more to helping an organisation or group (Rochester, 2006). Hospice community volunteering which is part of this research would be defined as formal volunteering. Volunteering has been shown to improve health and well-being for volunteers and outcomes for service users, although success is often seen as connected to the way volunteers are trained and managed (Casiday et al., 2008).

Volunteers are often described as fulfilling a social role and providing befriending or peer support on behalf of voluntary and statutory organisation across different settings in healthcare: in homes, hospitals and care homes (Faulkner and Davies, 2005; Hussein, 2011; Naylor et al., 2013). Examples of this can be seen in studies where volunteers support people with mental health conditions (Siette et al., 2017; Toner et al., 2018); and women during pregnancy and early motherhood (Barnet et al., 2002; McLeish and Redshaw, 2015; Taggart et al., 2000). The social role volunteers fulfil is often delivered at home and Naylor et al. (2013) suggest that volunteers can play crucial roles in a community: supporting service delivery, helping design services and strengthening relationships between communities and healthcare services and de-professionalising services.

Whilst, in the UK, the Department of Health's (2011) vision promotes a proportionate use of bureaucracy with volunteers, and although volunteers are not defined as employees, legislation such as the Health and Safety at Work Act, Data Protection and the Equality Act also applies to formal volunteers (Restall, 2009). Restall (2009) reminds charities that relationships with volunteers should be about expectation rather than obligation, otherwise the relationship would be subject to employment law. This highlights the problems that hospices and other voluntary organisations face in trying to keep volunteering work relatively informal, whilst at the same time having to comply with regulation and legislation. This informality could be important, as Field-Richards and Arthur (2012) suggest that volunteers are often attracted to the informality of the volunteering role, and that increasing regulation might adversely impact upon a hospice's ability to recruit and retain volunteers, if that informality was lost.

2.2.1 Volunteering in hospice and palliative care

Volunteering has played a crucial role in the formation and development of hospice care in the UK and across the world (Davis Smith, 2004). Many of the first hospices were founded by volunteers, who gave their time and expertise to develop hospice services, often fulfilling professional roles (Clark et al., 2005). Scott (2014) estimates there are over 125,000 hospice volunteers in the UK. Morris et al. (2015, p.1) suggest that volunteers provide an informal "symbolic 'link' with the local community" facilitating two-way information between the hospice and the external environment. This research will give some insight into that link from the perspective of the volunteers. Volunteers can also be found supporting people at the end of life in settings outside of a formal hospice or palliative care service, for example in hospital as described by Brighton et al.(2017) and Delaloye et al. (2015), and in prisons, as explored in Chapter 3 (Cloyes et al., 2013; Supiano et al., 2014).

Lynch et al.'s (2013) mapping of global palliative care development shows that more than half the world's countries have a palliative care service, although there is little information about the roles and numbers of volunteers. Woitha et al.'s (2015) review of the involvement of palliative care volunteers in seven European countries found wide variations in the numbers of volunteers, with most in England and the fewest in Spain. A review of palliative care services by Bingley and Clark (2008) in Cyprus, Egypt, Israel, Jordan, the Palestinian Authority, and Turkey, found volunteers tended to play a crucial part of every service, often setting up and running services, providing care and training; many of whom were trained health and social professionals, giving their services without charge.

Davis Smith (2004) found the demographics of volunteers in UK hospices were likely to be over 55, retired, female and white. It was not clear from the literature what the impact might be to have a predominantly female volunteer workforce. Whilst Weeks and MacQuarrie (2011) suggest that female hospice volunteers are likely to be more comfortable in developing relationships than men, who prefer to take on practical tasks, Claxton-Oldfield et al. (2009) found that male hospice volunteers were interested in giving counselling or advice, but were concerned about it being emotionally draining. Some authors may be making an assumption that men are more interested in practical aspects of volunteering rather than emotional aspects. My own anecdotal experience in running a volunteer scheme is that men are frustrated when they are only offered practical tasks, rather than companionship roles. In response to this, I ensured that I recruited a mixed gender cohort of volunteers for interview to understand how experiences may differ.

2.2.2   Community volunteering with people at the end of life

Using community volunteers to deliver palliative care has been seen as a solution to providing palliative care at scale in resource-poor or very rural areas. The Neighbourhood Network in Palliative Care in Kerala, India, encourages community participation and has over 10,000 local people trained as volunteers supporting over 2,500 people with chronic end of life conditions per week (Kumar, 2013; Sallnow et al., 2010). Projects in Uganda, Kenya and Malawi have all used volunteers alongside paid staff to improve palliative care in rural communities (Grant et al., 2011). In Canada and Australia, volunteers are seen as a crucial part of delivering better end of life care to more people at home (Horsfall et al., 2012; McKee et al., 2010). In the USA 96% of hospice care is delivered at home and involves volunteers in providing support (NHPCO, 2013).

In the UK increasing numbers of charities outside of the hospice sector are offering volunteer befriending services to support people in the community at the end of life (Marie Curie, 2018; We are Macmillan Cancer Support, 2018). In addition those volunteers offering support to the elderly and those with dementia could also be said to supporting people at the end of their lives (Gardiner and Barnes, 2016; Smith et al., 2018). However, hospices do not seem to be developing community volunteers in the same way.

The literature is not clear about how many UK hospice volunteers are involved with visiting patients in the community. Davis Smith (2004) found many volunteers involved in patient care, but few of those surveyed appeared to be involved with community services for patients (see Figure 2.1).

Figure 2.1 Volunteer roles in hospices
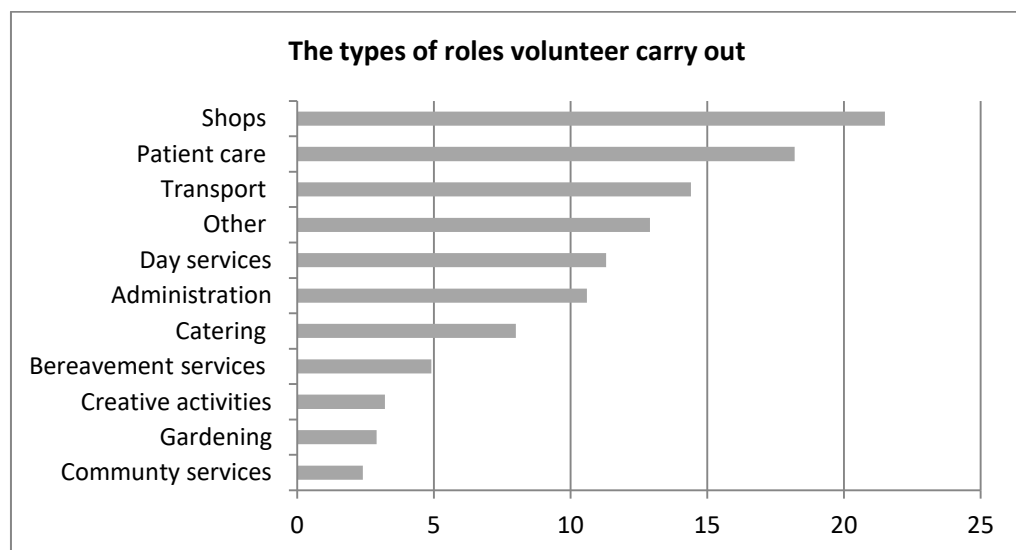
Source Davis Smith (2004, p.4)

The use of community volunteers by UK hospices appears to be increasing, as demonstrated by Burbeck et al.'s (2014b) survey of independent hospices which found that 32% of the volunteers undertaking direct patient activity were involved in home care. This is supported by other studies describing schemes where volunteers support people at home (Abel et al., 2011; Amoah, 2013; Morris et al., 2015; Page, 2011; Walshe et al., 2016). However, little is known about their numbers and their effectiveness and the effect of the work on the volunteers. A recent study by Walshe et al. (2016) evaluated the outcomes of a community volunteer service for people at the end of life. Whilst the qualitative component of the study reported that participants (patients, carers and volunteers) found overwhelming benefits from such a service, the outcome measures used showed no statistically significant effects on patients' quality of life, social support and loneliness (Walshe et al., 2016). Details of this study are discussed in Chapter 3.

It is unclear in the literature why UK hospices have been reluctant to use volunteers in the community compared to other voluntary and healthcare providers described earlier. Hospices may be responding to a requirement for volunteers to be more professional as put forward by Milligan and Fyfe (2006). Morris et al. (2015) suggest that it may be because of managers' concerns about regulations, cost and safety. Hoad (2002) examined 14 community volunteer schemes in England, from sitting services to working with hospitals and found that fears about boundaries often related to liability, insurance and contracts. However, other charities such as, AgeUK and the Red Cross appear to be able to manage these concerns, as both use large numbers of volunteers to support people in local communities (AgeUK, 2018; British Red Cross, 2018).

The role a hospice volunteer fulfils in the community may vary, from those fulfilling professional roles as described by Bingley and Clark (2008), to those extending the reach of the palliative care as seen in the studies by Grant et al. (2011) and Kumar (2013), or providing companionship and friendship as described by Amoah (2013). Walshe et al. (2016) suggest that the volunteering role in the community presents particular dilemmas which relate to volunteers' autonomy, the types of relationship they develop and the degree of training needed. This research will give insight into how volunteers might experience these dilemmas.

Professional beliefs and attitudes about volunteer activity may be connected to a fear that increasing use of volunteers may put their own jobs at risk, a concern identified by Andersson and Òhlén (2005) in Sweden. Hoad (1991) found that volunteers in British independent hospices felt tolerated by paid staff and were perceived to be in an ambiguous position, as neither professional nor lay carer, a theme also found in literature reviewed in Chapter 3.

There appears to be conflicting opinions in the reviewed hospice and palliative care literature about what roles volunteers should fulfil, as described by Watts (2012) and whether palliative care can only be delivered by trained paid professionals as debated by Sinclair (2007). Ganesh and McAllum (2012, p.153) suggest volunteers may be seen as forms of "unpaid, amateur, and low-status labor". Sinclair (2007) agrees with this and suggests that the notion of voluntary care, or work that is given as a gift and is philanthropic, may be seen as a service that is of a lesser value and only appropriate for a devalued class of people. If this belief exists, paid staff may believe that dying people should be cared for by trained professionals.

An example of this was seen in Horsfall et al.'s (2015) study of end of life care at home in Australia where the authors found a conflict between the approaches of the informal network and the professional service providers. The study describes how some participants were distressed when professionals "expressed a view that non-professionals were not capable of giving appropriate care to the dying person" (Horsfall et al., 2015, p. 40). However, in that study volunteers were seen as part of the formal network of care.

In contrast with the literature cited earlier which acknowledges the importance of the social role of the volunteer in providing peer support and befriending, there is concern identified in the literature about whether hospice volunteers should become friends with the people they are visiting. Payne (2002) expresses such concern but acknowledges that developing friendships were often why people volunteered and Planalp and Trost (2009) found that older or retired volunteers may be more attracted to the companionship nature of the role. Sanders et al. (2012) suggest that professional concerns about volunteers developing close relationships with clients is connected to professional ideas about burnout. Such concerns may explain why staff wish volunteers to behave more 'professionally'. Yet Payne (2002) found that volunteers may resist such influences, because of a fear of "becoming too clinical" (Payne, 2002, p.150).

The relationship that volunteers may form with patients is relevant to this research, as the act of visiting people at home is more likely to be conducive to the formation of closer relationships. Pennington and Knight's (2008) study of the social connectedness between volunteers and older adults people being visited at home, found that reciprocity was key to the development of meaningful relationships, which were helped by having shared interests and time together. This idea of a reciprocal relationship is supported by Sallnow et al. (2017), who highlight how volunteers who were part of a community led intervention, saw themselves as peers with those they were visiting. The authors suggest that a key process was the development of a mutual relationship that was constructed outside of the professional domain. Gardiner and Barnes (2016) propose that the benefit of such a friendship for the person being visited, particularly at the end of life, is that it can give them a more meaningful identity, instead of being seen as a 'patient'.

This thesis focuses on hearing the volunteers' experiences and listening to identify if any of the conflicts and dilemmas identified above are replicated in the volunteers' stories. Professional concerns about volunteers and the need for training and boundaries may be related to the professionalisation of volunteering and increasing regulation, as well as how death is managed by society today.

2.3 **Death and society**

How we deal with death in Western society has changed significantly over the last centuries. Howarth (2007) describes how dying in the twentieth century has moved from being the preserve of the Church into the preserve of medical science, and death has changed from an event that was part of everyday home life, to an event managed by healthcare professionals, usually occurring in hospital. Clark (2002) suggests that hospices may have contributed to the medicalisation of death with an increased focus on the science of dying and the use of specialist healthcare professionals. This medicalisation of death may have contributed to people feeling less familiar with death and a societal fear about dying, as stated in the England's End of Life Care Strategy (Department of Health, 2008). To address fears about death and dying, in the UK organisations such as Dying Matters use public awareness campaigns to try to encourage people to talk about death more openly (Dying Matters Coalition, 2015).

Conway (2008, p.111) warns that death is being increasingly seen as a "private matter" rather than a "routine human experience" and the continued professionalisation of loss and death risks excluding communities from being part of this experience. Sévigny et al. (2010) agrees with Conway and suggests that volunteers could have an active part to play in reintroducing death into a social experience, because of their role in palliative care. However, there are areas where death could be said to becoming less medicalised, for example in the study by Noonan et al. (2016) where people found the experience of caring for the dying improved their confidence in coping with death.

Horsfall et al. (2015) also show how caring for the dying can create a 'triumphal discourse' in a community, which overcomes the discourse that dying is stressful and needs to be managed by healthcare professionals:

> The way that carers and care network members spoke about their experiences following the death was often in triumphant terms – we made it, we got through, we did the job well and it changed us forever. (Horsfall et al., 2015, p. 47).

This research will be interested to see if the volunteers' experiences increase their confidence about coping with death, and if their experiences could contribute to a positive discourse about death.

2.4 Summary

This description and discussion of the context and background to the thesis highlights the different pressures on UK hospices of increasing need and bureaucracy. Regulation, funding arrangements and the medicalisation of death may have contributed to how little UK hospices use community volunteers; however, this is in contrast to other voluntary organisations in the UK, and internationally, which are increasingly using community volunteers to visit people at the end of life. If volunteers are to be part of the solution to increase the reach of hospice care and help death become more social, but are bound by regulation, it will be important to understand the impact of regulation on volunteers, a question this thesis explores. In addition, this chapter notes the tensions that are present between staff and volunteers and the mixed opinions about the relationships that might form between volunteers and dying people. I also highlight how communities may have become less confident about being involved with the dying and how increasing volunteer involvement could play a role in increasing that confidence.

3 Systematic review of the literature on the experiences of community hospice volunteers

This chapter describes the systematic review of the literature that was conducted about the experiences of community hospice volunteers and explains the rationale for using a narrative synthesis approach to this review. Previous literature reviews about hospice volunteering have explored a variety of themes. Wilson et al.'s (2005) review found the majority of the literature focused on volunteer roles, training and the outcomes for volunteers and end of life care. Morris et al. (2012) explored the contribution volunteers make to end of life care and Burbeck et al. (2014a) explored the role of the volunteer in specialist palliative care. Candy et al. (2015) reviewed how involving volunteers makes a difference to patient and family wellbeing, whilst Whittall et al. (2016) reviewed factors affecting rural volunteering in palliative care.

3.1 **Review methods**

The aim of this review is to systematically search, analyse and synthesise existing literature that examines the experiences of community hospice volunteers. The knowledge from this review could support the need for this research and inform the methods that could be used. The following question was used to undertake a systematic review of the published literature: "What is known about the experiences of hospice or palliative care volunteers who visit dying people in their homes and how these experiences affect their attitudes to death and dying".

In designing a literature review the question should inform the choice of method and the synthesis should be congruent with the research paradigm. To understand the literature about the experiences of community hospice volunteers a critical realist position is taken, discussed in more detail in Chapter 4. This position takes the view that reality is viewed through a lens which is shaped by perceptions, beliefs and external influences and knowledge is socially constructed (Braun and Clarke, 2013; Burr, 1995). To this end, narrative synthesis was selected over other methods, such as meta-analysis or content analysis, because of its ability to combine diverse information and because it adopts a textual approach to synthesising the information to tell the story of the findings (Popay et al., 2006).

Chapter 2 suggests that community hospice volunteering is an activity which may include volunteers fulfilling a social support role with people at home; however, there appear to be concerns raised that increasing regulation could be affecting the experiences of volunteers. Therefore this review is interested to see if these perspectives are reflected in the experiences of the volunteers in the literature identified. This exploration informs first, the search criteria and second, the studies to be included, which aims to answer the literature review question (see Table 3.1).

Table 3.1 Selection criteria

Inclusion criteria for papers	Exclusion criteria
• Articles in English reporting research or evaluation data • Including volunteers visiting in the community, even if that was not the major focus of the study • Community defined as outside of hospice or hospital buildings or in the ill person's usual place of residence. • Reporting the direct experiences or perspectives of hospice or palliative care volunteers • Quantitative or qualitative studies	• Volunteering which was related to dying children or bereavement • Studies where results could not be directly related to hospice or palliative care volunteers working in the community • Theoretical papers

Similar to the process of research, a systematic review of literature must demonstrate "rigour according to some explicit method and with purpose, method and results being clearly described". (Gough, 2007, p.216). The framework for this review follows the Guidance on Narrative Synthesis by Popay et al. (2006) that proposes four main elements which include: developing a theory about the experiences of volunteers; a preliminary synthesis of the findings of the reviewed studies; exploring relationships in the data and assessing the robustness of the synthesis.

3.2 **Search process**

To identify literature relevant to the topic of community hospice volunteers the following databases were searched from the inception date of 1946 to February 2014 and reviewed again in December 2017. The databases used included Ovid, CINAHL, MEDLINE, PubMed, PsyArticles, PsycINFO, Science Direct, Web of Science. Databases were searched using their specific subject headings, MeSH terms or thesaurus terms which related to hospice or palliative care volunteers (see Appendix 1). To answer the review question, studies were searched for using the selection criteria shown in Table 3.1.

Searches were undertaken looking for terms within abstracts and in any field that related to community hospice volunteering or visiting people at home, even though it may not have been the primary focus of the article. Reports, government papers and conference abstracts relating to community volunteering, were searched by hand for references relating to studies on the experiences of community hospice volunteers. Figure 3.1 outlines the process of screening using a PRISMA flow diagram (Moher et al., 2009). All search results were downloaded to Endnote and the duplicate references were removed.

Figure 3.1 Flow diagram showing selection of studies
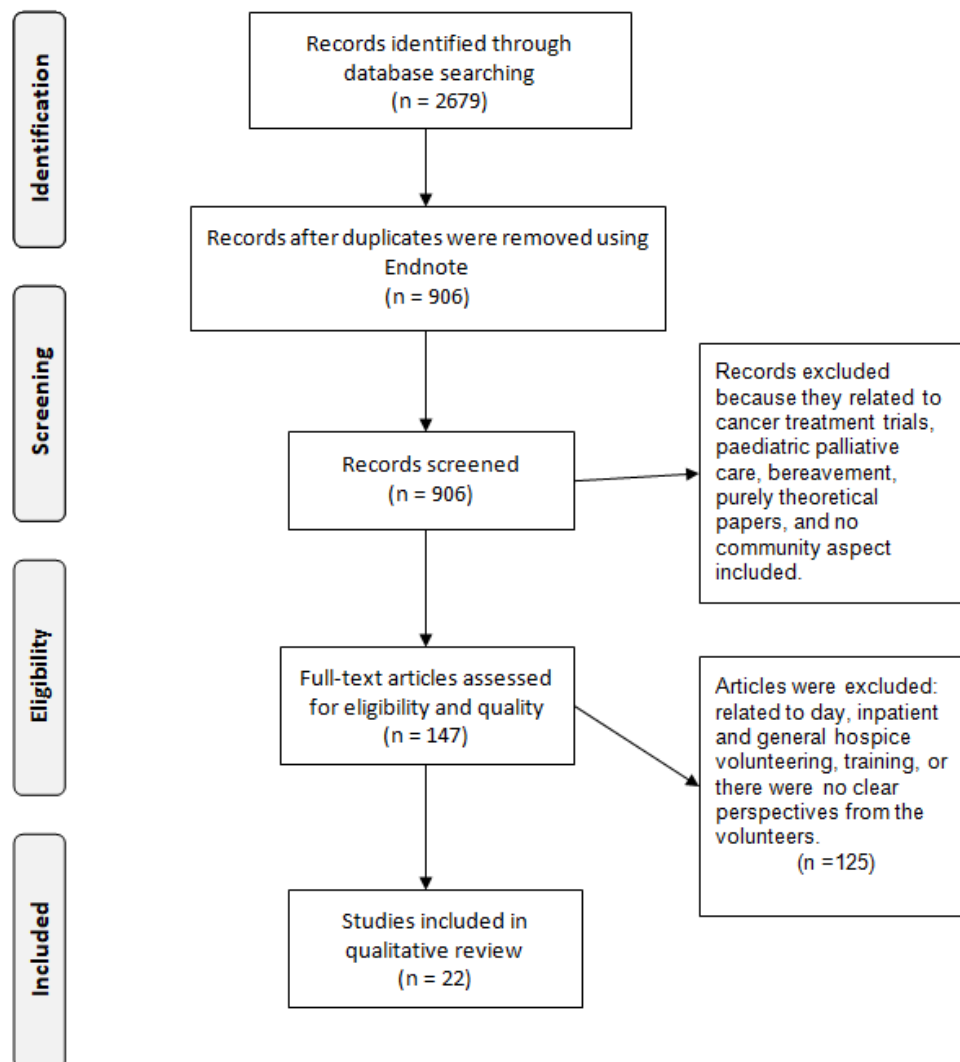
Source (Moher et al., 2009).

3.3 **Developing a theory**

In the reviewed literature only Sévigny et al.'s (2010) study uses a social system model as a theoretical framework to understand the experiences of the volunteers, suggesting that a person is surrounded by concentric circles of care (from formal political institutions to informal family care), but they make little reference to the different systems and the interaction and feedback between systems.

I suggest there are two implicit theories seen in the remaining reviewed literature: firstly, good experiences are connected to the relationships formed with the people volunteers are visiting and secondly, volunteers require clear boundaries, training and support to improve their experiences. However, the literature reviewed in Chapter 2 suggests that increasing regulation and boundaries may adversely affect the experiences of hospice volunteers. This thesis will be drawing on systems theory, discussed in Chapter 4, to explore these different implicit theories and understand the volunteers' experiences in relation to the system they form with the dying person within the context of systems that may include: the hospice, the community, regulatory and societal systems.

3.4 **Preliminary synthesis**

One hundred and forty seven articles were identified through the search process and 22 papers met the criteria. Only two papers related to community hospice volunteers in the UK. Two studies were also included from the USA, where community visits were being undertaken in a prison, with inmates acting as the volunteers (Cloyes et al., 2013; Supiano et al., 2014).

Only the studies by Guirguis–Younger and Grafanki (2008) and Söderhamn et al. (2017) focused on specifically exploring community volunteers' experiences and what their experiences meant to them, with Supiano et al. (2014) exploring inmates grief experiences. Claxton-Oldfield, S and Claxton-Oldfield, J (2007) and Jack et al. (2011b) examined the personal impact of being a volunteer. The remaining studies were focused on understanding community volunteers in relation to the wider community, motivations, satisfaction, training, ethical issues, service outcomes, roles, identity, stress and boundaries.

The twenty two articles were reviewed using Gough's (2007) weight of evidence framework using the following dimensions scoring high, medium or low in how the studies were able to answer the question being used for the review (see Table 3.2).

Table 3.2 Gough's Weight of Evidence

Dimension	Description of review
A. Coherence and integrity	A generic non review-specific judgement about the coherence and evidence on its own terms, using the generally accepted criteria for this type of evidence.
B. Appropriateness for answering the question	A review-specific judgement about the fitness for purpose of the evidence for answering the question.
C. Relevance and focus	A review-specific judgement about the relevance of the focus of the evidence for the question. This could include issues of propriety in how the research was conducted which could impact on its inclusion and interpretation.
D. Overall assessment	The three judgements above are then combined to give an overall assessment.

Source Gough's (2007, p.223)

Only 18 of the 22 articles scored medium or high, whilst many articles included volunteers, some lacked enough information about the volunteers' experiences to be able to answer the review question fully, a summary of the studies reviewed is shown in Table 3.3.

Table 3.3 Summary of studies included in the review

Gough score - high (H), medium (M) or low (L) for coherence, appropriateness, relevance and overall assessment.

First Author Country (Gough Score)	Study aims	Study methods and participants	Themes	Key findings
Azuero et al 2014 USA (MMM-M)	To explore the social processes of community volunteers working in teams with people with HIV/AIDS.	Ten semi-structured interviews with community volunteers.	Reciprocal relationships; life changing; benefits of being part of a team; lack of preparation; conflicting expectations; professional support.	Challenges included discrepancies between purpose and need or expectations; Professionals supportive.
Berry and Planalp 2009 Canada (MML-M)	To explore the ethical issues volunteers confront.	39 structured individual interviews with hospice volunteers, (rural and urban).	Boundary issues; hospice guidelines cause dilemmas; difficulties talking about suicide.	Dilemmas about volunteer roles boundaries, and death. Suggest need for training.
Brown 2011 USA (MML-M)	To explore stress in hospice volunteering.	Phenomenological study using questionnaires and individual semi-structured interviews with 15 community and inpatient volunteers.	Stress related to unsatisfactory experiences with patients, family members or hospice staff; fear of the unknown; learned to adapt over time.	Dealing with family members, hospice personnel and personal issues were of the most concern.
Chevrier et al 1994 Canada (MLL-L)	To determine the factors related to satisfaction for hospice volunteers.	Telephone survey using two questionnaires with 100 community volunteers.	Feeling work valuable; role met expectations; importance of training and staff support.	Satisfaction linked to: good support, helping clients, and community respect.

Table 3.3 Continued

First Author Country (Gough Score)	Study aims	Study methods and participants	Themes	Key findings
Claxton-Oldfield, S. and Claxton-Oldfield, J. 2007 Canada (MMM-M)	To examine the impact of palliative care work on volunteers' lives.	Individual structured interviews with 23 volunteers visiting at home and in hospital.	Life changing; making a difference; personal coping strategies; experience rewarding.	Volunteering had changed their outlook on life, more accepting of death. Developed strategies to cope with stress.
Claxton-Oldfield, S et al 2011 Canada (MML-M)	To examine boundary issues for volunteers, and if they have ever been done.	Statistical analysis of survey with 79 community volunteers.	Going against the rules; responding to patient and family needs.	Some issues required clear boundaries; Additional training seen as the solution.
Cloyes et al 2013 USA (HHL-M)	To describe and explore the beliefs and attitudes of volunteer inmate hospice volunteers.	Open-ended survey during a conference with 75 volunteers using grounded theory.	Life changing; belonging; redemption; God's work; bearing witness; social responsibility; compassion.	Emerging theory of identity construction. Volunteers expressed complex motivations and experienced personal transformations.
Fox 2006 USA (LMM-M)	To explore whether hospice volunteers are trained for and practise detached concern.	Ethnographic observations of volunteer training. 10 interviews with volunteers, some visiting at home. 4 patients and their families.	Friendships; overstepping hospice boundaries; prepared for death; managing loss.	Volunteers expressed concern about friendships and sadness when patients die. Training connected to detached concern.

Table 3.3 Continued

First Author Country (Gough Score)	Study aims	Study methods and participants	Themes	Key findings
Grant et al 2011 Uganda, Kenya and Malawi (MLL-L)	To describe patient, family, staff and local perspectives on the impact of three community interventions.	Individual, group interviews, direct observation. 25 volunteers, 27 family carers, 36 staff, 29 community leaders, 12 patients.	Grief; frustrations; back up from nurses; die with dignity; gain courage.	Volunteers provided the bridge between community and palliative care team.
Guirguis-Younger, M. & Grafanaki, S. 2008 Canada (MHH-H)	To elicit volunteers' experiences and the meaning of being a palliative care volunteer.	Focus groups with 17 volunteers, 13 from community.	Freedom and flexibility; emotional resilience; personal growth; managing boundaries; broadened view of life and death.	Importance of freedom to do what was needed; developing resilience and strong sense of community.
Ipsos Mori, 2012 UK (MML-M)	Qualitative Evaluation of the Marie Curie Helper Service.	Semi-structured individual interviews and focus groups. 12 helpers and four volunteer assessors, patients and carers.	Satisfaction; bending the rules; confusion about rules; struggling to maintain boundaries; support; difficult endings.	Volunteers spoke of the challenges about constraints and boundaries about their role and relationships.
Jack et al 2011 Uganda (MLL-L)	Evaluate the impact of the Community Volunteer Programme.	64 semi-structured individual and group interviews with patients, volunteers and the hospice clinicians.	Doing what is needed; preparations; bridge to hospice.	Volunteers highlighted practical challenges about transport and language, as well as patients' expectations.
Jack et al 2011 Uganda (HML-M)	To evaluate the motivation for becoming a volunteer and the personal impact of being a community volunteer.	Semi-structured individual and group interviews with 32 volunteers and 11 clinicians.	Personal pride; increased status.	Volunteers gained enormous pride, enhanced self esteem and improved status in their community.

Table 3.3 Continued

First Author Country (Gough Score)	Study aims	Study methods and participants	Themes	Key findings
MacLeod et al 2012 Canada (HMM-M)	To involve stakeholders in the provision of support for volunteers and family carers providing palliative care.	Community based participatory approach with focus groups and personal diaries. 18 community volunteers and 21 family members.	Dealing with loss; team communication; clarity of role; education and support; family tensions.	Volunteers identified issues relating to team communication, role, education and client relationships.
McKee et al 2007 Canada (HHH-H)	To understand the role of hospice volunteers in the rural communities.	Semi-structured telephone interviews with 13 volunteers who were also coordinators	Just being there; flexibility; developing long term friendships; friend and volunteer; local autonomy.	Volunteers able to focus on visiting the frail elderly at risk of dying alone. Volunteers saw long term visiting as crucial.
McKee et al 2010 Canada (MMM-M)	Explore a community's understanding of community hospice volunteers.	Ethnographic observation, focus groups and individual interviews. 46 participants, including volunteers.	Reciprocal relationship Becoming like family; friend and volunteer; friends with skills.	Volunteers valued relationship with those they were visiting, finding they received more than they gave.
Naidu et al 2012 Africa (HLL-L)	To investigate the identity of women volunteers who support HIV/AIDS patients in a rural community.	Three narrative interviews with 15 home based volunteers on- the nature of the work, social networks and resources.	Caring rooted in faith; natural helping; route to self improvement.	Volunteers able to develop narratives of comfort and hope in the context of discrimination, poverty and oppression.
Pesut et al 2017 Canada (HMM-M)	Evaluation of a community pilot where a nurse worked with volunteers to provide navigation support for adults early in their palliative illness.	One year pilot, using mixed method evaluation with 18 clients, seven volunteers, nurse navigator, and other stakeholders.	Satisfaction with role; reciprocity; friendships; navigating through life; need for flexibility; importance of support.	Volunteers found the role satisfying and were very resourceful in their navigation activities, building individual and community capacity.

Table 3.3 Continued

First Author Country (Gough Score)	Study aims	Study methods and participants	Themes	Key findings
Sévigny et al, 2010 Canada (MML-M)	To understand volunteer practices in home palliative care across three provinces.	Study based on social systems theory. Focus groups with volunteers; semi-structured interviews with coordinators. 64 community volunteers and coordinators.	Flexibility; knowing own boundaries; close relationships; personalised care; contributing to the community; training.	Highlighted the importance of relationships. Challenges about support and boundaries.
Söderhamn et al. 2017 Norway (HHM-H)	To describe the lived experiences of palliative care volunteers working in the community.	10 volunteers were interviewed and encouraged to talk about positive and challenging experiences	Positive and meaningful experiences; helping a privilege; the importance of being present; trust; experience enriching; managing confidentiality; importance of training and support.	Experience was meaningful, but highlighted the importance of training and support.
Supiano et 2014 USA (HMM-M)	To explore the grief experiences of prison inmate volunteers.	Meaning reconstruction theory used to inform study which used semi-structured interviews with 32 volunteers about their experiences of caring and death.	New perspective about mortality; relationships; peer support; coping with death.	Volunteers became responsive and capable in caring for dying inmates which was both effective and compassionate.
Walshe et al 2016 UK (HML-M)	To understand the impact of social action volunteer befriending services at the end-of-life.	12 week study. Interviews with 23 volunteers, 34 staff, 24 patients, three family carers. Staff meetings observed, service documents reviewed. 196 patients, 23 volunteers, 34 staff, and three family carers.	Giving back; different perspective about life; reduced volunteer isolation.	Volunteers reported benefits such as companionship and reduction in negative feelings.

3.5 **Exploring relationships between the studies**

The analysis identified themes in each study which were relevant to the review question (see Table 3.3). These themes were then re-read and five narrative threads were identified that could tell the story of what was being said about volunteers' experiences: *doing what is needed; becoming friends; volunteers need rules, training and support; being a bridge* and *experience can be transforming* (see Table 3.4).

Table 3.4 Narrative threads identified from the systematic review

Narrative threads	Groups of themes
Doing what is needed.	Responding to needs; freedom; presence; being there for the ill person; making a difference; flexibility.
Becoming friends.	Reciprocal relationships; matching; forming friendships; trust; like family; friends with skills; reduce isolation; friend and volunteer.
Volunteers need rules, training and support.	Boundary issues; guidelines cause dilemmas; importance of training, support and confidentiality; frustrations; clarity of role.
Being a bridge.	Helping their community; extending hospice reach; hospice support and training; increased status; peer support; differences in strength of connection to community or hospice, conflicting expectations.
Experience can be transforming.	Rewarding; life changing; bearing witness; personal coping strategies; managing loss; dignity; courage; broadened view of death; self improvement over time.

3.5.1 Doing what is needed

This thread highlights how enabling volunteers to be flexible in their approach can appear to improve the experience for the volunteer, the dying person and the family, and how perceived inflexibility caused by organisation rules, discussed later, can result in frustration for volunteers. Guirguis-Younger and Grafanaki (2008) found that volunteers in the community were usually working alone, with minimal supervision from paid staff and without a fixed task or agenda. The volunteers spoke of:

> I get satisfaction doing what needs to be done. If there were things that I thought I wanted to do for the clients, staff would say go ahead, as long as it is safe (Guirguis-Younger and Grafanaki, 2008, p.18).

Here staff appeared to trust the volunteer to make their own decision about what was safe. Flexibility appeared important for volunteers to meet people's needs as stated in the study by Pesut et al.; McKee et al. (2007, p.165-166) described how coordinators often used the term "we just" and spoke of being "accountable to the family and the client and we do whatever they need". Doing what was needed was part of a volunteer's role in Uganda and volunteers told how they "wash their clothes, clean their house, some we prepare them food (Jack et al., 2011a, p.711). However, the study by Jack et al. (2011a) found that such generosity from the volunteers meant that at times patients expected too much from volunteers a dilemma also raised by Azuero et al.'s (2014).

Flexibility may also attract people to volunteer. Guirguis-Younger and Grafanaki (2008) suggest that people volunteered because of the freedom it gave them to contribute as a whole person, because it was different from their professional life. This flexibility also related to the service being delivered. McKee et al. (2007; 2010) highlighted how local coordinators were given autonomy to expand the service to include the frail and chronically ill in their communities.

The flexibility in the role found in community schemes as described earlier was in contrast to the Marie Curie Helper scheme described by Ipsos MORI (2012) and the study by Walshe et al. (2016). In these studies a lack of flexibility led to frustrations for volunteers, when volunteers were not able to 'do what was needed' because organisational rules prevented them, a theme which is explored later. This thesis will give some insight into how volunteers might manage such dilemmas about rules and expectations.

The importance of the volunteers' 'presence' and 'being there' was highlighted by Söderhamn et al. (2017) and McKee et al. (2007), although the language used by the authors was different. Söderhamn et al. (2017) stress the importance of being receptive to the ill person and using active listening skills to become close to them, whilst the volunteers in the study by McKee et al. (2007) spoke of journeying with people and forging bonds of friendship. These differences could reflect the contrast between 'professional' language and a language related to friendship.

3.5.2 Becoming friends

The formation of friendships between patients and volunteers was a strong thread that ran through some of the reviewed literature. However, there were different views expressed by authors about the role of friendship. Sévigny et al. (2010) and McKee et al. (2007) saw developing a genuine relationship as a core volunteer function:

> long-term relationship building with seniors was not simply optional – it was the very foundation of successful hospice volunteering" (McKee et al., 2007, p.167)

Volunteers in the study by McKee et al. (2007) described themselves more in terms of 'friends' or 'like a member of the family' than as a 'member of a professional team'. This was replicated by the volunteers in the study by Pesut et al. (2017, p.6) where volunteers stated: "they became friends and part of my life", although the volunteers in this study felt they should be doing more in their role as navigator, and not just spending time building a relationship. This could suggest that the volunteers felt the relationship had a lesser value than practical help. However, it was significant in this study that, over time, the volunteers realised such relationships meant that their "role was not limited to navigating resources but that it was also about "helping people navigate this time of their life on an emotional level"." (Pesut et al., 2017, p.6).

The formation of these friendships may have been a result of a successful matching, as several papers describe how organisations use details about similar backgrounds or interests to match volunteers to patients (Claxton-Oldfield and Claxton-Oldfield, 2007; Ipsos MORI, 2012; McKee et al., 2007; Sévigny et al., 2010; Walshe et al., 2016). Sévigny et al. (2010) suggest that volunteering in someone's home may also contribute to the development of a friendship. Fox (2006) agrees that the formation of friendships seems to make the experience more rewarding for the volunteers and Supaino et al. (2014) found that volunteers appeared able to manage relationships with patients, relationships which varied, from brief and superficial to deep and personal.

However, the reviewed authors appeared to hold mixed opinions about such friendships. Authors appear to exhibit concerns that building close relationships might be seen as a potential risk to the volunteer. As seen in the study by Claxton-Oldfield, S et al. (2011a, p.430), who state that "the bottom line is that volunteers can still get close to their patients/families, just not too close." Fox's (2006) study highlights the challenges that volunteers might face, in that hospice training encourages them to develop concern and empathy for those they are visiting. Yet hospice rules, as discussed later, appear to recommend that volunteers should maintain a certain detachment, as getting too attached may have negative consequences.

Rather than seeing such friendships as a problem, the volunteers in the study by McKee et al. (2010) felt they were receiving more that they were giving and described relationships as 'two way' rather than 'one way'. This reciprocity was highlighted by Azuero et al.'s (2014), who found that volunteers spoke of how patients and volunteers benefited from the visits. A 'two way' relationship suggests that patients and carers have something to give, that they are not just passive receivers of care and support. This suggests that such a role could have social benefits for the volunteer as well, a perspective confirmed by Walshe et al. (2016) who found that volunteering reduced volunteers' own isolation.

The volunteers in the study by Söderhamn et al. (2017) express surprise how much they were trusted by the people they visited, despite the fact that they had not met before. Pesut et al.(2017) and McKee et al. (2007) suggest that trust is built during longer-term relationships. Walshe et al. (2016, p.26) propose that the formation of friendships, and the sharing of significant information, is helped by the position of 'distance' and 'trust' the volunteer is in: they are more distant than family and friends, but trusted to hear such information. Walshe et al. (2016, p.26) liken this to a counselling relationship and note that, although the volunteer's role was more like a neighbour, most volunteers had received substantial training. In contrast McKee et al. (2010, p.108-109) suggests that volunteers might in some way be "better than friends" as they are "friends with skills" providing a "third circle of care" fusing formal and informal caring.

3.5.3   Rules, training and support needed for volunteers

In Chapter 2 I suggest that regulations may affect the experiences of community hospice volunteers. Some of the reviewed literature appears to support this idea, as the application of rules and the formation of friendships seems to raise concerns in several of the studies. Boundaries were often discussed by authors which either related to the volunteer's role or to the emotional boundaries that were set. Although Walshe et al. (2016) suggest that some UK hospices are more flexible in their approach to boundaries for volunteers visiting at home, they found that managing boundaries was a substantial issue discussed at training and ongoing support meetings.

In the study by McKee et al. (2010) volunteers seemed to be able to manage being a volunteer and a friend, whereas in Berry and Planalp's (2009) study volunteers appear to struggle with balancing the role of being a friend and a representative of the hospice, and found they were being asked to do things that a friend might, but a volunteer could not. For example, in relation to the issue of accepting gifts, Berry and Planalp (2009, p.460) point out "professionals would probably not be offered gifts as often and friends would probably not refuse them". Here the organisational rules did not appear to fit with being a friend. In contrast, Söderhamn et al. (2017) make no mention of such a struggle, and were clear that the volunteer was not part of the family, and not a healthcare professional, and should not use any medical knowledge they might have (if they had healthcare experience), when volunteering.

There seems little recognition in some of the reviewed literature that volunteers may be able to manage their own boundaries, as described by the volunteers in the studies of McKee et al. (2007; 2010), Sévigny et al. (2010) and Söderhamn et al. (2017). Although, in Söderhamn et al.'s (2017) study this appears to be within the parameters of a clearly defined role. However, Sévigny et al. (2010) saw the fact that boundaries may vary as a negative consequence, as they would be dependent on what each individual volunteer feels comfortable with. Sévigny et al. (2010) note the challenges in setting limits for volunteers who are left alone to make autonomous decisions, but suggest this can be addressed by setting better limits, agreements and support for volunteers.

Robinson et al. (2010) and Söderhamn et al. (2017) both note that in a small community, volunteers may need to negotiate confidentiality as people become aware of who is being visited. This shared knowledge was not seen as a problem by McKee et al. (2010), where volunteers in small rural communities in Canada were often also friends and neighbours. Volunteers in the study by Guirguis-Younger and Grafanaki (2008) spoke of the importance of finding the right balance between clear personal boundaries and a deep emotional connection with patients and they emphasised the need for healthy boundaries to cope with the work. Interviewing volunteers from rural and urban areas allows an insight into any such differences in the UK.

Earlier in this chapter I examined how volunteer autonomy and flexibility to do what was important for the patient improved the experience for the patient and the volunteer. However, in the studies by, Berry and Planalp (2009), Ipsos MORI (2012) and Walshe et al. (2016), volunteers faced dilemmas when they found that what the patient and family needed did not match what the hospice allowed them to do, or what they felt able to do. Walshe et al. (2016, p.29) told how volunteers "flouted" rules set by their organisation, although it was not clear which rules were "flouted" or why.

Fox (2006) describes how hospice rules are designed to regulate the social interactions between patients and volunteers to help maintain emotional distance. In examining how volunteers might view restrictions placed around their role, Claxton-Oldfield, S et al. (2011a) found that from 27 potential boundary issues only 12 were felt to be something they should not do – things relating to money, legality or confidentiality. Other behaviours, which included sharing personal information like telephone numbers, or doing small jobs around the house, were seen as boundary issues by the volunteers, but many admitted to doing such things. These things could be said to be similar to the things a friend might do. Training was seen as part of the solution to resolve these problems. Training, especially in communications skills, was seen as necessary by the volunteers in the study by Söderhamn et al. (2017), especially for volunteers that lacked experience in healthcare, or experiences relating to illness and death.

Sévigny et al. (2010) suggest that volunteering in the community, in someone's home, may raise particular concerns for those responsible for ensuring volunteers' safety and emotional wellbeing, a concern highlighted in Chapter 2. In Söderhamn et al.'s (2017) study a palliative care coordinator was responsible for the volunteers' well being, their training, matching the volunteer to the dying person and providing ongoing support and mentoring. However, the volunteers' need to talk to their mentor after every assignment declined as volunteers gained in confidence.

This section highlights the concerns perhaps felt by managers and professionals in ensuring that volunteers maintain boundaries around their relationships, roles and behaviour. The rules and boundaries set for the volunteers may be aligned with developing a more professional service and professional fears about burnout highlighted in Chapter 2. These boundaries appear to be in direct contrast to the volunteers' wishes for autonomy and flexibility highlighted in the previous section and take no account of a volunteer's ability to manage boundaries themselves. If professionals believe this about relationships with patients, it may also affect how they influence volunteers' relationships with patients, a question which will be explored as part of this thesis.

3.5.4   Being a bridge

The role of the volunteer in the community appears to be multi-faceted, providing a bridge or link between patients and healthcare professionals, and connecting patients to the outside world. Some studies show how volunteers can help to extend the reach of hospice care. Jack et al. (2011a) and Grant et al. (2011) described how volunteers play a role in informing the hospice about patients in very rural areas, thus providing a link or a bridge between local people and the hospice and extending the reach of the hospice. One volunteer in this study explains "there are some villages that are very deep and the Hospice team cannot reach. I go there on my bicycle and get information and identify the patient for the Hospice team" (Jack et al., 2011a, p.713). Walshe et al. (2016) found that volunteers performed a monitoring role on a patient's condition which meant they could alert clinical staff about any changes and would also encourage patients to make use of health services. The authors suggested that this was an impact which could bring the greatest benefit to a patient's health.

McKee et al. (2007) make reference to seeing volunteers as having a role connecting patients to the outside world. "They bring life, news. They hold the dying person in the community" (McKee et al., 2010, p107). The volunteers in the study by McKee et al. (2010) were enthusiastic about the palliative care approach, but were clear they wanted to retain their independence and did not want to be part of the professional team. In the study by Pesut et al.(2017) the role of the volunteer was specifically to help patients navigate healthcare services and connect with their community. Several authors noted how volunteering in the community enhanced a volunteer's connection to that community and gave them a sense of belonging, as described by Guirguis-Younger and Grafanaki (2008) and McKee et al. (2007). In the study by Jack et al. (2011b) volunteers felt trusted and their volunteering enhanced their status in the community.

However, the idea of the volunteer providing this 'bridge' appears to cause difficulties in some studies. Berry and Planalp (2009, p. 460) suggest that the volunteers' position as "neither a professional nor personal caregiver" can cause the volunteers ethical dilemmas. This description appears to indicate that the volunteers felt themselves to be 'in the middle' between the patient and the family and the hospice team. This sense of being in the middle was seen in the study by Walshe et al. (2016) where volunteers felt they were neither professional nor next-of-kin and were in "that little bit of no man's land, that little bit of lost space in the middle" (Walshe et al., 2016, p.24). This perception may connect with the boundaries that might be set around the volunteer's role and are discussed later.

3.5.5   Experiences can be transforming

In the earlier section Claxton-Oldfield, S et al. (2011a) suggest that volunteers need to be protected from becoming too close to patients, to perhaps protect them from the stress of being close to someone who is dying. In Brown's (2011) study most volunteers felt their work was not stressful and found that any stress reduced over time, as they became more comfortable with the work. But Fox (2006) proposes that although volunteers may be involved and upset when the patient dies, it is the involvement than can make the experience for the volunteer meaningful. Fox (2006) notes that many volunteers will have been motivated to do such work because of an experience of death, therefore one might suppose that they may well have learnt how to cope with death. Their previous experiences of death or hospice care might explain the results of the Claxton-Oldfield, S and Claxton-Oldfield, J (2007) study, which found that some volunteers in their study did not feel the deaths had impacted on them at all.

Rather than death being a negative experience, the volunteers in the studies by McKee et al. (2007) and Söderhamn et al. (2017) saw being with a dying person as a privilege. This idea was noted by Guirguis-Younger and Grafanaki (2008, p.19) "I find it a privilege to witness someone die. It is a gift." Guirguis-Younger and Grafanaki (2008) suggest that such experiences appear to help volunteers develop resilience and resolve previous losses. Supiano et al.'s (2014) study of the exploration of how prison volunteers managed their grief found that they perceived their experiences to be more positive, compared to their previous experiences of death, which were often traumatic and linked to violence.

Some volunteers in the reviewed studies found the experience to be transforming in how it made them think about, and appreciate life (Claxton-Oldfield and Claxton-Oldfield, 2007; Cloyes et al., 2013; Guirguis-Younger and Grafanaki, 2008; Supiano et al., 2014). The inmate volunteers stated how "hospice changed my life. I never realized the well of compassion within me was depthless. It made me recreate myself as a person" (Cloyes et al., 2013, p.8). Volunteering in prison appeared to give people a chance to express compassion to others in a positive way whilst being in a prison culture, which normally constrained expressions of humanity. A similar narrative was found in the study by Naidu et al. (2012), where volunteers found that caring had helped them to reconnect with their personal identities and improved their perceptions about themselves.

There appeared to be mixed opinions about how much support volunteers need to cope with death. Macleod et al. (2012) suggest that support is needed for volunteers dealing with grief, yet in studies by Guirguis-Younger and Grafanaki (2008) and Claxton-Oldfield, S and Claxton-Oldfield, J (2007) volunteers seem to be able to manage their own feelings, taking time out or gaining support from others or from their own beliefs. Volunteers' views in the studies reviewed also varied. The volunteers in the study by Macleod et al. (2012) spoke of coping by looking after themselves and getting support from the hospice and their own informal networks. Whereas other studies reported how volunteers themselves highlighted the importance of support and guidance from hospice staff (Berry and Planalp, 2009; MacLeod et al., 2012; Pesut et al., 2017; Söderhamn et al., 2017).

3.6 **Discussion**

This systematic review found literature about community hospice volunteering from UK, Canada, USA, Norway, Africa (Uganda, Kenya, Malawi) and the Netherlands. Whilst the review showed how community volunteering could provide positive experiences for volunteers as they visited dying people at home, it also highlights the different perspectives taken by authors. The study in Norway emphasised the clarity of the role, and training and support needed for volunteers. Some studies in the USA, Canada and the UK were concerned about the role of volunteers and over-stepping boundaries. This was in contrast to the studies in Africa, where the flexibility of the role was crucial, as people's most urgent needs may have been related to more basic needs of food or shelter. The review describes the different roles that volunteers were taking on and although volunteers in Africa and India were actually involved in more practical tasks, many of the roles in Western countries seemed more social in nature as in the studies by McKee et al. (2007; 2010), Ipsos MORI (2012) and Walshe et al. (2016).

The reviewed literature reflected the dilemmas highlighted as suggested by Milligan and Fyfe (2006) and Guirguis-Younger et al. (2005) in Chapter 2, that increasing regulation may influence hospices to 'professionalise' volunteering and apply rules and boundaries to volunteers' roles. In addition, the medicalisation of dying explored by Howarth (2007) may be affecting a narrative that volunteers should behave more professionally than informally. This view was corroborated by the perspectives described in Chapter 2 by Sinclair (2007) and Ganesh and McAllum (2012) that the professionalisation of palliative care may be influencing paid staff to ensure that volunteers adhere to similar guidelines as paid staff.

There was some evidence of this in the concern expressed by authors in the study by Claxton-Oldfield, S and Claxton-Oldfield, J (2007), that volunteers need guidance and training about perhaps not getting too close. Yet it was the closeness of the relationship cited by McKee et al. (2007), Fox (2006) Pesut et al.(2017) that often made the relationship rewarding. There may be a danger that frameworks of best practice or regulations might jeopardise the human process relationship which the volunteer develops with the dying person, as suggested by Guirguis-Younger et al. (2005). This thesis may give a better understanding of how volunteers experience such guidance or rules.

The reviewed studies show the complexity of the volunteer role in relation to the professional palliative care team and potentially the people being visited. Volunteers may need to navigate their way around their relationships with professionals, patients and families and the local community and this thesis may give an insight into how volunteers experience and manage those different relationships. This supports the need for research into volunteers' experiences in the UK.

The studies of the community volunteer scheme in Canada by McKee et al. (2007; 2010) had similarities with the African literature by Jack et al. (2011a; 2011b) and Grant et al. (2011) in how they described the importance of relationships in the community and the ability of a volunteer to do what is needed. The reluctance of UK hospices to use community volunteers to the same extent of the USA or Canada is not clearly understood. It may be related to the constraints of regulation and concerns for volunteer safety, as suggested by Morris et al. (2015).

Chapter 2 mentions the criticism that hospices have received in appearing to deliver care to relatively few people and failing to reach marginalised groups, yet the studies reviewed here - Jack et al. (2011a), Grant et al. (2011), McKee et al. (2010), Cloyes et al. (2013) and Supiano et al. (2014), all demonstrate how volunteers can reach into rural and marginalised communities, such as those found in Africa, those dying in prison in USA and the elderly and chronically ill in Canada. These studies demonstrate how the use of volunteers has the potential to reach more people and potentially benefit volunteers and the community.

3.6.1 The robustness of this synthesis

In reviewing the robustness of this synthesis I reflected on the strengths and limitations. The narrative synthesis did enable a review that was able to answer the review questions and allowed a variety of studies to be included, which met the selection criteria. However, reviewing such different studies encompassing different volunteering experiences from different countries added a degree of complexity. As a lone reviewer I must also acknowledge the potential for bias in my review in relation to my identification of the different clusters of ideas and narrative threads. To mitigate this, the review was discussed with my research supervisors. Although the selection criteria allowed studies where volunteers' perspectives were only a part, their part was at times quite small, and revealed little information.

3.7 **Summary**

This review highlights the paucity of literature relating to community hospice volunteering in the UK and the limited literature available exploring the perspectives from volunteers themselves thus demonstrating the need for this research. Whilst this literature review of the studies found evidence that volunteering with dying people could be transforming for the volunteers, it also found similarly conflicting discourses as seen in Chapter 2.

The first discourse relates to the informality of the volunteer's role and the development of longer-term meaningful relationships and friendships with dying people. Volunteers themselves appeared to value their autonomy and flexibility and felt that the formation of friendships with the people they were visiting as an essential component of their role.

The second discourse suggests that volunteers should behave more professionally, rather than informally, and not get too close to patients. Such a discourse requires volunteers to have training and adhere to clear boundaries. In this discourse, volunteers are seen more as an extension of the hospice or palliative care service. This discourse may reflect the increasing regulation facing hospices and in society in general.

This thesis is interested to see if these conflicting discourses are found in the stories of the volunteers interviewed for this thesis and how they make sense of their experiences. Whilst the literature review indicates that many of their experiences may relate to their relationships, even friendships, with dying people, the context of their experiences in relation to organisational rules and the impact of regulation have featured little in the studies reviewed. Sévigny et al. (2010) were the only authors to use a theoretical framework to reflect on the boundaries between the different systems a volunteer might be working. Therefore to understand those relationships, and the wider contexts within which they occur, it is important to use a methodology and theoretical framework that facilitates the exploration of those issues.

4 Research paradigm and methodology

Previous chapters highlight the need for research which explores the experiences of community hospice volunteers visiting dying people at home, acknowledging the suggestion that increasing regulation could be affecting their experiences. The aim of this research is to add to knowledge about community hospice volunteers and inform the type of support and training needed by volunteers. My objectives for this research were: to understand what it was like for volunteers to visit dying people in their own homes, to hear how being with dying people might change volunteers' attitudes to death and dying, to understand whether regulations might be impacting on volunteers' experiences.

In this chapter I examine the philosophical paradigm which underpins this research and the narrative methodology used to understand 'how does community hospice volunteering with people at the end of life impact on volunteers, in relation to their experiences and their attitudes to death and dying?' I conclude by discussing the rationale for using systems theory as developed by Gregory Bateson (1972) to understand the findings in this research.

4.1 **Research paradigm**

A paradigm can be defined as a basic set of beliefs that guides actions (Denzin and Lincoln, 2011). In deciding which philosophical paradigm is best suited to the research question I needed to ensure congruence between the research question, philosophical paradigm and methodology (Silverman, 2000). A philosophical paradigm encompasses how I, as a researcher, perceive reality (ontological position) and how then how I make sense of that reality (epistemological position).

The studies reviewed in Chapter 3 show the different roles the volunteers may fulfil, the value they place on friendships, as well as the factors that may influence a volunteer's experience; factors which include the increasing regulation affecting hospice and societal discourses about death. Therefore a research paradigm is needed that facilitates exploring those experiences, taking into account the wider factors and contexts that could influence volunteers' experiences. Critical realism provides that paradigm and is therefore used in this research and is more suitable than a relativist or a realist paradigm. Braun and Clarke (2013) describe the differences between the such paradigms, using the analogy of looking through glass (Figure 4.1).

Figure 4.1 Ontological positions and the position of this research

Relativism	Critical realism	Realism

Reality is dependent on the ways we come to know it	A pre-social reality exists but we can only ever partially know it	A pre-social reality exists that we can access through research

Looking through different glass

Prisoners only have one view from their window, each view is different and could be a hologram, there is no way to know if it is true.	This view is through a prism, so what is seen is shaped by the prism (culture, history).	Looking through this glass you see a perfect view corresponding with exactly what is outside the window

Position of this research

Source (Braun and Clarke, 2013, p.26).

Maxwell (2012) explains how critical realists acknowledge there is a reality, but knowledge about this is never complete and is constructed from our own viewpoint, shaped by our beliefs. This paradigm sees the researcher's view as part of the construction of the knowledge through the research process, rather than uncovering knowledge that is independent of the researcher (Braun and Clarke, 2013). This will also be relevant to the research participants' views of reality which are shaped by their beliefs. The idea that critical realists treat people's beliefs and the meanings they hold as important as real physical objects, is a core concept for this research in validating the experiences of volunteers, and what those experiences might mean to the volunteers (Maxwell, 2012).

Whilst a critical realist position explains the view of reality, social constructionism provides the epistemological position that informs how to make sense of the reality explored in this research. Whilst positivism would see the findings of research as something to be discovered and an objective version of reality; social constructionism sees reality as something that has been jointly constructed by the participants involved (and the researcher) and the cultural context that surrounds them (Gergen, 1999; Wetherell et al., 2001).

Some of the literature reviewed in Chapter 3 explored how volunteers expressed their choices about rules or motivations to volunteer (Brown, 2011; Claxton-Oldfield et al., 2011b; Planalp and Trost, 2009). I suggest that these studies perhaps see behaviour as a result of an act of individual will or personal agency, without always acknowledging the wider contexts and influences on the self. A social constructionist paradigm as described by Burr (1995, p.195) widens the perspective and describes the self as "socially contingent rather than pre-existent".

Burr (1995) and Mead (1934) argue that language, social interaction and reflection are crucial to the development of the self and inform people's choices in how they act. Dallos and Draper (2000, p. 93) develop this and note the importance of our own personal backgrounds, as words "are soaked in the legacy of meanings of our cultural contexts". In the context of this thesis, these assertions mean that not only do I listen for how the participants' backgrounds and the contexts may influence their stories; I recognise that I bring my own 'legacy of meanings', which I acknowledge and reflect on throughout this thesis.

The choice of a critical realist approach and the use social constructionism therefore provides a socially-orientated base from which to explore the volunteers' experiences, taking into account the contexts and backgrounds which influence their experiences. To explore these experiences therefore requires a methodology which enables the participants to talk about their experiences, and a way of analysing and understanding those experiences. A qualitative methodology provides that framework as it is "committed to seeing the social world from the point of view of the research participant" (Bryman, 2008, p. 299). A qualitative methodology also takes account of the meaning, the contexts, the process that happens and the role of subjectivity, and is line with a critical realist paradigm (Maxwell and Reybold, 2015).

Previous chapters highlight the need for research that allows volunteers' experiences and voices to be heard. In Chapter 3, studies using qualitative methods, such as interviews or focus groups with open or semi-structured questions, appear to encourage participants a better opportunity to share their perspectives (Claxton-Oldfield and Claxton-Oldfield, 2007; Guirguis-Younger and Grafanaki, 2008; Naidu et al., 2012). These findings suggest that the most effective method to elicit volunteers' experiences and how they make sense of their visits to dying people is one that is relatively unstructured and which encourages them to tell their own stories about their experiences. Therefore this thesis requires a methodology which enables the participant's voices and perspectives to be the main focus of the thesis, as it is *their experiences* and how they make sense of those experiences that I am interested in. Therefore it was important to use an approach where the volunteers could feel free to talk about their experiences in an open or unstructured way, rather than using a structured interview or a questionnaire with a predetermined focus.

A narrative approach was chosen over other approaches, such as grounded theory or a phenomenological approach, both of which have been used to understand the lived experiences of people in relation to illness. Firstly, grounded theory is used to generate theories about the interaction between people and their human experiences (Gilbert, 2008), whereas, this thesis is using systems theory, which is discussed later in this chapter, to understand the experiences of the volunteers. Secondly, the use of themes in grounded theory can result in fragmentation of data as categories are developed and refined (Charmaz, 2015).

Whilst a phenomenological approach, has similarities with a narrative approach, in that it is interested in the experiences of the participants and how they make sense of those experiences, recognising and the role the researcher has in constructing the telling of those experiences (Smith, 2009). A phenomenological approach also focuses on the process of interpretation as the researcher tries to make sense of "the participant trying to make sense of their personal and social world" (Smith, 2004, p. 40). Like grounded theory, the use of codes and themes is used to explore connections between accounts (Smith, 2009). Both of these approaches tend to fragment the story using themes and code, this is in contrast to a narrative approach ensures that the data is preserved as stories (Riessman, 2008).

However, my research focus was on the narrative events described by the volunteers and it was important to me that the voices, words and perspectives of the volunteers should be a highlight of this thesis. Because a storytelling methodology enables the experiences of participants to be conveyed in a manner that fits with 'being human' a narrative approach was chosen, Sparkes and Smith (2008) describe stories as the 'vehicle' through which people describe themselves and their world. A narrative approach also aligns with critical realist and social constructionist paradigms, as the focus of interest is not just in the internal lives of the individuals, but how their experiences are socially constructed and the realities they create with their stories (Chase, 2005; Elliott, 2005; Riessman, 2008).

4.2 **Narrative theory**

Narratives are said to play a central role in social life. Roland Barthes suggests:

> The narratives of the world are numberless. Narrative is first and foremost a prodigious variety of genres... narrative is present in every age, in every place, in every society; it begins with the very history of mankind and there nowhere is nor has been a people without narrative (Barthes, 1977, p. 79).

Some authors like Frank (2000) and Riessman (2008) use the term 'narrative' and 'story' interchangeably, although Frank warns that losing the term 'story' may risk shifting attention away from the person telling the story, "as people do not tell narratives, they tell stories" (Frank, 2000, p.354). Riessman (2008) describes how the term 'narrative' has a life beyond the individual, because groups, communities, governments and nations construct preferred narratives about themselves. Therefore this thesis uses the term 'story' in relation to personal stories and 'narrative' when relating to narratives from groups and institutions. To understand what distinguishes a story from other types of language, I use Riessman's definition where a speaker:

> connects events into a sequence that is consequential for later action and for the meanings that the speaker wants listeners to take away from the story. Events perceived by the speaker as important are selected, organized, connected, and evaluated as meaningful for a particular audience (Riessman, 2008, p.3).

The beginnings of narrative can be found in Aristotle's examination of the stories used in the Greek tragedies. Aristotle identified a classic structure with a beginning, middle and end, coming together in a plot which alerts the audience to a story (Greenhalgh et al., 2005; Riessman, 2008). Elliott (2005) defines a plot as an explicit causal link between events. This is often seen as a crucial component of a story and what distinguishes a story from a chronological account in how it connects and organises events into meaning. Czarniawska explains the difference:

> 'The company suffered unprecedented losses' and 'the top managers were forced to resign' are two mysterious events that call for interpretation.

> 'With the company suffering unprecedented losses, the top managers were forced to resign' is a narrative. (Czarniawska, 2004, p.7).

Enabling volunteers to tell stories about their experiences could allow them to include such 'causal links', giving an insight into how they make sense of their experiences. Encouraging patients to tell their stories is being seen as an increasingly important part of improving health care. Charon (2006), and Greenhalgh and Hurwitz (1999) suggest that listening to a patient's story can give a doctor access to information and an understanding of their suffering and what the illness means to them, which could be missed using a biomedical model of questioning. Listening to volunteers' stories about their relationships with the people they are visiting may give an understanding of their perspectives that a more rigid set of questions might miss.

Clark et al. (2005) remind us that storytelling has always formed an important part of hospice care. Telling stories can help people make sense of their illness experiences and help them to create a new identity for themselves in a world of illness (Bingley et al., 2006; Frank, 1995). People's motivations for sharing their stories may vary, perhaps using stories to highlight satisfaction or dissatisfaction with medical

treatment (Bingley et al., 2006; Mishler, 2005). However, stories may not always have a positive impact: as Ziebland and Wyke (2012) warn some stories can also be misleading and irrelevant, a perspective of which I will need to be aware.

Modern technology and the growth of social media via the Internet has provided many more people with a place to share personal stories (Bingley et al., 2006; Riessman, 2008). This social aspect of storytelling is relevant to this thesis; as stories also go on to construct a version of reality in their own right (Frank, 2010). Hearing what stories the volunteers might be telling to friends or family about their experiences will give some insight into the wider impact of their stories. This wider influence may be said to apply to the thesis itself as I interpret and attempt to make sense of, and create meaning from, the 'story' of the thesis (Chase, 2005).

4.2.1 Narrative research

Narrative research has been applied to a broad range of topics, from the examination of the social linguistics in individual accounts, to applications in social history and anthropology (Riessman, 2008). Stories have the potential to give an 'insider' view, or a different perspective. This can be seen in early forms of narrative research used by sociologists from the Chicago School in the 1920s to examine life histories and personal documents (Riessman, 2008). Whilst Atkinson (2009, 2010) criticises narratives, suggesting they should not be privileged or seen as more authentic than any other research, Bochner (2010) highlights that the use of narrative has played a part in exploring topics that are related to social injustice. Narrative research has given a 'voice' to more personal perspectives and played a part in the feminist and the civil rights movement in the 1960s (Chase, 2005).

Since the 1980s, narrative research has been used in the fields of health, illness and dying to bring to light personal or 'lay' perspectives of health and illness, which may

not always have been heard within the field of medicine (Bingley et al., 2008; Elliott, 2005; Frank, 1995). This concept of bringing to light personal perspectives could also be applied to volunteers' voices within hospice care. As the literature review highlights, there appears to have been limited opportunity for volunteers' voices to be heard despite the contribution they make to hospice care. This thesis addresses this perceived gap by listening to the stories of such volunteers.

4.2.1.1 Validity in narrative research

Elliott (2005) describes validity in qualitative research as problematic, as the traditional terms used to define validity are more relevant to quantitative research than qualitative research, and to ensure the research is credible a researcher needs to address internal and external validity. Riessman (2008) suggests that exploring the 'trustworthiness' of the qualitative research data may be a more helpful way to look at validity.

The implications of this for this narrative research relates to my ability to show methodological rigour and demonstrate the craft of analysis without losing the essence of the story (Riessman, 2008; Thomas, 2010). Thus, I will not only gain insight into individuals' experiences, but also the meanings they make of them, which in turn may provide insight into how people make sense of their experiences (Elliott, 2005). Whether these insights will have relevance to other hospice volunteers may depend on the coherence of how I present the findings and my transparency and reflexivity. To ensure internal validity I use sections of text to demonstrate how the analysis is grounded in what was said.

4.2.1.2 *My role as the researcher*

Whilst Goodwin et al. (2003) stress the importance of the skill of the researcher in eliciting a story from the participants as part of the data collection, I also need to be aware that I am an active participant "who jointly constructs narrative and meaning" with the interviewees (Riessman, 2008, p. 23). The narrative method requires me to immerse myself in the story and think 'with' a story rather than 'about' a story (Frank, 1995).

I also considered my position in relation to the terms 'insider' and 'outsider'. Gair (2012) describes an 'insider' as someone who shares with the participants a common lived experience or membership of the group being studied. As an 'insider' I share the characteristics of working in hospice care and for the participants from my own hospice, I share membership of that hospice. However, I may also be seen as an 'outsider', because I am a manager, not a volunteer, and not a member of some of the hospices from which I was recruiting. Therefore I agree with Dwyer and Buckle (2009) who suggest the solution is to occupy a space which allows the position of both 'insider' and 'outsider', as this fits with the methodology being used, as described above.

I was also aware that the stories themselves might have influenced me in the interview and analysis. I might choose some stories over other stories by being emotionally affected by them (Frank, 2010). An example of this is how I was affected by Anita's story as I explain in my reflections in Chapter 6. I was also conscious that my role as a hospice CEO may have affected the research, either by influencing or deterring volunteers from taking part, as well as influencing the stories they told.

Hammersley and Atkinson (2007, p.64) warn that there may also be a "serious mismatch" between the participants' expectations of the researcher and his or her intentions, and may regard the researcher either as expert or critic. For example, volunteers may feel they need to show me that they are complying with hospice rules, as they might believe, as a CEO, I would expect them to. To mitigate this, I was transparent about my role as a senior manager and attempted to build a rapport with the participants so that they engaged with me as a researcher, rather than as a CEO, for instance by wearing less formal clothing as suggested by Rubin and Rubin (2005).

4.3 **Theoretical framework**

In this chapter I have explained how a critical realist and social constructionist paradigm has led to a narrative methodology which will provide a base from which to answer the research question. However, as identified earlier, a theoretical framework is required to understand and explore the interpersonal nature of experiences, as well as informing an understanding of how the wider contexts influence the volunteers' experiences and their attitudes to death.

A wide variety of theoretical frameworks have been linked to volunteering, from psychological theories that emphasise individual characteristics like personality and motivation, to economic theories that see volunteerism as unpaid work and sociological theories that focus on class, gender and contextual phenomena like social networks and community characteristics (Wilson, 2012). In the reviewed literature, only Sevigny et al. (2010) study explored volunteers' behaviour within a social system model, however, they make little reference to the interaction and feedback between systems, an aspect that is explored in this thesis.

To this end, in this thesis I use systems theory developed by Gregory Bateson (1972) to underpin this research and explore and understand the stories produced, as systems theory focuses on understanding experiences and behaviour in terms of interpersonal relationships within the contexts of wider systems.

4.3.1 Systems theory

The reviewed literature in Chapters 2 and 3 highlights the different perspectives about volunteering, about formal and informal roles, as well as the influence of regulatory systems and the medicalisation and professionalisation of death. Systems theory provides a framework to understand and explore how these systems and beliefs may affect volunteers' behaviours and experiences. The choice of Bateson's systems theory was influenced by my own experiences. As a family therapist and manager, I found that systems theory informed my understanding of how relationships, beliefs and the power of systems could influence people's behaviour, including my own influence and the systems that influenced me. Burck and Speed (1995, p.4) remind us that it "depends on where we stand in a system" and "with whom we are standing" which determines what we see. This quote has particular resonance for me as I try to stand as a researcher, and a manager, in hearing the stories, and writing the analysis and discussion, and my view is a thread that I will reflect on throughout this thesis.

Early systems theorists in the 1940s and 1950s were interested in how systems maintained equilibrium. Ludwig von Bertalanffy, a biologist, proposed a general systems theory about the organisation of organisms that focused on the whole system rather than the individual parts (Rasheed, 2010). Norbert Wiener (1954), a mathematician, started using the term 'cybernetics' to describe the communication and control within machine systems to maintain stability through a circular process of readjustment. An example of a cybernetic system, is a thermostatically controlled central heating system, which can respond to feedback about changing weather and a homeowner's preferences (Bale, 1995). The anthropologist Gregory Bateson thought cybernetics might provide a tool to explain how people behave in social systems (Guttman, 1991). Bateson's (1972) theory proposes that all systems are structured around feedback, and systems will form habits or patterns of responses, which will either regulate or deviate behaviour.

Bateson's systems theory was used to develop an alternative approach to psychoanalytic and individual models of treatment. Dallos and Draper (2000) explain how psychodynamic therapy had been more interested in the past and what was happening in an individual's subconscious, cognitive and emotional states. Systems theory offered a shift in emphasis, seeing psychological problems as a result of inter-relationship processes and patterns of behaviour, rather than individual deficit or pathology.

4.3.2   The application of systems theory

In 1954, Bateson joined psychiatrists in Palo Alto, USA, to study the behaviour and interaction of families where a member of the family was diagnosed with schizophrenia. These early studies resulted in psychiatrists and psychotherapists starting to work with family members as a group and Family Therapy Institutes developed in the UK, USA and Italy. Early models of family therapy saw these 'system' ideas applied to families: family therapists would look for the patterns and rules that were causing problems in a family and work to try and adjust them. Systems theory has been criticised for applying a mechanistic approach to human interaction. However, Bertrando (2000) explains that Bateson was using the concept of cybernetics to purely explain human interaction and suggests that it was Bateson's followers who were perhaps guilty of regarding families as machines to be mended.

From the 1980s, family therapists working with systems theory were influenced by social constructionism as they took into account the influence of wider societal factors (Dallos and Draper, 2010). Vetere and Dallos (2003) explain that the systems theory used by family therapists today places more emphasis on the meanings and beliefs held in a family system, and how those beliefs influence patterns of behaviour and interpersonal relationships. This emphasis will inform how systems theory is used in this thesis. Systems theory also has some synergy with narrative theory and how people use stories to make sense of their experiences, and some family therapists integrate systemic and narrative ideas to help people to create new stories and meaning about their experiences (Dallos and Vetere, 2014; White and Epston, 1990).

Systems theory has also been used in the study of organisations, widening the perspective from the individual and their skills and capabilities to the complexity of the system they work within (Campbell, 1991; Campbell et al., 1994; Senge and Sterman, 1992). Campbell (1991) explains how belief systems will influence how people perceive reality and choose to act, as personal beliefs about morality and achievement, and organisational beliefs about loyalty, competition and risk, will all influence how people perceive relationships.

4.3.3   Key principles of systems theory

A system could be described as any unit or group structured on feedback (Bateson, 1972). Figure 4.2 highlights the different systems that might occur as part of community volunteer visiting. However, the main interests of this thesis are the systems the volunteer is part of, with the dying person and hospice staff.

Figure 4.2 Different systems
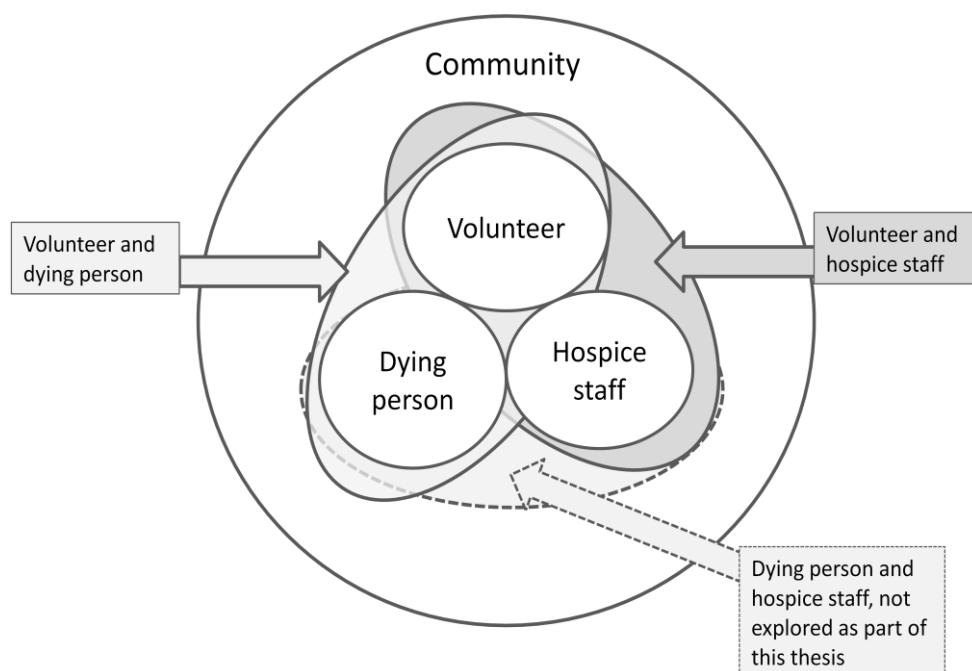
A core concept in systems theory is that people exist in the context of other systems: families, communities and organisations, each with their different rules and beliefs (Winek, 2009). Understanding the context and power in those systems connects with the descriptions in Chapter 2, where regulation and commissioning systems are seen as an increasing influence on hospices and potentially on volunteers, and will be important in this research. I am therefore interested in how the contexts of societal beliefs about death, and the influence of regulation on systems and beliefs affect volunteers' behaviours and experiences (Figure 4.3). Systems theory therefore provides a theoretical base on which to broaden the perspective, not only looking at the one system, but the contexts and power of other systems that surround and influence the volunteer's behaviours and experiences.

Figure 4.3 The contexts of systems
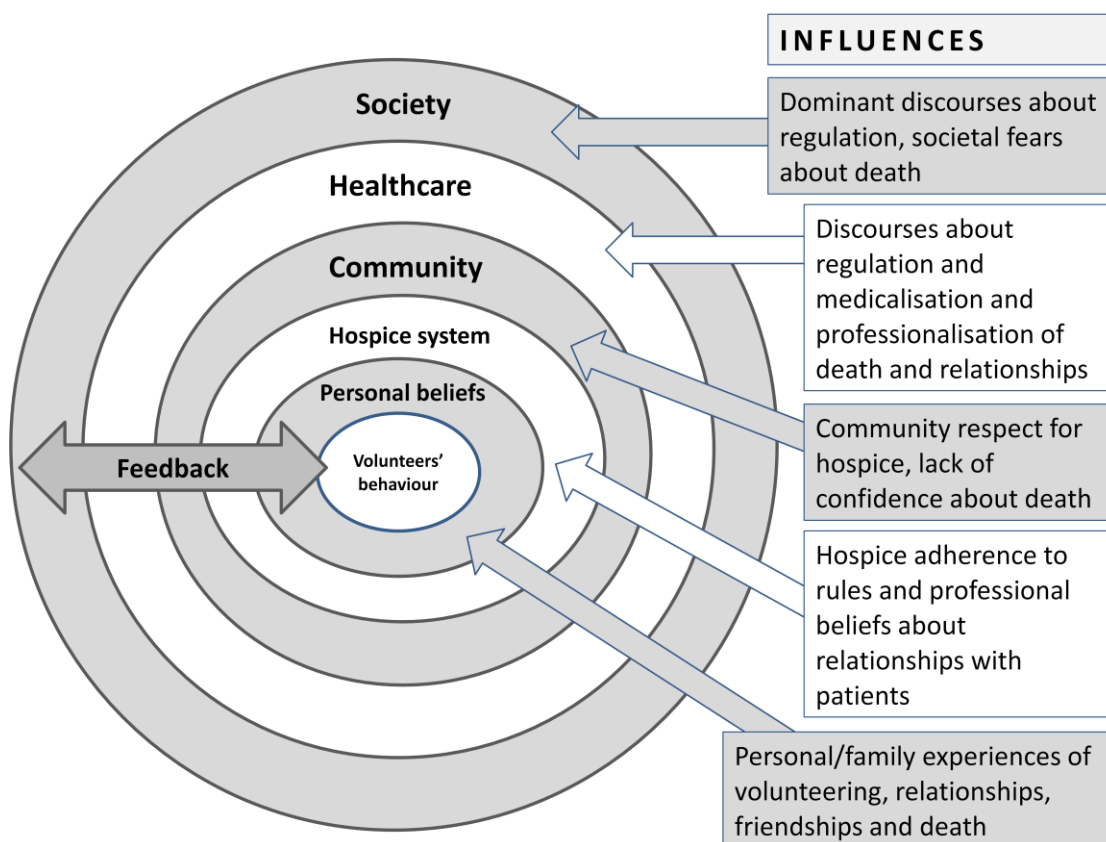
The rules in systems that influence behaviour can be described as either 'overt', being something expressed routinely, or 'covert' and not expressed out loud (Vetere and Dallos, 2003). Examples of overt and covert rules are seen in the study by Claxton-Oldfield, S et al. (2011a). An overt rule expressed in this study was that a volunteer should never accept money from a patient or family, whereas a more covert rule was that volunteers "can still get close to their patients/families, just not too close" (Claxton-Oldfield et al., 2011a, p. 430).

It is clear from the studies reviewed in Chapter 3 that the presence of rules does not mean that people will apply them, as how people decide to apply rules is influenced by their personal beliefs about those rules, the meaning they attribute to them and the feedback they receive (Dallos and Draper, 2010). The different beliefs and meaning about professionalism and volunteering were evident in Chapters 2 and 3, therefore exploring the beliefs and meaning told by the volunteers interviewed form an important part of this thesis. Chapters 2 and 3 highlight the importance of relationships with dying people and how regulation and societal opinion about death may affect those relationships. Bateson (1972) suggests that when we seek to explain behaviour we should look for differences in behaviour. Therefore, I focus on looking for differences in the stories to see how volunteers might respond differently in their relationships with the people they are visiting and with hospice staff, who will be part of a hospice system.

Systems theory proposes that how people behave in relationships may depend on the feedback they receive from others. Feedback can either help people adapt or may cause them to be stuck in a pattern of behaviour. Figure 4.4 shows the boundaries and feedback which will be present between the volunteer, the dying person and the hospice staff, acknowledging that hospice staff will be part of a process of feedback with the wider hospice system. In this thesis I am particularly curious about the stories volunteers tell about how they manage their relationships with the dying person and the hospice staff.

Figure 4.4 Relationships and boundaries
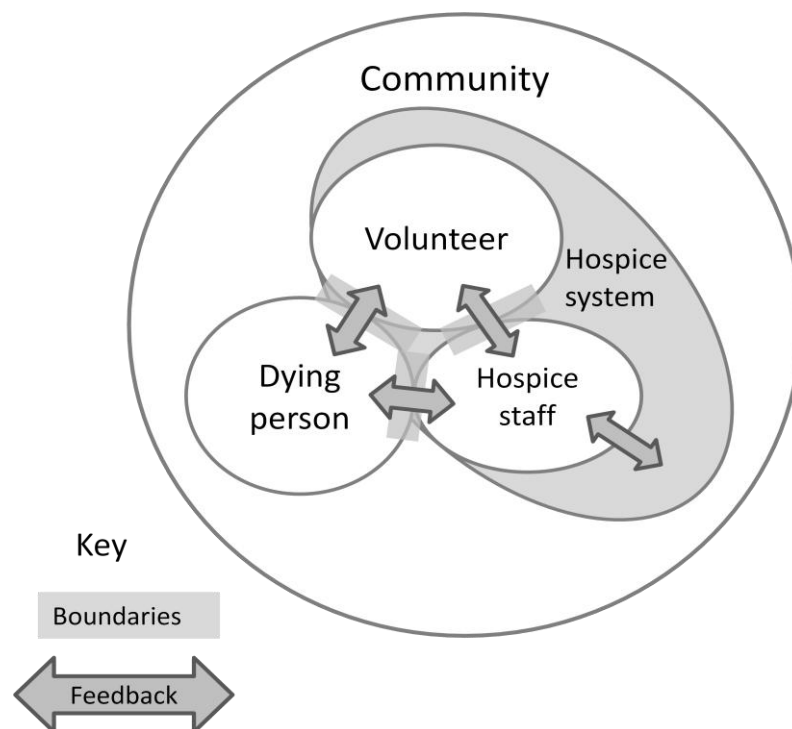
Campbell (1991, p.12) describes "feedback as the lifeblood" of any systems and suggests that an organisation must be able to respond to internal and external feedback. Campbell (1991) warns that organisations can find themselves needing to balance the need for stability and the need for change and often use what could be described as covert rules to manage that tension, which may also hinder change. This has particular relevance to hospices as they face a need to change because of growing demand.

From this theoretical base the focus in this thesis is on exploring: the context surrounding the volunteers' experiences, the meaning and beliefs held by the volunteers, the boundaries of their relationships, the systems that surround them and the feedback between those systems.

4.4 **Summary**

In this chapter I have explained the process through which a narrative methodology was chosen to answer the research question. I have explored how a philosophical paradigm that takes a critical realist position and uses a social constructionist base to understand the knowledge created through the research process is congruent with the aims of the research. I have also demonstrated the benefit of using systems theory to understand the experiences told by the volunteers, because of its focus on understanding how people behave in relation to others and respond to the rules and to the wider systems that influence their experiences and behaviours.

5 Research methods

As described in Chapter 4 a narrative methodology has been selected to answer the research question to understand the experiences of community hospice volunteers and their attitudes to death and dying. This chapter describes how the study was designed and the methods used to generate and analyse the data.

When planning the research, I discussed my research ideas with nine community hospice volunteers at my own hospice. Most felt that one needed to be face to face to tell a story, rather than using a diary or video. The group thought that volunteers might talk about training, support, thoughts about death and dying and how they felt about the work they did. These ideas helped shape the design of the research, particularly my approach to interviews.

5.1 **Ethical considerations**

To ensure the research was undertaken in a manner that complied with principles of ethical research and conducted with integrity and transparency (Economic and Social Research Council, 2018) I ensured that my methods addressed issues of informed consent, confidentiality, the avoidance of harm and managing distress, the impact of my role on the process and its effect on the independence of the research.

5.1.1   **Research ethics approval**

I gained research approval from Faculty of Health and Medicine Research Ethics Committee at Lancaster University, including a minor amendment to use a transcriber (see Appendix 2). I also complied with the ethics policies of each of the hospices involved.

5.1.2 Consent and confidentiality

To ensure that participants understood the research process and their right to withdraw, each participant signed a consent form (see Appendix 3). The confidentiality of participants and people mentioned was protected by the use of pseudonyms, and all identifying information in relation to the hospice or place names was removed or changed. This was particularly important as few volunteers appeared to be involved in community visiting and thus may be easily identifiable. All participants were offered the opportunity to choose their own pseudonym, which a few did; otherwise one was allocated to them. Because only one Asian volunteer came forward, a non-Asian name was allocated to them to protect their confidentiality. All personal data held in relation to the research was stored according to guidance from the Data Protection Act (UK Parliament, 1998) and the secretary I used to transcribe some of the interviews signed a confidentiality form (see Appendix 4).

5.1.3 Participants' feelings and perspectives

The use of an interview provided participants with space to explore their experiences about visiting dying people. Although talking about dying and death may be distressing, this may not be a source of harm. Elliott (2005) suggests that people can benefit from reflecting and talking about experiences, or even find it empowering. In seeking ethical approval, I was aware that distress may not always mean that the participant was unwilling or unable to continue with the interview, and I believed that my skill in managing the interview should minimise any negative effects on the participant and be able to ascertain that the participant was willing to continue.

It is not just the interview that may have an effect on the participant; the way I analyse and interpret the data may also have a positive or negative impact on the participant (Elliott, 2005). An example of this is seen in Riessman's (2008) study when a participant questioned the interpretations that had been made; as she felt her story about her infertility was different from the story she told during the study. Although this does not negate Riessman's (2008) interpretation, it confirms Frank's (2006) ideas that people's narratives may change with time. I am aware that the stories I heard from participants took place in 2014. The participants may disagree with my interpretation, as their thoughts about their experiences may have changed. However, this should not detract from the research, because my interpretations of these versions of their stories are relevant for that moment in time.

5.1.4 Power and reflexivity

One of the hospice volunteer services suitable for the research was my own hospice. I initially tried to identify hospices other than my own to be part of the research, but because using community volunteers is a new phenomenon in the UK, I was required to invite my own volunteers to take part in the research. I am aware that the role I hold in the hospice influenced how the participants expressed their experiences as they may have been either more reticent or more willing to share their thoughts and feelings.

Frank (2010) warns that people within institutional settings may feel the need to conform to the institutional narrative. Volunteers in this thesis may have felt they needed to tell stories in a particular way, because of their relationship with their hospice, or perhaps out of loyalty or dissatisfaction. My role as a manager of a hospice and researcher will also have influenced the volunteers to tell a particular version of their story and my own beliefs will have influenced me to tell a particular version of what I heard. The issue of power was particularly relevant for the volunteers interviewed that came from my own hospice. In reflecting my part in co-constructing the stories, I was aware, during some of the interviews, that I asked questions about rules, and particularly about sharing telephone numbers, as I was aware that this was often a point of debate, and I tried to encourage participants to talk about how they felt about such rules and kept notes of my reflections in a research diary.

Because of my impact on the thesis, I need to show an understanding of my standpoint (Frank, 2000). That is, my professional background in palliative care nursing and family therapy, my current role as CEO of a hospice, as well as my motivations for this research, all play a part in the co-construction of the interview, the analysis and writing up. For example, my role as CEO may influence the stories that are told to me and my specific interest in relationships may influence how I interpret the stories. Therefore my reflections included in this thesis to help the reader understand how my theoretical or biographical perspective may have impacted the participants and the interpretation of the data (Elliott, 2005).

5.2 **Participant sample**

I planned to recruit volunteers (see Table 5.1) from independent adult hospices. Independent hospices were chosen rather than NHS hospices, because of their history of using volunteers, identified in Chapter 2. I aimed to recruit 15 to 20 interviewees to provide a richness of data required by qualitative methodology (Braun and Clarke, 2013). A purposeful sampling approach was used when selecting participants that came forward, to ensure participants were interviewed to generate sufficient data from a range of people (Bryman, 2008). This range would include those working in rural or urban areas, and a mix of gender and ethnicity. Davis Smith (2004) highlighted the fact that volunteers in the UK are likely to be over 55, female and white. By interviewing volunteers from a range of demographics, my intention was to gain insight into how volunteer diversity shapes experiences of volunteering and how it impacts upon the ways in which people make sense of death and dying.

Table 5.1 Participant inclusion criteria

Volunteers included who are:	Volunteers excluded who are
- Working for an independent hospice in London, central and eastern England, that has been using volunteers in their local community for over 1 year, with people at the end of life - Over the age of 18 years - Working as a hospice volunteer within their own community in either a rural or urban area - Have visited people who are at the end of their lives - Able to speak English	- Working for an NHS Hospice - Only providing bereavement support - Unable to speak English - Under 18

5.2.1 Recruitment

The participants were recruited from hospices that had been running community volunteer support for over one year, as this would ensure that the service was relatively well established. The research did not specify the length of time the participants should have volunteered, as their story might be related to a single visit or several visits. As I was conducting this research alongside my current role, a geographical area was chosen which would ensure that an interview could be completed in one day. Because of the potential time impact of identifying translators the research was limited to those who speak English.

To recruit participants an advert was placed in UK Hospice Online (Help the Hospices, 2013) asking for Hospice Volunteer Services Managers (HVSM) to come forward if they had volunteers that met the criteria in Table 5.1 (see Appendix 5). When insufficient hospices came forward, the advert was sent directly to HVSMs in the geographical area, using information from the UK Hospice Directory.

Initially four hospices came forward in response to the advert and email. One was out of the geographical area and two were in London. I selected the nearest London hospice to me to limit travelling time. Each hospice that came forward circulated a leaflet about the study to their volunteers (see Appendix 6). When few volunteers came forward from Hospices 1 and 2, and no other hospices came forward from more rural areas, I gained permission from my own hospice to try and recruit volunteers. Interested participants received a letter or email with an Information Leaflet with (see Appendices 7 and 8).

In hospices 3 and 4, 22 volunteers came forward and 11 were interviewed. I attempted to interview volunteers that ranged in age and gender. Sixteen volunteers were interviewed in total; interviews were limited by participant availability. Prior to the interviews some general information was taken from each hospice about the numbers of volunteers used in the community in relation to other clinical volunteers. This information would be useful in understanding the context of volunteering in each hospice.

5.2.2 Interviewing

Narrative interviewing requires a slightly different style from other qualitative interviews, creating a 'climate' for storytelling, with as little interruption as possible (Wengraf, 2001). Whilst my skill in emotional attentiveness and engagement with the participants could contribute to such a 'climate', I was aware that my own biases, body language, listening, questioning and engagement with the participant would shape the interview and the story being told (Rubin and Rubin, 2005).

Eliciting stories may not always be easy as some participants may not feel their experience warrants a story. Therefore, I encouraged participants to talk about their experiences and avoid the 'why' question, and used 'open' rather than 'closed' questions asking them to 'tell me about your experiences' (Hollway and Jefferson, 2000). I also tried to be alert to a story unfolding, and let the participant "hold the floor" (Mishler, 1991, p.74). To ensure the interview remained connected to the research question I used an interview schedule as a guide (see Appendix 9).

Interviews occurred either at the volunteer's home or at their local hospice, whichever was more convenient for them and where they felt most at ease and able to talk without interruption. I also made notes by hand of events in the interview that might not be picked up by the audio recording. Rubin and Rubin (2005) note that the end of the interview is equally as important as the beginning, especially when exploring sensitive issues, so I let the participant know that they were coming towards the end of the interview, to give them the opportunity to raise any additional aspects of their story.

I transcribed 12 of the interviews myself, and four were transcribed by a secretary. In transcribing the interviews I was aware that a transcript is unable to capture everything that is communicated during an interview and that it should be viewed as a compromise (Elliott, 2005; Riessman, 2008). As well as reflecting the words used, in the transcription I included notes of any emotions expressed, how the words were said, or anything else of significance.

5.3 **Narrative analysis**

Narrative analysis encompasses a number of different techniques that use texts which are in a 'storied form' as the object of analysis, each being underpinned by methodological and epistemological differences (Elliott, 2005; Riessman, 2008). The research question, "how does community hospice volunteering with people at the end of life impact on volunteers in relation to their experiences and their attitudes to death and dying?" required a type of narrative analysis which supported an examination of the full descriptions that volunteers gave about their experiences and kept their stories as a whole and not fragmented. In line with a critical realist and social constructionist paradigm, the analysis needed to explore how the story was constructed and the contexts and influences on the stories told, including my influence as the researcher. Therefore a dialogical approach to analysis was taken as it is an approach that attempts to deal with these questions. Riessman (2008) explains how a dialogical approach focuses on how a story is co-produced between speaker and listener within the context of their different history and culture:

> "Stories don't fall from the sky (or emerge from the innermost "self"); they are composed and received in contexts - interactional, historical, institutional, and discursive - to name a few. Stories are social artifacts, telling us as much about society and culture as they do about a person or group." (Riessman, 2008, p.105).

The stories could therefore give an insight into the society and culture around volunteers' experiences. A dialogical approach differs from a structural or thematic approaches which explores '*what*' is spoken and '*how*', and instead looks at '*who*' the story is directed to, '*when*' and '*why*', and '*for what purpose*' (Riessman, 2008). Whilst Riessman (2008) and Phoenix et al. (2010) describe this approach both as dialogical or performative, for the purposes of this thesis I use the term 'dialogical'. A dialogical approach is more suited to dealing with large amounts of data, as opposed to structural models as described by Labov and Waletzky (1967). Structural models are more appropriate to an 'event' and short sections of narrative and may neglect other elements, such as the interaction between storyteller and audience in the co-construction of the story (Elliott, 2005; Squire, 2008).

Frank (2002) states that a dialogical narrative analysis is about speaking '*with*' a participant rather than '*about*' them. Elliott (2005) and Mishler (1999) both stress the importance of immersing myself in the data. Thomas et al. (2009) use a 'river' allegory, developed by Thomas, which requires me to engage with the data as if wading in a river, rather than looking on from the side and examining the 'content'. The river analogy is helpful in considering how the river banks and river bed affect the flow of the water, to understand the influences that shape the story. The influences may include, for example, the present and past social and cultural landscape, significant events and experiences. Thinking about myself 'wading in the river' acknowledges my part in the co-construction of the story as my presence in the river affects its path and flow.

My dialogical approach used the following questions (Figure 5.1) to further interrogate such stories, the questions used in the analysis have been drawn from Frank (2010), Smith (2013) and Riessman (2008).

Figure 5.1 Dialogical analysis questions

- What is being told and why?

- What or who is shaping this story?

- What are the stories doing and for whom?

- What are the effects of the telling?

Smith (2013) suggests the craft of narrative analysis can be developed by reading other pieces of narrative analysis, and by writing and rewriting about the data. This advice was particularly helpful as I analysed the data. I took long excerpts from a few interviews and wrote about the stories that were being told and how I thought I was influencing them. These were sent to my supervisors as a basis for discussion.

I analysed and wrote notes about each transcript separately using a mind map (see Appendix 10). I explored possible storylines before moving on to the next transcript, ensuring I was thoroughly immersed in each story (Riessman, 2008). I always returned to the original recordings to ensure the accuracy of my interpretation (Mishler, 1991). After the first readings I used the questions above (Figure 5.1), as well as looking for storylines individual to each participant and connections between stories. I then used ATLAS.ti to ensure that the narrative threads were linked to the original transcript (see Appendix 11 for examples of the groups of threads identified).

During the analysis I listened for stories in the data, where volunteers were using 'plots' to create meaning about events, aware that stories can be short in length as seen in this example from Mike's interview:

> Mike: H*er wave at the door as you drive away, after an afternoon, is yeah, that makes you feel good, makes you feel you've really contributed somebody's happiness.*

Here Mike is connecting his afternoon visit with her wave. He makes sense of the events suggesting that it has helped her happiness, and made him feel good. Mike's story showed how he may have wanted to portray his visits as beneficial to persuade me, the researcher, that the service was making a difference to people, perhaps using a positive way of telling the story to persuade others. As a volunteer he may also wish his stories to confirm for himself that the time he was giving was worthwhile.

My initial analysis identified narrative threads about 'making a difference' (see Table 5.2).

Table 5.2 Initial narrative threads identified

Major story threads	Minor story threads
Making a difference to life	To the dying person – - friendship and companionship, reducing isolation - practical help - connecting to community and professionals
	To the volunteer – - friendship, - thinking differently about life - learning from dying people
Making a difference to participants' attitudes to death and dying	Making death less scary Learning to cope with loss – from doctors and nurses
The difficulties in trying to make a difference	Hospice, personal and own professional beliefs about volunteering Influence of the hospice system and stories about rules

These threads may have reflected the participants' wish to portray their experiences as worthwhile to the people they were visiting and to themselves. Frank (2012) suggests commitment to a dialogical narrative analysis is not to summarise the findings, but to open up further possibilities for listening and responding to what is being heard. Frank (2010) also warns about the use of typologies (classifying stories into groups). These can both assist the reader and risk putting stories into boxes which become more real than the stories. As I continued my analysis I re-read the interviews following the questions in Figure 5.1 and this section below (Figure 5.2) uses an extract from Christine's interview to show how I approached 'what is the story doing?' and 'what is shaping the story?'

Figure 5.2 Example showing how key questions were used in the analysis

What is the story doing?		What is shaping this story?

What is the story doing?

The initial part sets the scene explaining why she was there, part of her story of herself as a caring person and he was in her thoughts doing it on a Saturday

Story of how she was thinking through what to do and whether to be there or not, perhaps fearful, especially when she hadn't wanted to be around death but yet she seemed to find it to be the right thing to do – as if she in talking about it was justifying it again

She demonstrates her knowledge of the couple in relation to their religious beliefs

Showed how she made a decision

Even though wife arrived she still stayed

Emphasising how quickly he died

Support from hospice staff as if saying she didn't need / deserve it / shouldn't have needed it, almost apologising

Acknowledging how this was not what she expected to be doing as a volunteer or wanted to do, but how it felt right

Her willingness to get involved with the wife

[Centre column transcript]

Christine: so and what had happened was that was in January, and my daughter had a party in town and so I dropped her off and I knew Fred was in the hospice and I thought I can't drive past without going to see him really it was a Saturday, I thought I'm just going to nip in and I got there and his breathing was very laboured and I kind of, I have been around that kind of breathing so I sort of recognised what was happening and I stayed there for a little while and I thought I can't, I need to step out for a minute so I went into the chapel and I lit a candle and I grabbed one of the crosses and just said a little prayer and I took it back into him and I'm thinking right I'm going to go now 'cause I was only going to pop in and so I've got this cross in my hand and I said this to a few people I was like ok I popped it in his hand and he then I was like I don't know shall I leave it in the hand and then I took it out and I put it back on the side I was like no only because I knew that they have got religious beliefs and I'd been there when they're having communion

B: right

Christine: 'cause the priest had come to the house

B: and was she there as well

Christine: no his wife wasn't there and I didn't know that they'd called for her either

B: right

Christine: a few hours before, so it was a little bit strange anyway so in the end I'd settled at no I'm going to leave it in his hand and I'm now going to go, I'd sort of at that point Margaret walked in

B: right

Christine: and basically within 10 minutes he died

B: right

Christine: I did feel, I got upset, I don't think the hospice staff didn't really know who I was at that point, and so yeah they sort of put their arm round me (emphasis) even and I'm thinking oh crikey I don't feel very professional here it's not how I'm supposed to be, 'cause I just didn't you know and this is from me going meeting Joan in the January going I really can't be around somebody when they're gonna you know, so anyway we then had tea and coffee there at the hospice and they were lovely, and it just felt completely right to stay there with Margaret, I'd rung my husband and I'd explained what had happened, my daughter's being picked up, I said "I don't know how long I'm going to be" he said "that's fine don't worry" and so I ended up ringing the funeral directors for her while we were there and we sorted that and then obviously I drove her home and again I said the

What is shaping this story?

I had explained myself as an experience palliative care professional this may have influenced Christine in telling a story that showed her as able / wanting to cope with such situations

Her previous experience of death meant she recognised what was happening

Her worry about perhaps rules and uncertainty not sure what as the 'right' thing to do plus her fear about being around death – perhaps the impact it might have on her

Her own religious beliefs and ease with religious symbols as well as her connection to the priest

My own concern (not mentioned) that staff and volunteers not working together – volunteer perhaps perceived as a friend or family rather than a member of their team

Staff making her feel at ease

Belief that she has to be 'professional' as a volunteer and not get upset – ? especially to me

That things need to feel right

Supportive family

Continued to do things for the wife as she had done before – protection / help / but could be seen as taking over

Exploring what might be shaping the story highlighted beliefs about 'being professional' and 'doing the right thing'. Further analysis led me to explore what the stories were saying about the influences on their stories about making a difference. Returning to the analogy of the prism in critical realism, I was curious about the 'prism' in these stories and what was shaping the stories I was listening to and influencing the volunteers' stories, and how volunteers were making sense of those influences. This analysis led me to develop the three major threads about: *managing relationships; adapting to the hospice system and changing beliefs about life and death* which are discussed in Chapter 6.

5.4 **Summary**

This chapter has described the methods used to design this research, and explained the rationale for using dialogical analysis to examine the stories generated by the volunteers and shown how I applied dialogical analysis to the data generated by the interviews. I have also described how the ethics of the research have been addressed and some of the challenges for me as a researcher in undertaking this research.

6 Results and findings: volunteers' stories of relationships, death and rules

This Chapter examines the results and findings of this research to understand how community hospice volunteering impacts on volunteers' experiences and their attitudes to death and dying. I begin with a description of the volunteers who came forward to be interviewed. I then examine the narrative threads that emerged during the analysis: *managing relationships; adapting to the hospice system,* and *changing beliefs about life and death*, threads which give insight into how volunteers make sense of their different experiences. Concepts from systems theory are drawn upon to understand the findings about the boundaries and beliefs in the different relationships the volunteers have told about. I explore how *rules* and *being professional* are strong influencing factors in all the threads and I conclude with my own reflections on the research process.

6.1 **Participants**

Sixteen volunteers were recruited from four hospices. The following information from each hospice demonstrates how community volunteering relates to other clinical volunteer activity. Two hospices had only developed community schemes in the previous two years and two hospices had been using community volunteers for several years. Figure 6.1 shows: how many volunteers were part of 'clinical' departments and involved with patients, families or the bereaved; how many visited people in the community, including for bereavement support; and how many visited ill patients at home. Using the term 'clinical volunteers' may also have included volunteers involved with driving or catering.

Figure 6.1 Where volunteers work clinically within each hospice
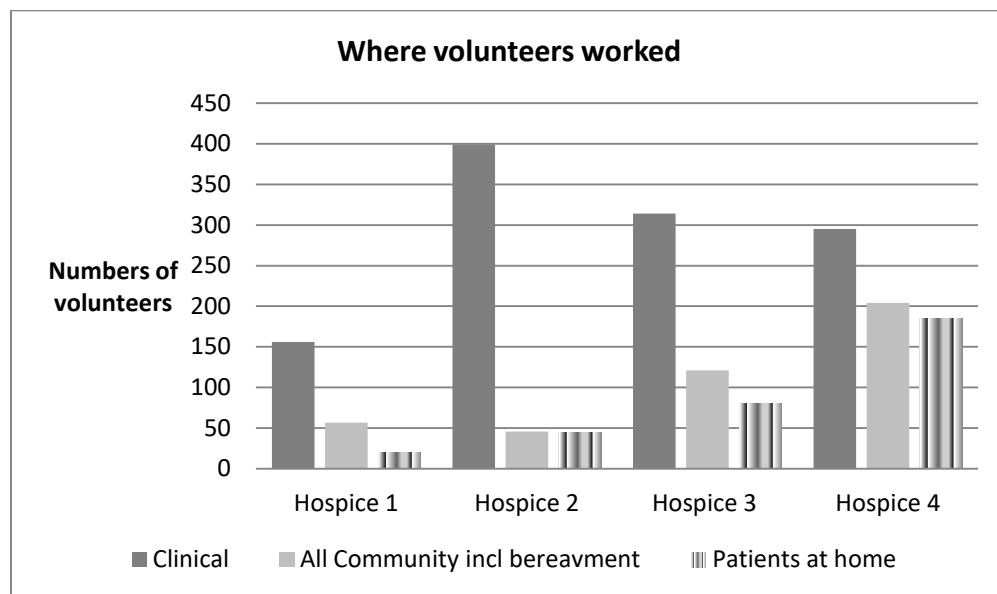
The small numbers of community volunteers visiting patients at home in three of the four hospices were similar to the findings of Burbeck et al. (2014b), which were that only 32% of the volunteers undertaking direct patient activity were involved in home care. Hospice four, my own hospice, had markedly greater numbers of volunteers visiting patients in the community.

The literature reviewed in Chapter 3 appears to show that the majority of volunteers working in hospice care are over 55, white and female and from a professional background (Davis Smith, 2004). This was corroborated, in part, by those who came forward for this research and were subsequently interviewed. Figure 6.1 shows the volunteers' ages, gender, professional background and ethnicity. However, the self selection recruitment process means that those who came forward or who were interviewed cannot be seen as a representative sample of a hospice volunteer workforce.

Table 6.1 Participants' demographic details

		Volunteers (*n*=16)
Age	Mean age in years (range)	59 (range 33-81)
	33-44	3
	45-64	7
	65-69	4
	70+	2
Gender	Male	6
	Female	10
Professional background	Administration	1
	Animal Health	1
	Business	2
	Education	4
	Finance	2
	Health and Social Care	5
	None stated	1
Working, or retired	Working	2
	Not working	4
	Retired	10
Ethnicity	White	15
	Asian	1

Whilst six of the volunteers interviewed had had previous experience of volunteering, for 10 others this was their first experience of being a hospice volunteer. The latter was perhaps because individuals had been recruited for a new community visiting scheme. Many, but not all, of the volunteers usually visited people in their local communities; some chose not to, or chose to travel to wherever visits were needed. The purposeful sampling which was used did result in a slightly greater range of diversity, in terms of age and gender, than reviewed studies in Chapter 3. Only one volunteer that came forward and was interviewed was Asian. The majority of volunteers also came from professional backgrounds, as found by Claxton-Oldfield, S. and Claxton-Oldfield, J. (2007) and MacLeod et al. (2012).

Three of the interviews took place in the local hospice at the volunteers' requests, and the remainder at the volunteers' homes. Interview times ranged between 37 minutes and 109 minutes and were conducted between May and December 2014. The median time for an interview was 62 minutes.

6.2 Emerging narrative threads

The sixteen participants told a variety of stories about the people they had visited, what the visits had been like, the relationships they had formed and some of the challenges they had faced. There were strong threads that ran through the interviews about relationships, rules, and death and dying. The dialogical analysis encouraged me to look at the influences on the stories and how volunteers were making sense of their experiences. The interviews gave detailed insight into how volunteers managed and thought about the relationships they formed with the people they visited, how they felt about hospice influences and how their experiences changed their attitudes to death and dying.

These insights formed the three major threads which emerged and are discussed in this Chapter (Table 6.2). The first thread related to stories about *managing relationships* with the people they visited, either by developing friendships or by maintaining more professional boundaries. The second thread, *adapting to the hospice system,* reveals volunteers' stories about how they changed their behaviour with dying people because of hospice guidance. The final thread, c*hanging beliefs about life, death and grief,* brings together stories about how their experiences changed their ideas about death and life. Throughout the interviews there were also threads about rules which were found across the major threads.

Table 6.2 Major and minor narrative threads

Major threads	Minor threads	Threads about rules
Managing relationships	Pleasure of friendships – trust and sharing Becoming part of the your life and family Sharing stories about visits with others Developing relationships	Getting too close Rules are over the top You cannot be a friend and a volunteer Personal and professional beliefs about boundaries Blurring boundaries
Adapting to the hospice system	Not there to share of yourself Volunteers break the rules, but do not tell the hospice Hospice is the expert Volunteers should not give advice	Hospice rules constrain and restrict Frustration about rules Rules and training are there for protection You need to be professional
Changing beliefs about life and death	Learning from dying people Death becomes less scary Learning to cope with death like doctors and nurses Different from personal grief Getting used to death	

When exploring *what or who is shaping the stories*, volunteers told stories of how they responded to rules about what they should or should not do as a volunteer. These rules or beliefs mostly emanated from the hospice they were working with, but also appeared to stem from their own beliefs systems. In deciding which stories to include, I was aware that my own concerns about over-regulation and constraints on volunteers made me particularly sensitive to certain stories, which influenced my desire to highlight where volunteers were able to manage their work and relationships, and where they felt constrained or frustrated in some way. My reflections are included as part of this chapter.

6.3 Managing relationships with the person at home

The first section explores narrative threads about relationships formed between the volunteers and the people they were visiting, and beliefs about those relationships. Many of the volunteers referred to the guidance or rules they had been given by the hospice, yet the volunteers responded differently to such guidance. The stories show how some volunteers used their own belief systems in how they managed such relationships, which, for some, came from their professional backgrounds.

6.3.1   Developing friendships

These stories about friendships appeared to be told in a quite positive way and may have been told for a variety of reasons, for example: in support of their hospice; to promote the service to me and for future readers; and perhaps to persuade the volunteers themselves that what they were doing was worthwhile and connected to their motivations to volunteer.

Scott was a retired accountant who took up volunteering as he was keen to put something back into his community. Scott started by telling me about his visits to George who, like him, loved sport:

> Scott: *I think looking back I was very very lucky, because we hit it off straight away and it was such a good start for me. I think one of the key things I realise now, is that the hospice has to match up the volunteer with the patient.*

Here Scott seems to attribute the success of his relationship with George down to the hospice matching and their common interests. Like many volunteers, Scott also felt his training had helped him. He said: "*I wouldn't have liked to go in cold, with no knowledge at all*". Scott set the scene about his visits to George:

> Scott*: his whole life was in that room, he had carers came in four times a day to get him up, to give him breakfast, get him in his chair, then came in lunch time, tea time, and then in the evening to put him to bed. And I found out they were in for maybe twenty minutes, half an hour at time, and apart from that he was just sat there on his own.*

Here, Scott was clear to point out how his visits were in such contrast to George's carers, who were there for only short periods of time. Scott told how they talked for hours about sport and history. Scott said "*I could see that he did enjoy it, but also I enjoyed talking to him so much*". Scott often got to know about the families of the people he was visiting and told how he would "*talk a bit about obviously about my family*". When talking about Bert, someone he took out shopping, he told how when they were out, Bert would say *"this is my friend and he's helping me".* Scott's stories about George and Bert tell a story of the companionship role that Scott is fulfilling, a role that helps reduce the isolation that George and Bert might be experiencing; stories which were replicated by other volunteers, as can be seen later.

Scott did feel that some hospice rules were a bit "*over the top*" although he appeared to accept them. He mentioned how some of the people he visited had made a note of his telephone number when he forgot to add 141 before dialling (which would hide his number) but he said:

> Scott: *It has not been a problem at all, no, they say don't give out details of exactly where you live, don't give your phone number, as it could can, cause problems, but I've not had any problems whatsoever".*

Scott felt the reason the hospice gave for such a rule was a worry about dependence on the volunteer and that it might result in:

> Scott: *phoning up at all sorts of times and things like that, I personally think it's possibly a bit over the top, but if that's the rule then I'll follow it when I remember to.*

This section shows how Scott reflects on his experience that breaking the rule did not cause the dependence expected by the hospice and resulted in him not sticking to the rules. Perhaps, if he had felt people were becoming dependent on him, he might have adhered to the rule. Scott was aware that he needed to be careful when going shopping with people if monies changed hands, but he could not understand the rule why he could not tell people where he lived:

> Scott: *I tell them roughly where I live, I think it would be, to me it would be rude not to, like particularly when I was bringing Bert into town, he'd say "where do I live" and I'd say "just up the road there" because it would be slightly offensive to them if I didn't trust them.*

Here Scott appears to manage his own boundaries with the people he was visiting, judging what, and what not, to share. The rule not to share where he lived meant, for Scott, that he did not trust the person he was visiting, something he felt was "*offensive*". Scott's story appears to be persuading me that he understood the rules, but they did not fit with his experiences of the relationship he developed with the people he visited, although he did not say whether or not he reported this back to the hospice. In Scott's story, the hospice rules seemed to indicate that the hospice believed that volunteers needed to be protected from patients becoming too dependent on them, but the hospice rules were not adapted where dependence was not a problem.

Mike was a retired teacher, and the idea of helping people to stay in their own homes appealed to him. Mike's first patient, Tom, had dementia and he found his training helped him to know what to do. One day, he and Tom looked at holiday postcards:

> Mike: *I'd say "what's this one Tom, tell me about this one" "oh that's when we went to Ireland, used to love going to Ireland" and away he'd go and he'd light up, and of course Edna was getting a bit of a break.*

When Tom was less well, Mike found himself becoming involved with conversations with Edna (Tom's wife) about problems with Tom's carers. Mike kept in touch with his coordinator (also a volunteer) to ask advice about what he should or should not do:

> Mike: *I reported back each week by email and then I would get a reply if I raised any questions. So really my questions were fairly general, about how much should I be involved here, should I get involved with the doctor's surgery, should I get involved with the carers that are coming in and so on; and the advice was "not too much, whatever you feel is appropriate"*

When Tom had to go into a home, Mike checked with the coordinator before he took Edna to see her husband:

> Mike: *Edna was just so thrilled to have seen him, and to see where he was and the people he was with, and the people who were looking after him and so on. That sort of, her wave at the door as you drive away, after an afternoon, is yeah, that makes you feel good, makes you feel you've really contributed somebody's happiness.*

Both these stories show how Mike is helping not only Tom, but his wife Edna, and contributing to Mike's own wellbeing. The stories about checking with the coordinator show how Mike appeared to feel that he could not make these decisions himself. However, the coordinator appears to be letting him use his own discretion. This flexibility may reflect the rules and beliefs of the particular hospice about what volunteers should or should not do in their role. The fact that the coordinator themselves is a volunteer and may therefore feel less constrained than a paid member of staff, might also be an influencing factor, a factor I discuss further in Chapter 7. Mike did keep in touch with Edna, but appears to struggle with how to end his relationship with her:

> Mike: *I phoned Edna once more after the funeral, I didn't say I wouldn't phone again, but I implied, and I haven't phoned and she hasn't phoned since. Not easy that exit, not easy. But I felt that well, that no, in that we know that people are close to end of life, I hadn't seen the relationship developing, and particularly with Edna, how, and how that might come to close.*

Although Mike was advised to use his discretion earlier, a lack of guidance or preparation may have contributed to his concerns about how to end his relationship with Edna. Mike was also surprised how his visits had become connected to his own family:

> Mike: *when he* [Tom] *died, my wife and I went to the funeral. Because one of the things I hadn't seen coming, was that to get involved with this, they become part of my family. Because I come home on a Thursday, and my wife says "how did it go"? And then you get to tell stories, and for example Edna and Tom had a tortoise, who would walk up to you in the garden. And not exactly head butt, because he would tuck his head in, but would shell butt your shoe to say hello. Anyway things like that you get to share, then our children are in their twenties and making their way in the world and say "what have you been doing" and then it becomes "how was Tom this week?"*

Mike did not seem to express concern about talking about Tom with his family, or taking his wife to the funeral. This contrasts with Tina and Nina's story described later in this chapter, who did not feel they should talk with family or friends about the people they were visiting.

Sarah's story had similarities with Mike's, in that she, too, felt the hospice rules about relationships to be slightly 'over the top', but she described how she managed them by making her own decisions. Sarah was a retired teacher, drawn to volunteering because she felt there was a need to support those caring for people at home. Sarah had had seven years of experience of hospice community visiting, and started with a story of how she had been to the funeral of a woman she had visited for almost two years and felt she "*maybe, in some ways got a little bit too close*". Sarah talks more about this 'closeness', as she felt the person she was visiting was someone, in different circumstances, she would have become friends with:

Sarah: *We went through some very great highs, and some very very low lows. But most of the time, it was just like a couple of friends like. She, I would go round to her house, or we'd meet for a coffee and we'd have a chat about things. And she would say "God I haven't thought about it, you know it's great, I haven't thought about this for", so you know it was a very rewarding"*

So yeah, she definitely enhanced my life was, it was, it was kind of, there was a friendship with someone that I probably would never have met in the course of my life.

Hospice staff expressed concern about the length of their relationship and asked Sarah *"maybe, maybe we put someone in too soon?"* So Sarah asked the woman she was visiting:

Sarah: *I said to her one day "do you think they put, you know, do you think it's too soon?"* [The woman's response] *"It might have been too soon for them, but it was exactly the right time for me".*

Sarah also felt the hospice worried about looking after her as a volunteer, commenting that "*they're very good at protecting us*", but felt she could look after herself:

Sarah: *in all honesty, because you know I'm quite a strong, might only be little, but I'm quite a tough little thing. And I've, I've learned to protect myself, and I kept sort of saying "I'm ok, if I'm anxious, if I'm worried, if I'm upset I'll ring". And there is always somebody there on the end of a phone, and you can always go and talk to someone if you like, I think they probably thought that I might be blurring boundaries.*

I can't see how you can spend that amount of time with someone over that length of time and not become friends unless you absolutely hate each other and then you wouldn't spend that length of time, because someone else would go in. So we know, we sort of probably did.

Sarah's story shows the differing beliefs held by Sarah and the hospice; the hospice perhaps holding a belief that a longer-term relationship might end up in 'blurred boundaries' with a potentially negative impact on Sarah's wellbeing, in contrast to Sarah's belief that the longer relationship was part of their friendship, and this relationship was a source of pleasure to her, and that she felt able to look after her own wellbeing. This sense of personal pleasure was part of many volunteers' stories.

Sarah had a different relationship with hospice rules from other volunteers, who felt they needed to adapt and adhere to the rules. Sarah reflected "*as much as there are rules, I would say they're guidelines*". For example, Sarah said, "*you know, we're told not to share anything about ourselves*," however she went on to say:

Sarah: *as I suspect I break the rules a little bit* [laugh] *so I try not to, I leave that one, but I do think when I had, we had a little appraisal, which made me smile, but off I went and I did say, "I can't sit and have a conversation with someone and go and visit people week after, and in some cases month after month, and in one case year after year, without their knowing a little bit about me".*

Here Sarah feels able to challenge the rules set by the hospice, although she admits to avoiding topics in supervisions that are against the rules. Sarah's story at times seemed to be defending the position she had taken in response to the hospice's rules about boundaries. Sarah may have felt that I would have expected her to stick to the rules and therefore she needed to explain herself. It is not clear from the interview why Sarah felt able to challenge hospice rules; it may have come from experience as a teacher, or her own belief system about rules. Sarah's belief that she could look after herself may have also made her less reliant on the hospice for advice and support in her volunteering.

Mary's story shows how she is beginning to think differently about her relationship with her client. Mary, like Sarah, also talked about 'blurred boundaries'. Mary was a retired teacher who had had many years of experience volunteering with a variety of organisations and was drawn to community volunteering after her son died. Mary talked about visiting a woman with Motor Neurone Disease (MND), who lived alone, was of a similar age to her, and also had a teaching background. Mary reflected that she went into volunteering thinking "*things were going to be short sharp chunks*", but she now imagined that she would be visiting this woman for much longer, and this was making her question her role and how the boundaries between them were becoming a "*little more blurred*". Mary explains:

Mary: *I think for the other clients, because I've known they, that they've a terminal illness that **may** [emphasise] cause them to not live very much longer, I've been able to interact with them hopefully the level they wanted and I wanted, but then put it away and come away and, you know bring it back to the front of my brain on the next visit sort of thing, whereas when something's more long term, it's not that I come home and think about her a lot. But there are situations, where I think, oh I must tell her about, you know, like you would with a friend.*

Here, like Sarah earlier, Mary describes how the length of time could change the relationship. In her stories about her other clients she talks about '*interaction*', but with this client she talks about '*friendship*'. Later in the interview I was curious about the '*blurring*' and asked her to say more. Mary said that should she ever stop volunteering, the woman with MND was "*a person that I would want to carry on seeing*" and "*she was someone she would have formed a friendship with*". Mary talks about their friendship:

Mary: *I think you have to be careful not to become a friend too soon, I dunno if that's the right way to put it. I want her to feel she can talk about anything. But I don't, but I think if you became too friendly too soon, you might almost push her to talking about things that she may not feel ready to do so. And also with friends you obviously share a lot more of yourself. And I think that is an issue with volunteering how much of yourself do you share.*

So I tend to, sort of have said perhaps a little bit more than I would. But obviously, you still hold you know some things back. Because I've had cancer myself, I've lost a child. Those are my problems. I don't want to, I don't want to offload them onto her as you would with a friend.

> *Yes I think there is still a boundary, isn't there. I think where, you know, because she's vulnerable herself, and you relate, well, to her. I think it would be, easy to off-load some of your own issues, you know, on her. Which I don't need to do, as I have a supportive network. So, you know, that's fine. So I suppose I do stop the friendship bit there, and just tell her, you know, the basic facts, if she asks. But I don't go into any, you know, any sort of detail yeah. But I'm, but not sure if I saw her for the next three years, whether that might, might change.*

In contrast to the previous section, where volunteers saw the purpose of rules was to protect the volunteer, here Mary sees the rules as protection for a vulnerable client. Mary appears to be exploring some of the, what might be described as more *covert,* rules of her relationship. The belief that appears to govern how Mary perceives the boundaries in their relationship, is that she sees her client as 'vulnerable' and perhaps in need of protection; that being too friendly might push her client into talking about things she is not ready for; and this also means that Mary should not share some of her own problems, which might add to the client's burden. It is not clear if these unwritten rules have come from the hospice, or Mary's other volunteer experience or her own professional background. However, Mary does appear to use the space in the interview to reflect on how this might change in the future, suggesting that the rules she is currently using are not fixed. My own reflections on the interview made me want to know if Mary's client would have described herself as vulnerable and needing protection.

Some volunteers expressed little concern about being friends with the person they were visiting. Tina was drawn to community hospice volunteering after seeing an advert at the hospice shop. Tina explained how she hit it off quickly with Jane:

> Tina: *as soon as she picked up the phone, yeah we just honestly, we just got on like a house on fire, she was so jovial and fun and yeah, she was just absolutely gorgeous. And then the first time I went round there, we had a laugh, we had a chat, we just became friends straight away.*

Unlike other volunteers who were concerned about sharing personal information, Tina told:

> Tina: *it got to a stage, where we became, we'd send each other Christmas cards and presents and she met my kids just outside a couple of times.*

The fact that Tina had had no previous experience of hospice care or volunteering may have made her feel freer to develop a close friendship. When talking about the *"dos and don'ts"* she worried that she might get *"too close",* but reflected *"that's my nature, I can't really help that".* Tina did find it difficult that she could not talk about the people she visited, because *"it's sometimes good to have an outlet, just have a chat with a friend".* Like Mary and Mike, Tina found that the people she visited "*they become part of my life*".

This section has seen how longer relationships, shared interests and backgrounds can contribute to the formation of friendships and how these friendships become part of the volunteers' lives and families. It has also highlighted the different beliefs about the formation of friendships, and how hospice staff appear to be concerned about volunteers getting 'too close' to the people they are visiting. Volunteers themselves also express similar concerns and use language about the 'blurring of boundaries' and getting 'too close'.

6.3.2   Using professional beliefs

The next group of stories demonstrates how volunteers drew on beliefs from their professional backgrounds to manage relationships with the people they were visiting. Sabrina, who was a retired nurse, spoke of how her "*nurse's hat*" influenced how she thought about what you should and should not do as a volunteer. However, Sabrina felt that her "*nurse's hat*" was not always "*a good thing really*", as she sometimes wanted to know more about what was wrong with a patient than she was told. When talking about relationships Sabrina explains:

> Sabrina: *my own feeling on that is it depends how close your relationship was with that person. If you have got a close relationship, I feel that you should be there as a friend rather than a hospice visitor.*

Sabrina told of a family that had asked her if she would be one of the people that could be rung if their lifeline alarm went off and she agreed "*but that was when I said I'd rather go back out from the hospice side of it, and just go and see her as a friend*". Sabrina seemed to believe that being on call for the alarm was something a friend could do, but not a volunteer, so she stopped visiting as a volunteer and carried on as a friend.

Sabrina's story was very clearly linked to her nursing background and the interview included stories from her nursing career. She may have felt that I expected this perspective from her, as she asked if I "*was in charge of a hospice*". Sabrina's stories were more about sitting with people rather than developing friendships. Sabrina explained how she thought that patients should save their energy for family and not "*do small talk with somebody they didn't know*". For Sabrina, holding these boundaries may have meant that she was holding on to her '*nurse's hat'*, a '*hat'* that had been very important to her for many years, even though she had been retired for some time.

Nina compared her experiences as a volunteer to when she worked as a social worker. She started by explaining how she had "*missed going into people's homes*" and felt volunteering would help "*keeping my hand in, keeping the skills going*". Unlike other volunteers who were matched because of similar interests, Nina felt that she was matched because of her skills as a social worker, and admitted that she could not turn off her "*social work eyes*" as she was always on the lookout for risks and safeguarding issues. However, her '*social work eyes'* did not stop her sharing of herself with patients. Nina, like Scott, talks about trust:

> Nina: *it's about the trust and the confidentiality. I think it's the trust at the end of the day, that's the key one, and you can tell them, they can ask you about yourself and your family. That's the other thing that makes a difference, and some people feel not comfortable to want to tell anybody something, that's up to them, I mean I'm a boundaried open book, as they say* [laugh]. *Like, she got to know that my dad is sick, and I'd be going up, and she'd be saying "how's your dad" and things like that. Which somebody, as a professional, might not want to do.*

Nina then reflected that how she shared with patients was less about being a 'volunteer' or a 'social worker', but more about how she had always worked:

> Nina: *and I'm thinking to myself, is that different as a volunteer, or is that just me? It's making me think, now have I always worked like that, and I probably have. Yeah if it was mental health, I'd say "yeah my brother is mentally ill".*

Nina found defining her role difficult:

> Nina: *we have to be careful to say 'befriender', because then we're not a befriender service, 'cause there are befriender services, and that's when you start thinking, it does make you sort of think, how do we define ourselves?*

Despite not using the word 'friend', the relationships she described seemed quite close, one was a "*lovely relationship*" where they cooked together and shared family recipes. Nina initially explained that she was drawn to volunteering so she would be "*freer*" and *"less caught up with the boundaries and the limitations of your employer, in how you might do something"*. But her stories included how she tried to manage the boundaries of her work as a volunteer and what she could tell people:

> Nina: *I mean this is an interesting one, the boundaries of keeping things inside the organisation as a volunteer, what do you do? And I thought this is tricky and I do need to talk about it, and I did talk to a friend about it and we're allowed to, anonymously not use the name, and not give too much away.*
>
> *But if you feel there is somebody or your partner or whoever, that you just say, it's like coming home you say "my God, that day I had this happen" and they're never ever gonna know or meet that person.*

> *But as a volunteer it did bring up, all that you're not, you shouldn't even talk to your family about it. And some people don't at all and some people do, and as volunteers we, you know, share with each other that we do break boundaries*

Here, Nina's need to talk things through seems stronger than her belief that the rules needed to be kept. This connects with Scott's story earlier, who also did not always stick to rules because they did not fit with his beliefs. Nina also mentions this covert rule amongst volunteers that they frequently break the 'rules'.

Nina also had experience of being treated differently as a volunteer. She felt paid staff had "*an attitude towards volunteers*" and felt it was a type of "*professional snobbery, for want of a better word*", stating that she thought some paid staff felt:

> Nina: *volunteers are just people who are stupid, or don't know anything or old biddies just passing their time, or young people who don't have enough life experience and it's quite a putdown, dismissive attitude*.

The stories above show how some volunteers had a flexible approach to the boundaries with the person they were visiting, even when the hospice (as in Sarah's story) might have been seen to have quite rigid boundaries. What influences their different responses to hospice rules varies between how the rules do not match their own experience (as in Scott's and Sarah's stories) or their own personal professional beliefs or ways of working (as in Sabrina's and Nina's stories). The relationship hospice staff have with the volunteers as described by Nina, may also affect how volunteers respect the rules set by staff and feedback to them, a theme seen later in Anita's story. These different ideas will be explored further in Chapter 7.

6.4 Adapting to the hospice system

This section explores stories from Brian and Anita who felt they needed to adapt their relationship with the dying person, and their role, to align with hospice rules and how they felt about this adaptation. Their stories are explored, examining where the belief systems that may have influenced their adaptation might have emanated from.

Brian's story was about frustration. He started his story by saying how his interest in dying and bereavement began as a student nurse and continued during his career in mental health. When he retired and came to volunteer at the hospice, he felt "*they were quite keen to have me anyway, because of the vast experience I'd had*". In reflecting why Brian was telling this story to me and in this way, it seemed he was setting the scene about his experience and portraying himself as an experienced clinician who was wanted by the hospice.

When talking about the visiting he had done in the community, it was mainly in a "*sitter role*" to give the relative a break. He told of one man he visited where they shared a great interest in sport and how they "*clicked straight away*". He visited for over a year and it was "*lovely, absolutely lovely, that's that's the real business of people looking after people*". But he still felt frustrated that his experience was not being used, as he wanted to be involved with 'talking' with people about their issues, as he describes:

> Brian: *If they are feeling, "I know he pretends to care for me but a bit me tells me that he doesn't", you know that's food and drink to me I'd love to get stuck into that.*

His frustration was related to hospice rules about what he could, and could not, do. Brian reflected upon why he could not do certain things and how he understood and coped with it:

> Brian: *I am constrained in what I can do, and there are times and I can see something or other, and I would love to be the one who took that forward, in a clinical way or whatever. And I can't do that anymore.*
>
> *So it's understandable really, that I experience a lot of frustration in situations like that, because there's a lot I could do, that I can't. However, what I do, is turn my mind away from that quickly and try to look at what I can do, rather than what I can't.*

Brian's story of frustration appeared to centre on his experience that his skills were wanted, but were not being used by the hospice, and that clinical work should be done by paid staff. Brian's stories might be seen as a form of persuasion for readers or listeners to understand his potential value as a volunteer to the hospice. Brian might have hoped the story he was telling may have had an impact as a vehicle for change. All of these factors may have contributed to Brian perhaps thinking that, by telling his story, I might have some power to influence change and relieve his frustrations.

Unlike the stories in the previous section, where volunteers did not always follow hospice rules, Brian's response was to adapt to the hospice system, even though it caused him frustration. Brian's own belief systems about hospice rules may have been influenced by his own professional belief systems, that one should follow the rules in a clinical organisation and respect clinical decisions.

Anita also told of how she had adapted to doing things in the hospice way. Anita's story began about how hospice staff supported her to care for her husband, who died at home. Later, when she retired from administrative work, she chose to volunteer for the hospice, as well as some other charities. She describes the training:

> Anita: *very enlightening and it was very very different from what I expected, as for a lot of the others, because I had done work in the past for another charity, and visiting with the hospice was different, because you're restricted*.

These restrictions meant that volunteers were not allowed to do anything that was medical, nor tidy the house for people, nor answer the telephone. The reason for not answering the phone was related to confidentiality, as Anita explained, "*just in case that person doesn't want a member of the family knowing that they've got somebody from the hospice going*". Hospice volunteering was very different from her experiences with another charity:

> Anita: *one of them in particular, I was, I befriended for about nine years and I became her power of attorney, because she was on her own then, and I used to do her decorating and gardening, take her shopping*.

Several times Anita explained how she had come around to the hospice way of doing things, which meant not sharing things about herself, expressing opinions or giving advice:

Anita: *but it's not a problem, but it's very difficult I must admit I'm, I think I've sat with, well I'll go through the people I've sat with, but it's, it's coming home now. Because it's a natural thing, when you go there and people ask you questions. We are actually there to talk about them, we're there to listen to them...I won't say it's difficult, it's a technique in knowing. Because in the beginning, we all said, you can't just say to someone I'm sorry I can't answer that question, so as you go along you learn this technique. When I first did it I was, like before I said anything, I was thinking "can I say this?"*

Anita explained 'not sharing of yourself' was difficult, as patients and carers were keen to have conversations. Like other volunteers, Anita mentioned the rule about getting too close: *"a few of the volunteers they've had people die and they've got quite close to them, which you're not supposed to"*. Anita did feel at times able to challenge these rules and got permission from her manager when someone at a carers' group wanted to hear about Anita's experiences of caring. In my notes I reflected that if Anita had attended the group as a carer she could have shared her story, but not as a volunteer.

There were several moments of laughter in the interview, often about the hospice rules. There seemed to be in-house jokes that were shared with other volunteers, about what you did and did not say in supervision. One story was about when she visited Kate, at Easter, and took her some daffodils, which Anita said is "*not really the thing you do*". A covert rule that was shared by the volunteers was that there are things that you might do when visiting people, but you do not mention them in supervision. Anita tells her story:

Anita: *So all the way to the hospice I had this little joke with myself, don't mention the daffodils, don't mention the daffodils, whatever you do Anita don't mention the daffodils. So what do I do. I said oh I said,* "Kate 's deteriorating *and I said it's getting to a point now where she can't go to the toilet", da de da de da, "but her husband's arranged for, if she needs the toilet while I'm there I pull the cord, and one of the carers comes to take her to the toilet".* [Her manager]. *"Oh well done Anita yes that's good, that's how it should be". I said* "so we went we had a nice chat, I took her some daffodils" [laugh].

Her face [laugh] *and they all went like this at me* [raises her eyes] *well "it was Easter", I said, "and she needed cheering up". So the week, two weeks before then, I'd been on holiday and I'd taken her my holiday photographs. But I didn't tell supervision that I'd taken my holiday photographs. 'Cause we're not supposed to talk about ourselves in that respect. But I sit with Kate for two hours, she doesn't see anybody else. And when I'm there she likes to know what I've done. Where have I been, and that sort of thing and she was, and John* [Kate's husband] *said "she loved your photographs".*

Anita felt she held back from telling her manager about the photographs, because "*she would have probably said that could have upset her, because I'd gone on holiday and she can't*". But Anita, in perhaps trying to justify her actions to me, told how Kate was not upset, and Anita was able to "*suss a situation out*". Anita frequently explained why volunteering must be like this and spoke strongly on several occasions that "*advice*" was only to be given by professionals, that volunteers should be "*impartial*" and she was "*not the expert*". Anita then told of how she made sense of the rules:

Anita*: you know giving advice or getting involved in that way, it's very easy because I've gone through it with my husband and my sister. I'm thinking, oh remember Anita you can't give advice, because he might say to the nurse, well Anita from the hospice says, and you know, the nurse will say, hang on a minute.*

I think, they, there's a line there, and you don't cross it, you don't cross it this much, that much or just this much. [Used a line on the sofa, and put her nail across it in varying degrees]*. I feel that anything that's untoward you have to report back immediately, for safety, for yourself. And I'm, I'm beginning to realise, and I have to say to myself when I go to visit someone, I'm not their friend, I'm a representative from the hospice and that's what it all boils down to. Because it'll all come back, that lady from the hospice came. Now they'll forget, they won't know if it was a nurse or a volunteer or what, so I have to be careful.*

Anita later told a story where she felt she had got it wrong in the eyes of hospice staff and even considered stopping volunteering. She was asked to visit a gentleman in a nursing home. The first time she visited, she found he was in a wet bed and eventually the staff came and changed him, but she noticed other things as well:

Anita: *his curtains were drawn too, it was very dark in the room. The television was on, but the remote was over there somewhere. He was very uncomfortable, he was laying 'like this' in the bed,* [demonstrated a curled up position on her side]. *And I just wanted to get hold of him, squash his pillows, and cosy him round, and put his covers up. You know his hair wasn't, his hair was lank and greasy, he hadn't had a shave, he looked dreadful.*

So she left, and sent in her report to the hospice explaining he was wet, but the second time she went it was just the same, and she also noticed that his medication had been left and there had been no attempt to feed him. As she was worried, she went straight back to the hospice to report to her "*boss*" and seemed surprised at their reaction:

> Anita: "*the reaction I got was, "why didn't you mention this before"* [raised voice]. *I got this "well it's his choice, if he doesn't want to eat he doesn't have to eat, that's his choice". So I thought "well, does he not want to eat, or can he not eat", that was my reaction. Not, "he's chosen not to eat, so that's his choice".*

> *Then I said about the medication I said the medication was there, the nurse came in, put the medication on the trolley and put the tablets there, and walked out.* [Manager] *"Well if he doesn't want to take them", and I thought ooh you know I'm at the wrong angle here*.

Her report resulted in changes and she did see his care improve, but she compared how she had cared for her relatives, by encouraging and tempting them to eat, to the contrasting opinion that not eating might be someone's choice. Anita told how the experience had upset her, so she asked her manager if she should stop and was told "*no*". The experience seemed to stay with Anita:

> Anita: *I looked back on that loads and loads of times and think right did I fail, did I look at it from the wrong point of view, you know because I did feel that, I don't say I got a telling off, but it wasn't very pleasant*.

Anita explained that some rules were there because the hospice feared that people might "*put on you*" but Anita felt volunteers could manage such situations themselves, as she explained:

> Anita: *well you're an adult, you know when they're putting on you, or anything. But you haven't to give them that opportunity, to put on you, so you have to turn round and say no, I'm sorry I can't.*

Anita's story about her distress at getting it wrong, alongside her stories of how she had cared for people, were perhaps in part giving some defence to how staff treated her. Her distress may also have been compounded by the fact that she felt herself to be a caring person with some experience and that her knowledge did not seem to be recognised and was even criticised, leaving her feeling that she had failed, which she found upsetting. Anita's stories show how the feedback she received influenced how she behaved and responded. The feedback from her 'boss' about 'getting it wrong', as well as the responses to the stories told in supervision, may have led her to withhold some aspects of what she did in supervision. The rules and the hospice way of doing things may have played a strong part in influencing her stories. Her own professional background, working in administration, may have also contributed to her inclination to stick to the rules and agree with the reasons behind them.

Anita's repeated expressions of support for doing things the *'hospice way'* may have been influenced by a wish not to be disrespectful to the hospice and her stories may have been intended to demonstrate that she had adapted. Her gratitude for the support the hospice had given her in caring for her husband may also have contributed to her belief that the hospice knew best. Anita did not say to me overtly in her story that she wished it to be different, quite the reverse: she appeared to be trying to say how she had accepted the hospice way of doing things. Perhaps in telling the story she was trying to make sense of this adaptation. She may have thought that as a researcher or hospice manager I would have expected her to adapt and maybe she felt the need to persuade me that she had. However, her use of humour to challenge some of the rules showed how her acceptance was not complete. My smiling and laughing with her during the interview may have given her feedback that I was not discouraging her from telling such stories.

In contrast to the stories told by the volunteers who were able to manage their relationships with the people they were visiting and how they did not always comply with hospice rules, the volunteers in this section told stories of frustration and needing to adapt to hospice rules. These stories show how the feedback that volunteers received from hospice staff, and the belief systems held by the volunteers, contributed to how the volunteers managed their relationships with the people they were visiting. These results will be discussed further in Chapter 7.

6.5 Changing beliefs about life, death and grief

In Chapter 2, it was suggested that as a society we have become less familiar with, and less confident about, death and dying. This chapter explores some of the volunteers' stories about how their experiences changed the way they thought about life and death. The stories often included what volunteers had learnt from the people they visited:

> Scott*: I've been amazed by how strong they are, how accepting they are of their position, and again it makes you think would you be like that? I enjoy my health, I enjoy going walking, cycling whatever, would I be able to accept it as easily, and maybe by seeing these people it could help me in the future.*

Scott's surprise suggests that he expected dying people to be different, that he may have expected them to be not accepting or less strong. Other volunteers, such as Jenny shared Scott's perspective that seeing other people dying could make you think differently. Jenny explains:

> Jenny: *you know I think the biggest thing about what I've been doing, is just seeing that we're all, you know we're all people, it's not them and us, and sick people and healthy people.*

Some participants thought that hospice work might help them to reconcile how they thought about death. Tina linked her fear of death to losing her mother when she was young:

Tina: *been really scared of it and I'm thinking to myself in retrospect is that kind of what drew me to the hospice, I'm wondering whether subconsciously something was drawing me to it, to sort of make me address the issue and face up to it in a way*

Christine had been drawn to hospice volunteering because of a personal experience with another hospice and a wish to keep busy while she was taking a career break. Christine initially doubted whether she would be accepted as a volunteer because "*I was on antidepressants, 'cause I just thought do you know they might think, don't really know, you're going to be alright for this*" and she had experienced two deaths the previous year. When interviewed for the role she made it clear that she did not really want to be around people when they died. This belief was explained later when she talked about how she "*had only ever had my own personal grief, which has completely affected me*". Christine began the story about Fred's death:

Christine*: my daughter had a party in town and so I dropped her off and I knew Fred was in the hospice and I thought I can't drive past without going to see him really, it was a Saturday, I thought I'm just going to nip in and I got there and his breathing was very laboured. And I kind of, I have been around that kind of breathing, so I sort of recognised what was happening and I stayed there for a little while. And I thought I can't, I need to step out for a minute, so I went into the chapel and I lit a candle, and I grabbed one of the crosses and just said a little prayer and I took it back into him.*

Here, Christine sets the scene explaining why she was there, that he was in her thoughts. Her story shows how she was thinking through whether to be there or not. Christine then tells of Fred's death, which happened ten minutes after his wife arrived:

Christine*: I did feel, I got upset, I don't think the hospice staff didn't really know who I was at that point, and so yeah they sort of put their arm round* **me** [emphasise] *even, and I'm thinking oh crikey I don't feel very professional here, it's not how I'm supposed to be, 'cause I just didn't, you know, and this is from me going meeting Joan* [the volunteer manager] *in the January going, I really can't be around somebody when they're gonna, you know. So anyway we then had tea and coffee there at the hospice and they were lovely, and it just felt completely right to stay there with Margaret, I'd rung my husband and I'd explained what had happened, my daughter's being picked up, I said, I don't know how long I'm going to be, he said "that's fine don't worry" and so I ended up ringing the funeral directors for her while we were there and we sorted that and then obviously I drove her home."*

The way Christine spoke about the support offered by hospice staff was as if she was almost apologising to me, maybe thinking I would have expected her to behave differently – perhaps more professionally. In telling this story, Christine perhaps sees herself in a different light compared to the person who initially did not want to be involved with death. Her fear of being around death may have been related to her previous experiences, but those experiences may also have prepared her for what dying looked like. Christine then talked about how she felt about Fred's death:

Christine: *it had brought me down a little bit, but also feeling very privileged to have been there you know because I've been around a few people when they've died and I do think it's an, immensely, a privilege to be there when somebody passes away. So yeah, I think I kind of had to have a little bit of a chat with myself after a couple of days and just sort of think, right ok now can I continue, can I actually continue being a community hospice volunteer? 'Cause this was the crunch point, you know, as to whether 'cause if it's going to affect my home life I then couldn't continue…*

So I then came to the conclusion that when I went to the funeral I didn't wear my badge, but my next visit after that I had my badge back on and I then became I had more of a professional, I was back into that, so whilst I did grieve and I did care, I guess it's probably what nurses go through in that way, is that you have to then, it's not that you don't care anymore, but you have to draw a line in order to start keep helping other people and that was very new for me, because I had only ever had my own personal grief which has completed affected me, so yeah that was a big learning curve but actually a very, very valuable one.

By calling this a '*crunch point'* Christine seems to mark it as a pivotal moment in her story, as well as seeing her experience as a "*learning curve*" to find herself experiencing grief differently. In answer to my question about how the experience had made a difference to her, she felt it had made her look at death slightly differently:

Christine: *I guess it's not quite as scary as you think it could be, and as I say, putting people at ease where you can, as well, and their relatives as well as the person..I have I mean I'm not on anti-depressants any more I mean I stopped them I was on them for about 18 months, but it's I think it's helped my own well being.*

Here, she is coming to the end of her story and demonstrating how she feels she has become more at ease with death and dying than she expected. Like other volunteers, Christine uses nurses as an example of how to cope, perhaps using a belief that you cannot get too involved if you want to help people, yet it does not stop you caring. Christine was perhaps holding a worry that volunteering might be damaging to her, as previous grief had affected her. Taking the badge off seems to represent separating herself from volunteering and being herself. Christine's story connects with other stories earlier in this chapter about how friendship and volunteering cannot be combined. This finding will be discussed in Chapter 7.

Sarah told that it was being with her mother when she died in hospital that changed her ideas about death.

> Sarah: *I'd always been frightened of, of what dying would actually be. I'd never, never seen it. And so we were able to be with her and it was just the most peaceful. And I thought then, maybe it's the living that's the scary bit, actually the dying is not so it's not scary at all, 'cause she kind of slipped very beautifully, very peacefully away.*

Sarah also talked of how she had learnt to cope with death and spoke about the death of one of her first clients, where she had developed a sort of "*mother-son relationship*" with the client's husband, as he was about the same age as her own son:

Sarah*: I was absolutely distraught, stopped had a little howl in the car and then went round to see my daughter in law and she said "what's the matter" I said "oh nothing" "come on" so I told her. And then you kind of and this sounds really awful, you get used to it. Because that's what happens and what you have to accept is that for the time that you've been there you may have made a positive difference and that's kind of all you can do and then you do learn to not become too attached to people.*

But I had a little bit of crisis of conscience, then thinking does that make me a hard horrible person, because I, you know, I'm spending time with these people and then the inevitable happens, and I can sort of get over it and move on to the next person.

Sarah felt helped by her "*very supportive family network*" and the hospice letting her take a break from visiting if she needed to, like Christine and Scott, Sarah used the example given by doctors or nurses in how to cope with the loss of people they were visiting:

Sarah*: I think a little bit like if you were a nurse or a doctor working in the hospice, patients die. If you're going to go pieces every time someone dies, you can't help the next person along. So I've kind of, I don't think I'm hard at all, I still cry with people, but I, I can, I've learned that when I drive away I kind of leave it there.*

Not all volunteers changed their views about death. Ron, had done different forms of community and pastoral visiting for many years, said, "*I view death as part of life, it's got to be*". Mary also did not think that volunteering had changed her attitudes to death and dying but said, "*it's enabled me to be more accepting of it, it hasn't come as a big shock*", although she admitted that she found she had been thinking more about the future death of the woman with MND and what might it mean. This was similar to Tina, who spoke of her sadness when Jane died. Tina thought she would be "ok" because she had "*had so long to prepare for it*":

> Tina: *but then she died and it was pretty sudden in the grand scheme of things, and I was I was absolutely devastated* [laugh] *so that was a bit of a shock to the system but the hospice was good.. they made sure I was alright*

Sabrina gives some insight into she coped with death as a nurse:

> Sabrina: *because I'm a trained nurse you tend to be able to sort of compartmentalise things a little bit .. just without thinking of it, you put that little shield up, I don't know it's hard to say, and you try not to get too close to them.*

Nina also spoke of going into *"professional mode"* when she was with someone who died. This type of compartmentalisation could be seen in Christine's story when she talks about taking her badge on and off, and reflects what could be interpreted as a professional belief that you should not get too close to patients.

These stories show how volunteers coped with the deaths of the people they were visiting, and how being with dying people was inspiring. This suggests that telling such stories about their experiences is creating new narratives for volunteers about dying and death. The stories also show the extent to which some of the volunteers used the hospice staff for support, and how volunteers such as Christine, Sarah and Scott drew on the example of how doctors and nurses behave when coping with death, to be able to leave it behind and move on, as if this gave them a 'professional' way to cope with death, an idea which will be discussed further in Chapter 7.

6.6 **Reflections**

My own reflections about the volunteers' stories found that some of them affected me more than others. I was moved by Anita's story, feeling sympathy and frustration for how she felt the need to adapt to the hospice way, and how her voice had not been heard by staff. Her story perhaps realised my fears, that hospices could be enforcing rigid models of practice and not listening to volunteers' perspectives and feelings. Although her story was not replicated in the same way by other volunteers, I felt strongly that there were aspects of her story that I, as a CEO and as a researcher, should listen to and learn from, so her voice was not further marginalised.

6.6.1 Reflections on the methodology

The inclusion criteria and purposeful sampling enabled a wide range of volunteers to come forward. However, those that had only made a few visits to people at home found they had little to tell, their stories being focused more on becoming a volunteer and the training they received, than the experience of visiting people at home. Adjusting the criteria to include volunteers who had made a certain number of visits may have prevented this. This also connects with previous studies which stressed the impact of a longer-term relationship (McKee et al., 2007; Walshe et al., 2016). Widening the criteria to include the coordinators of the volunteers might also have given a different perspective and understanding about hospice rules and boundaries, and may have highlighted differences between paid and volunteer coordinators. Whilst criteria to identify urban and rural volunteers had been used, there was no difference found in the stories between those working in rural and urban locations.

A narrative approach enabled the volunteers to tell stories which were important to them and the dialogical analysis enabled me to keep the voices and stories in their entirety as stated in Chapter 4. The challenge of narrative interviewing, which I raised in the Chapter 5, is a balance between letting the participants tell their story and meeting the objectives of the research (Wengraf, 2001). I struggled with how much to control the interview with Brian to keep it within the terms of the research. I highlighted in the methodology Mishler's (1991, p.74) recommendation to let the participant "hold the floor", so whilst I felt initially that I had let Brian talk perhaps too much about what was important to him and too little about visiting people at home, I recognised later that I had opened the 'floodgates' as described by Rubin and Rubin (2005).

I was frequently reminded of the literature about how using a narrative approach enables us to hear stories that are not accessible by a more structured approach (Charon, 2006; Greenhalgh and Hurwitz, 1999). When transcribing and analysing Brian's story, I felt that if I had constrained him I may have missed hearing the stories which were important to him and which had influenced his experience as a volunteer as his stories about his professional and personal life may have contributed to his experiences of being a volunteer.

As I explained in Chapter 5, some of the volunteers I interviewed came from my own hospice, which I had thought was not discouraging volunteers from developing friendships and getting 'too close'. But several volunteers, including those from my own hospice, voiced concerns about developing friendships, sharing telephone numbers, and uncertainty about what they could or could not do as a volunteer, suggesting to me that there are still beliefs in my own hospice which agree with Claxton-Oldfield, S et al. (2011a) that friendships should not be 'too close'. However, I became aware that it may not just be the hospice's beliefs which influence volunteers to think that one should not get too close to dying people. Volunteers may be drawing on their own beliefs and experiences about other volunteering, relationships or loss, and that getting too close may be too much to cope with or is not what they believe is expected of them.

6.6.2   My influence as the researcher

I am aware that my own beliefs that volunteers, who are visiting as 'friends', may be trusted to develop relationships that they and the person being visited feel is appropriate and that such a relationships need not be bound by professional rules and regulations, has influenced how I have analysed and explored the findings, and debated them in this thesis.

The insider/outsider dilemmas discussed in Chapter 4 felt present throughout the process. My reputation in the field helped me connect with some hospices and gain their permission to undertake research. I was most aware of my position within my own hospice, particularly when potentially interviewing volunteers who were known to me. I was aware that I might either constrain or encourage their stories because of our relationship and my knowledge about their work, yet by not interviewing those known to me, I might miss stories relevant to my research.

Whilst more informal dress may have helped in some instances to mitigate the impact of my manager role for volunteers, it was the power differential that I was most aware of. This issue of power seemed more relevant in the interviews than the issue of distress mentioned in Chapter 5. During the interviews I felt more concerned that I may need to give people permission to discuss matters they may have felt were about breaking rules and might have been reluctant to tell me. To encourage this, at times I asked about the sharing of telephone numbers and used humour to encourage them to tell their stories, as with Anita, which seemed to be effective. My role felt more present in the interviews with Brian, Sabrina and Louise. Brian's story was perhaps intended to effect some change for him personally.

6.7 **Conclusion**

The findings in this chapter give new insights into how volunteers experience visiting dying people at home and how it affects their attitudes to death and dying. My narrative approach saw three narrative threads emerge: *managing relationships*; *adapting to the hospice system;* and *changing beliefs about life, death and grief.* Whilst volunteer participants told how being with those who are dying can be *life enriching* and can make death *less scary,* their stories also included threads about adhering to hospice rules, needing to be professional, not getting too close and using the example set by doctors and nurses to cope with death.

The findings appear to demonstrate how community hospice volunteering, which primarily provides companionship and friendship, does not sit easily with a professional hospice system, which is heavily regulated. This clash of systems results in the volunteers needing to adapt, by balancing the rules in both systems, or finding themselves trying to apply the hospice rules with the person at home, which for some volunteers appears to cause difficulties. The use of systems theory has also highlighted the role of feedback and the findings demonstrate how some volunteers and hospice staff are stuck in patterns of behaviour, with volunteers not feeding back their experiences (because they are against the rules) and staff appearing to reinforce rules that volunteers are not complying with. The implications of these findings are discussed in Chapter 7.

7 Discussion – community volunteer visiting and the hospice system

In this chapter, I reflect on the research process and how this has given me new insight into the experiences of community hospice volunteers. This thesis began with my interest in wanting to understand what it was like for hospice volunteers to visit dying people at home. I was initially curious to understand their experiences and if being with dying people changed their attitudes to death and dying, I was also concerned that volunteers were being affected by increasing regulation. Examining the background and context to this thesis, and undertaking a systematic literature review, confirmed to me the potential growing influence of regulation on hospice volunteering, and a tension between the social role a community volunteer might fulfil and a requirement for them to be more professional.

The findings demonstrate how community hospice visiting appeared to enrich the lives of the volunteer participants and help some to feel more confident about being with dying people. Volunteers told how they learnt to cope with multiple deaths, at times drawing on the example of doctors and nurses. However, the findings also showed how volunteers struggled to cope with rules which often emanated from the hospice and often related to the relationships they formed with dying people. These rules appeared to result in some volunteers expressing concern about whether or not they could be a friend and a volunteer, that they needed to behave professionally; and whether or not they could share their experiences with others.

In this chapter, I draw on these findings to argue that the context of working with a rigid professional hospice system seemed to contribute to a poor experience for some volunteer participants in this research, as the rules of the hospice system at times clashed with a home visiting service based on companionship and friendship. I also argue that the findings indicate that a rigid approach to feedback between the hospice and the volunteer may also inhibit the opportunities for volunteers and hospices, to adapt and respond, to changing environments. I draw on systems theory to explore these new insights in greater depth, and discuss these ideas in relation to the literature reviewed in Chapters 2 and 3. I focus on factors which help understand the findings including: the context of the hospice and wider systems; dominant discourses that affect personal and organisational beliefs; and the importance of feedback.

Finally, I suggest that home visiting, which is focused on companionship and friendship, may require a more informal system and set of rules, negotiated between the person being visited and the volunteer. This would require hospices to be more flexible and responsive in how they work with community volunteers, trusting volunteers to be more autonomous. I discuss how using this alternative approach to working with community volunteers might help solve some of the dilemmas raised in this thesis.

7.1 Context and influences

In Chapter 4 I outlined how community hospice volunteers could be part of systems with hospice staff and with the dying person. I suggested that community hospice volunteers were likely to be defined as formal volunteers, as they could be seen as part of the hospice system and the findings appear to demonstrate that the home visiting service is seen as part of the hospice system (Figure 7.1). This supports literature which describes hospice volunteers as an integral part of hospice care and often playing a crucial role in supporting the delivery of services (Clark et al., 2005; Davis Smith, 2004). However, the findings demonstrate how the influence of a rigid hospice system can be detrimental to the volunteer participants' experiences and does not fit with a home visiting service based on companionship.

**Figure 7.1 Home visiting as part of the hospice system**
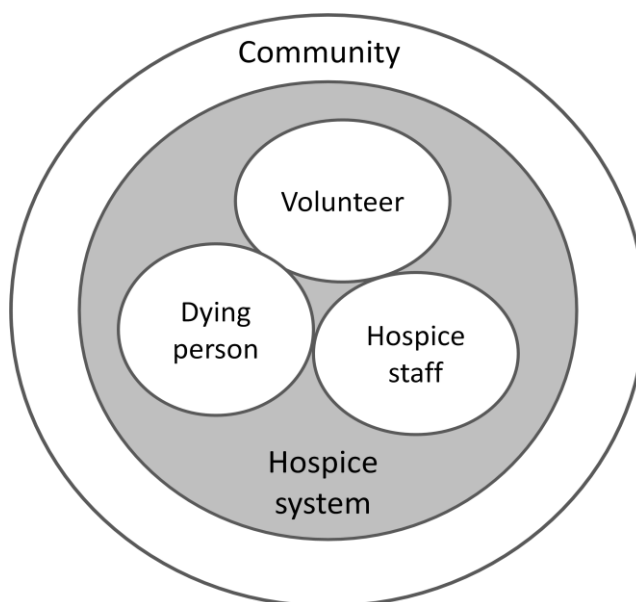
In the literature reviewed, authors did not necessarily portray volunteers as formally part of the hospice system, but instead described how the position of the volunteer varied in relation to their connection with the community, the dying person and the professional staff, from either being strongly connected to the community, as seen in the study by McKee et al. (2007), or in the middle, as described by Berry and Planalp (2009), Walshe et al. (2016) and Söderhamn et al. (2017), or connected to the professional team, as shown by Jack et al. (2011a) and Grant et al. (2011). The findings in this research did not identify volunteers occupying a particular position; instead variations were seen in how participant volunteers spoke of their different relationships with the dying person, professional staff and their own friends and family. The influence of rurality on how volunteers managed their relationships, seen in the reviewed literature (Grant et al., 2011; Jack et al., 2011a; McKee et al., 2010) was not replicated in the findings. There appeared to be no difference between the stories told by those volunteering in London and those volunteering in more rural areas. However, rural areas in this research were in communities that were probably far less isolated than those studied in Canada and Africa and the context of the extreme rurality may contribute to volunteers needing to manage friendship alongside volunteering.

Drawing on systems theory to examine how the volunteers in this research made sense of their different relationships provides a greater depth of understanding of the different beliefs that may be influencing them and, in particular the impact of the hospice system on the volunteers' experiences and behaviours. As Dallos and Draper (2000, p.99) explain: "like buying clothes off the shelf, we attempt to fit our experiences into the narratives that are available". These dominant influences will also affect the hospice system and staff, as they too may be fitting their responses into the narratives that are available to them. Figure 7.2 demonstrates the influences identified in Chapters 2 and 3, which I will be exploring alongside the key findings described in Chapter 6.

Figure 7.2 The impact of contextual beliefs and systems on volunteers' experiences
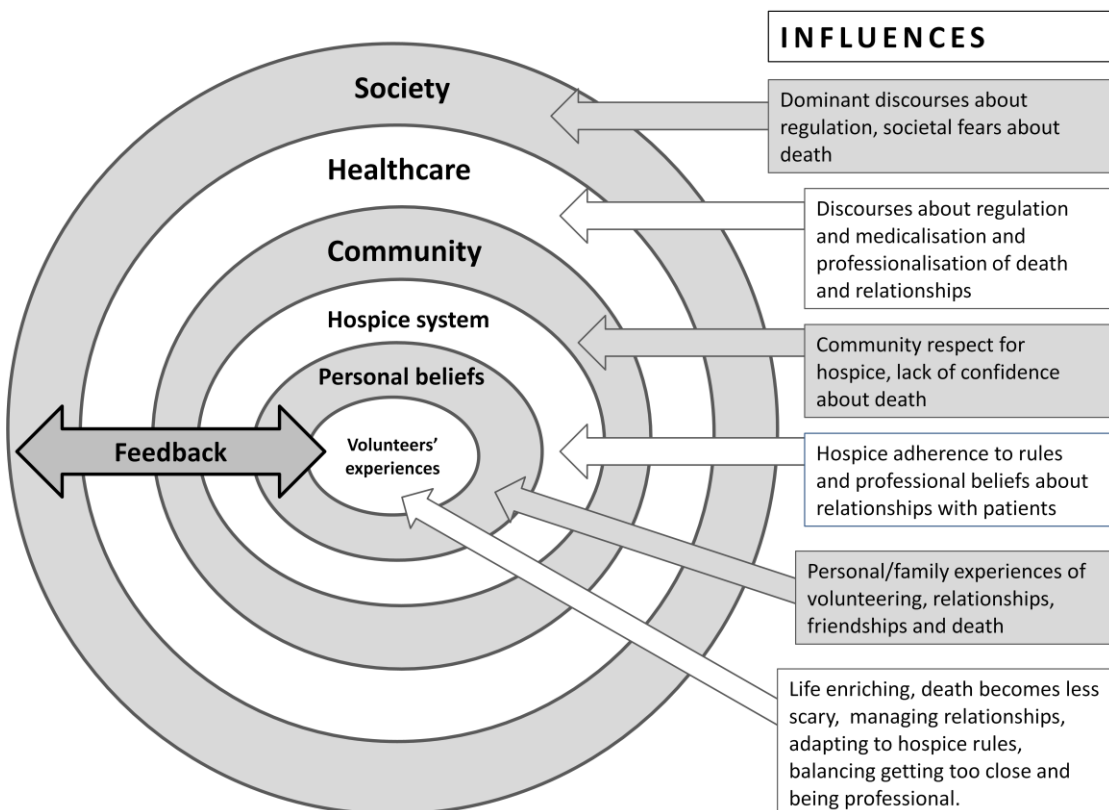
7.2 Influences on attitudes to death and dying

As I outlined earlier, one of my objectives for this thesis was to explore volunteers' experiences of being with dying people and how this affected volunteers' attitudes to death and dying. Whilst the findings show how the experiences enriched volunteers' lives and how they leant to cope with dying and death, their stories included concerns about getting 'too close' and needing to be 'professional'. In addition, some volunteers felt unable to share their experiences with, or seek support from, family and friends.

Many volunteer participants expressed surprise and pleasure at how good their experiences were. The belief that both the visiting, and coping with death, were going to be difficult may be reflective of the dominant discourses described in Chapter 2; that as a society we are frightened of death and have little experience of being with dying people (Department of Health, 2008; Howarth, 2007). It may also echo the professional discourses, relating to stress and burnout, which volunteers may have experienced as part of volunteer training, or ongoing support (Sanders et al., 2012). Although the volunteers were probably prepared for the death of the person they were visiting, the findings highlight how some volunteer participants appeared to think that being with dying people would be the same as a personal loss, and overwhelming. Therefore many participants expressed appreciation of the role of the hospice in preparing them to be with dying people. Figure 7.3 shows some of the perspectives seen in the findings.

Figure 7.3 Different beliefs about death
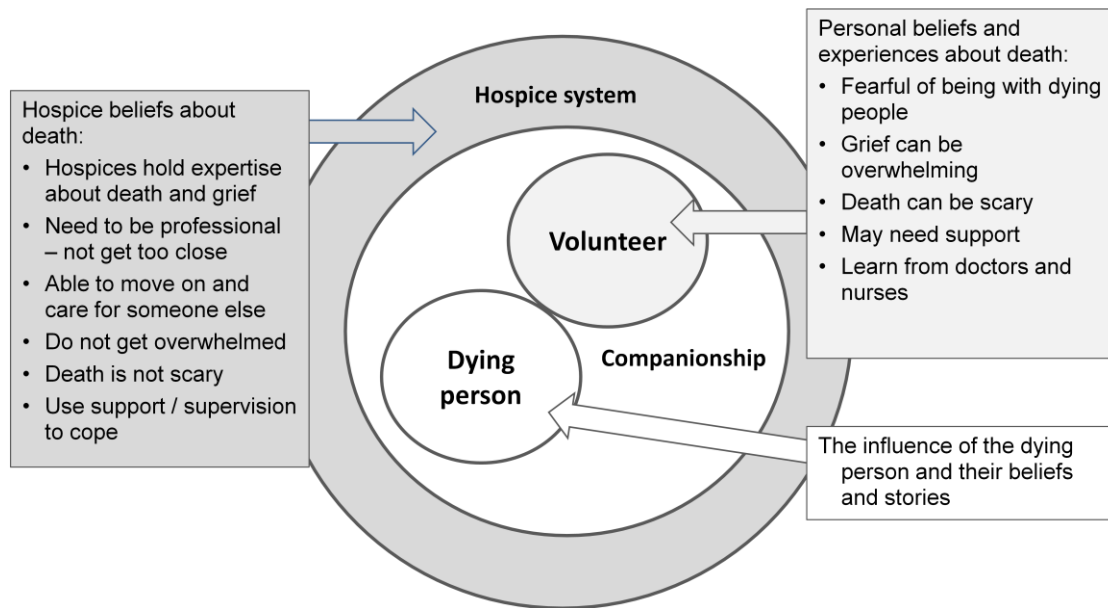
The additional factor seen in the findings was the influence of the dying person. Volunteer participants told how being alongside dying people gave them a more positive story about death and dying, and these experiences changed how they thought about life. The potential benefits of being with dying people were highlighted by a number of other authors (Brown, 2011; Claxton-Oldfield and Claxton-Oldfield, 2007; Cloyes et al., 2013; Guirguis-Younger and Grafanaki, 2008). However, in this research, hospice rules appeared to constrain the volunteers from sharing their experiences, and not all volunteers felt that they could, or should, share stories outside the hospice system.

The studies by Robinson et al. (2010) and McKee et al. (2010) demonstrate that volunteers appear able to manage to negotiate such dilemmas about confidentiality. However, Morris et al. (2015) suggest that hospice managers may be concerned about regulating community volunteer activity and therefore managers may be reticent to let volunteer make such decisions themselves. Stories have been used throughout the history of hospice care and can be powerful vehicles for change (Clark et al., 2005); however, constraining volunteers from talking about their experiences, may further contribute to the narrative that death and dying can only be talked about within the confines of a medical professional system.

The rule perceived by volunteer participants that sharing stories outside the hospice was not allowed also appeared to prevent volunteers from seeking emotional support from friends and family. Whilst some volunteer participants drew on their own informal network for support, as described by Macleod et al (2012), others told how they turned to hospice staff for support and guidance after someone had died. This could be viewed in several ways: that volunteers had a good relationship with staff and could turn to them for support; or that they needed to do so because using family and friends for support was not allowed; or that they felt that only hospice staff would be able to support them. Hospice staff may also have offered themselves as a source of support, which may have given the volunteers the impression that they should use hospice staff, rather than anyone else.

The need, as expressed in the findings, to be 'professional' in coping with loss appears to connect with the idea of not getting 'too close'. This need to be 'professional' could be seen to be a result of feeling part of a formal hospice system and having to comply with hospice guidance, or that volunteers may feel they need to emulate how hospice staff coped with death and loss. It is not clear from the stories where the volunteer participants acquired the idea to use the role model of doctors and nurses to help them cope with repeated deaths and be able to 'move on': possibly from their own experience of witnessing the behaviour of doctors and nurses, or from palliative care staff, or perhaps even from the seeing doctors and nurses on television. The stories of either being 'too close' or behaving 'professionally'; and 'following the role model of doctors and nurses' may also reflect particular narratives that are available to people when making sense of their experiences, as suggested by Dallos and Draper (2000). Although the volunteers did find this strategy useful in coping with multiple losses so that it need not be perceived as negative, there is a risk it perpetuates the idea that doctors and nurses are the experts on death and coping with loss.

These findings appear to strongly support the perspective, noted by Howarth (2007), that dying in the Western world has moved into the domain of healthcare professionals and that people are less familiar with death. The dominance of this discourse may be a direct result of death mainly occurring in hospitals and care homes, rather than at home amongst families and friends (Gomes et al., 2011). It was clear that volunteers did not always feed back their experiences to staff, so staff may not be aware how volunteers are developing their confidence to cope with death and, as a result, may not need as much protection or support as staff think. This lack of feedback may result in staff being unaware of the potential to work with volunteers differently, and is discussed later in this chapter.

The findings demonstrate that spending time with dying people has the potential to offer a new narrative about dying and death, and coping with repeated losses, which might not have been available to those who had not experienced multiple deaths before. In the same way that the carers in the study by Horsfall et al. (2015) developed a 'triumphal' discourse, the volunteer participants' positive stories about coping with repeated losses, without being overwhelmed by them, could provide a new narrative about death, and have the potential to contradict the discourses seen in the literature that, as a society, we are frightened of death and dying. If volunteers did feel able to share their stories, they themselves might become role models for coping with death, rather than doctors and nurses. However, hospice rules about confidentiality, and over-arching laws about data protection, could be said to be constraining volunteers from sharing these positive stories about dying and death.

7.3 Rules and relationships

The findings found similar results to the studies reviewed in the literature, where the formation of friendships appeared to be important to the volunteer participants' experiences. Both men and women volunteer participants spoke of the friendships that they developed with the people they were visiting, which was in contrast to the comments by Weeks and MacQuarrie (2011) who felt men were more interested in practical tasks. However, the dilemmas seen in the literature reviewed also appeared to be reflected in the volunteer participants' experiences, in that, for some, such close relationships caused dilemmas, and challenged them to consider whether friendship and volunteering was compatible. However, the findings provide an in-depth insight into how the volunteer participants appear to manage and make sense of their different relationships with dying people, hospice staff, their own families and friends and the wider community, and the boundaries around these relationships.

In considering the context of the relationship between the volunteer and the dying person, hospices appear to be setting up services where volunteers are encouraged to spend time with people who may be isolated. Similar to studies in the literature reviewed, this research saw volunteers matched to dying people using similar backgrounds, interests and gender (Claxton-Oldfield and Claxton-Oldfield, 2007; Ipsos MORI, 2012; McKee et al., 2007; Sévigny et al., 2010; Walshe et al., 2016). In addition, volunteer participants were provided with training by their hospice, which is likely to have included training about communication and empathy, as described by Fox (2006). It is, therefore, perhaps not unexpected that friendships would develop.

Longer term relationships also appeared to contribute to the development of a friendship, as described in the literature reviewed. McKee et al. (2007), Walshe et al. (2016) and Pesut et al.(2017) were clear that longer-term relationships were seen to give greater benefits to dying people and volunteers. The different views about friendships seen in the findings may be reflective of the different opinions and expectations of each hospice which are reflected in the literature reviewed: where McKee et al. (2007) describe friendship as core to the role, Walshe et al. (2016) liken it more to a counselling relationship, and Claxton-Oldfield, S et al. (2011a, p.430) suggests that volunteers must not get "too close". This concern about becoming 'too close' was also a strong thread throughout the findings.

In line with some studies reviewed in Chapter 3 (Berry and Planalp, 2009; Ipsos MORI, 2012), the volunteers' stories in this thesis highlighted the differences between what the hospice expected of them, and what volunteer participants perceived was expected of them, in terms of their relationship with the dying person. Figure 7.4 shows some of the different beliefs heard in the volunteer participants' stories. These differences could be said to demonstrate how the hospice system and beliefs about relationships were in conflict with the type of relationship the volunteer participants perceived was needed by the person they were visiting. Figure 7.4 also includes a connection to the volunteer's family, as several volunteer participants found their relationship with the dying person then became a part of their own lives as they talked to their family about their experiences with dying person, although for some volunteer participants this was perceived to be against the rules.

Figure 7.4 Differing beliefs about relationship boundaries

Hospice beliefs that professional relationships need to bounded by rules which include:
- Do not get too close
- Keep visits confidential
- Advice only to be given by professional staff
- Do not accept gifts
- Listen to their story, but do not share your personal stories / information / telephone number.

Volunteer's family and friends

Volunteer

Dying person

Hospice staff

Hospice system

Personal beliefs that companionship is negotiated between volunteer and dying person, where volunteers might:
- Share stories
- Share personal information
- Give advice
- Exchange gifts
- Connect with wider friends and families
- Become close

System of companionship

In the previous section I highlight the role the dying person played in helping the volunteer create new narratives about dying and death, in line with studies by Azuero et al.'s (2014), McKee et al. (2010) and Pesut et al (2017); many volunteer participants in this research also appeared to feel they received more than they gave. This reciprocity appeared to be an important part of the relationship and seemed to give pleasure to many volunteer participants, however, there were also dilemmas about how they managed the relationship with the dying person, and raised concerns about what they could or should share of themselves. These dilemmas show a vivid example of how a professional system, which encourages empathy and listening, but then warns against a reciprocal friendship, is in direct conflict with the type of relationship that might develop between the volunteer and the dying person, and provide a good experience for the volunteer. The application of such a professional system is also in direct conflict with the development of a mutual peer relationship as described by Sallnow et al. (2017) and the potential for volunteers to de-professionalise death, as they have for mental health support as noted by Naylor et al. (2013).

7.3.1 Responding to rules

When listening to the stories, I was surprised by how accepting the volunteers appeared to be of the hospice rules, and how little they seemed to challenge hospice staff, even when they disagreed with them. The findings demonstrate how the volunteer participants perceived that some of the overt rules set by the hospice did not fit with their experiences of home visiting; this resulted in volunteers not complying with the rules and creating a covert rule of not telling the hospice what they were doing. The volunteer participants told how they adapted their behaviour with the different systems they were working with, either adapting to the hospice system or adapting to being in part of a longer-term relationship.

Although I saw similar findings to Claxton-Oldfield, S et al. (2011a), that the presence of rules does not mean that volunteers will comply with them, the findings give new insights into why volunteers might not comply with rules. Bateson (1972) encourages looking for the 'differences' and the findings showed clear differences between the volunteer participants' responses to hospice rules and the friendships they formed with the people they visited. Their responses to rules varied in their compliance, which seemed to be related to their own beliefs, the type of rule, and what the rule meant to the volunteer. These responses, which sometimes went against the rules, could be described in several ways: some might see it as volunteers being flexible and autonomous as described by McKee et al. (2007; 2010) and Guirguis-Younger and Grafanaki (2008); others might see it as not complying with, or flouting rules, as noted by Walshe et al. (2016) and Claxton-Oldfield, S et al. (2011a).

My own experience suggests that there is a dominant discourse in UK hospices where staff assume that volunteers do not adhere to rules, which may contribute to hospice staff continually trying to reinforce them, rather than attempting to understand why rules are not being complied with. The findings also highlight a discourse held between volunteers that volunteers do break the rules. The volunteer participants' different responses to hospice rules also appears to have been influenced by what the hospice meant to them, and their own experiences and expectations of being a volunteer (Figure 7.5). A stronger connection to the hospice system and the respect volunteers may have for the hospice may also contribute to their attempt to either adapt to the rules or not tell the hospice if they are ignoring them.

Figure 7.5 Meaning, experiences and expectations
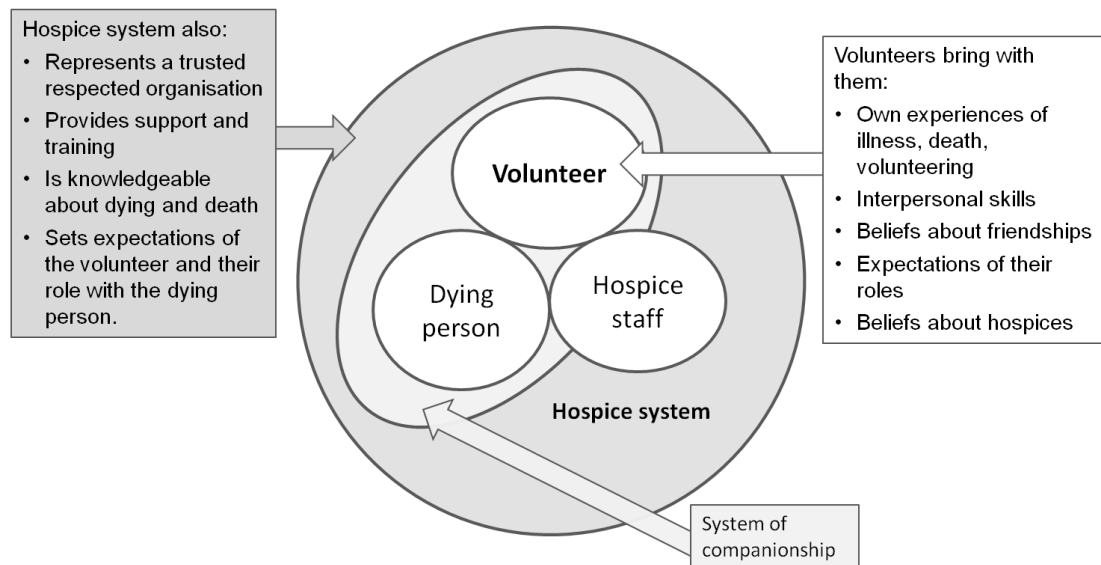
Whilst different expectations about relationships appeared to affect the volunteer participants, they may also have been affected by each hospice's aim of what volunteers were expected to provide. Understanding the expectations of each participant hospice was not part of this research. However, in the literature reviewed, volunteer experiences did not appear to be negatively impacted when the volunteers' expectations matched that of the hospice or palliative care team. For example, the wish to meet community need seemed to be shared by the volunteers and the hospice or palliative care system as seen in the studies by McKee et al. (2007), Jack et al. (2011a; 2011b) and Grant et al. (2011). In these studies, there appears to be a more flexible approach to boundaries, where volunteers are also part of the community, in contrast to the more rigid approach seen in some of these findings, where the hospice's expectations of the relationship appear to be different from the actual experience.

By considering the expectations of different services could give some insight into why some hospices have responded differently to other charities that are using volunteers widely in the community, as I highlight in Chapter 2. It is clear in many studies the social role of the volunteer in providing peer support and friendship is core to their role (Faulkner and Davies, 2005; Gardiner and Barnes, 2016; Hussein, 2011; Naylor et al., 2013; Siette et al., 2017). Whereas, in hospice care, the expectation of a volunteer's role appears more aligned to a role that should be 'professional' and not encompass a reciprocal friendship, and the volunteers interviewed in this research, at times appeared to agree with this expectation.

7.3.2   Personal beliefs

The personal beliefs of the volunteer appeared to be strong factors in influencing how they responded to rules. Those with a professional health or social care background admitted to finding it hard to 'turn their skills off', and their beliefs and ways of doing things stayed with them, even as volunteers, which may indicate why these volunteers were more likely to adhere to hospice rules. Beliefs about complying with rules were not just seen in volunteers with clinical skills, as Anita appeared to hold a strong belief that she had to comply with rules, which may have arisen from her administrative background. Whilst professional people may be attracted to the informality of the role, as described by Guirguis-Younger and Grafanaki (2008) and Field-Richards and Arthur (2012), those with a clinical or professional background may still hold on to the dominant beliefs which were part of their profession: that is, they should comply with rules, rather than challenge them.

Dominant discourses in society about rules and litigation may also influence volunteers to expect to be constrained by rules and regulations when they joined the hospice, as highlighted by Restall (2009). Rules in society may be perceived as a form of protection. Some volunteer participants appeared to agree with the belief that they, as volunteers, and the people they were visiting, needed rules to protect them. This may contribute to a discourse that volunteers and dying people are in need of protection. Yet volunteers also appeared able to make their own decisions and look after themselves, perhaps disproving the idea that the hospice always needed to be responsible for protecting them. However, staff did not always appear to hear these perspectives.

The volunteer participants' acceptance of hospice rules and their lack of challenge suggest that the volunteers appear to be influenced by dominant discourses which perceives healthcare professionals and hospices to be the experts in the field of death and dying (Conway, 2008; Howarth, 2007). The importance of training was heard in the volunteers' stories, and this importance may contribute to a discourse that volunteers have less knowledge than hospice staff. Even though some volunteers had personal experiences of hospice care, as noted by Guirguis-Younger and Grafanaki (2008), this may further influence them towards the tendency to see staff as experts, rather than recognising their own experience. However, the findings also highlight how much the volunteer participants appear to learn from dying people and these dominant discourses about the expertise of healthcare professionals does not appear to include the influence of the dying person.

For volunteers like Scott and Anita, some hospices' rules meant that neither the volunteers, nor the people they were visiting, were to be trusted. Yet trustworthiness is a trait that is sought when recruiting volunteers and is cited as important to the role of the volunteer when visiting people at home (Guirguis-Younger and Grafanaki, 2008; Sévigny et al., 2010; Walshe et al., 2016). Trust is also seen as crucial to the formation of a long-term relationship with the person being visited (McKee et al., 2007). The relationship of trust which appeared to develop between the volunteer participant and the dying person may also have been influenced by the volunteer's connection with the hospice, an organisation that may have considerable standing in the local community. The importance of the volunteer's relationship with the dying person, and this perceived lack of trust by staff for volunteers, could explain why some volunteers ignored some rules, as their trusting relationship with the person they were visiting appeared to have greater importance to the volunteer than the hospice's rules.

7.3.3   Hospice beliefs

The findings suggest that hospices are using rules with volunteers, which appear more aligned to a professional or counselling relationship than a friendship. Hospice staff may believe this to be appropriate, or may have no other system of rules available to apply to a relationship, which is related to *friendship* rather than *professional*. Staff may believe the need for volunteers to be 'professional' is an organisational requirement necessary to keep volunteers, patients and the organisation safe, as described by Morris et al. (2015).

The expectations of the service and the training that volunteers undergo may contribute to volunteers feeling part of the hospice system. This may promote a culture of behaving 'professionally', even though their role could be described as one of companionship or friendship. A professional belief about emotional distance, and protecting volunteers from the danger of getting 'too close', connects with the studies by Claxton-Oldfield, S et al. (2011a), who suggested that working with death might be seen as inherently stressful. Such beliefs may contribute to the professional view that volunteers may need protection from such stress and lead to enforcing rules to protect them, as discussed earlier.

The belief of staff, highlighted by Sinclair (2007), that palliative care and advice could only be delivered by paid professional staff, was evident in some stories. Several volunteers interviewed in this thesis had significant experience either professionally, or as a family carer, yet they felt their experience or knowledge was not equal to that of a paid staff member. These findings also confirm the perspectives described in Chapter 2, that volunteers within the UK hospices are less likely to fulfil professional roles and that patient care needs to be delivered by trained staff (Burbeck et al., 2014a; Morris et al., 2012; Watts, 2012).

The findings suggest that volunteers managed by volunteers may have more flexibility than those managed by paid staff but, without further research into the volunteer coordinators' experiences, I cannot presume this flexibility was related to their role as a volunteer, or their own background and beliefs. Managing volunteers in a more 'professional' way could also be the result of increasing regulation as described by Howarth (2007) and Macmillan and Townsend (2006). My findings appear strongly to support the warning expressed by Guirguis-Younger et al. (2005) that increasing regulation and professionalism may jeopardise the human relationships which volunteers find so rewarding.

However, whilst increasing regulation may affect how hospices manage volunteers, as my findings show, volunteers may also be responding to being part of a more regulated society and may believe they have to behave professionally. The volunteers in the study by Söderhamn et al. (2017) appeared to be an example of this, as these volunteers were very clear that their role was not as family member, or healthcare professional. Whilst Sallnow et al. (2016) suggest that those working in communities are likely to be more flexible, my findings highlight that volunteers who feel part of a hospice system and part of a society bound by regulation may not feel able to be flexible about boundaries.

My findings may also reflect UK hospices' limited experience of working with volunteers in the community, compared to other charities and organisations that have significant experience as described by Naylor et al. (2013). Anita's story clearly highlighted the difference she experienced between volunteering for another charity and the hospice, where she found herself much more restricted. However, it is not clear why there is a difference between how hospices and other organisations use community volunteers, although as Morris et al (2015) suggest, hospices may feel overly constrained by regulation and concerns about safety. I suggest that staff beliefs about providing a professional service to the dying and concerns about volunteer 'burnout' may together contribute to a reticence to use community volunteers at scale in a befriending role.

The findings appear to demonstrate that being part of a rigid hospice system, within a wider, more regulated, society, may be detrimental to the experience of the volunteers, and that a rigid approach to boundaries stops volunteers from responding flexibly and with autonomy. Therefore, freeing people from being constrained by a rigid hospice system may release them from needing to make the choice of whether they are behaving professionally or not, and whether they need to respond as a friend or a volunteer.

7.4 The importance of feedback in systems

The previous sections highlight a potential conflict between the hospice system and a system of friendship and companionship, which was also apparent in some of the literature reviewed: Horsfall et al. (2015) identified difficult relationships between formal and informal caregivers, and other authors identified differences between professional rules and volunteers' practices (Berry and Planalp, 2009; Claxton-Oldfield et al., 2011a; Walshe et al., 2016). However, there was little evidence found in the literature reviewed about how to resolve these conflicts, other than increased training and guidance for volunteers, and help for volunteers to become more professional (Claxton-Oldfield et al., 2011a; The Commission into the Future of Hospice Care, 2013). Yet, the findings appear to show that training volunteers to be more professional will not solve the dilemma if the relationship that is perceived to be required is one of friendship and companionship.

I suggest that using the concept of feedback from systems theory provides a framework to understand the relationship between the two conflicting systems and how it could be improved, as these systems need to be able to work together effectively, despite their differences. In Chapter 3, I describe the importance of feedback between systems and how feedback can help people and systems adapt to changing circumstances, instead of becoming stuck in repeating patterns of behaviour. Feedback is said to be especially important in an organisation, as organisations need to respond to external demands as well as to internal changes, balancing the need for stability and change (Campbell, 1991). This concept has significant relevance to hospices as they face the challenges described in Chapter 2.

Anita's story shows a clear example of a system which appears stuck in a pattern of behaviour, leaving Anita feeling she has little autonomy or flexibility. The feedback from the hospice to Anita, which led her to believe that she 'got things wrong' may have reinforced her behaviour of withholding some information from staff. However, by withholding her stories and her ideas of how she and other volunteers were managing dilemmas, she denied hospice staff the chance to hear how the hospice rules affected volunteers' experiences and their relationships with the people they were visiting.

Figure 7.6 shows the cycle of feedback, which appeared to result in repeated patterns of behaviour and no change occurring, as friendships formed and hospice staff continually tried to reinforce rules which were in conflict with a relationship based on friendship. The dominant discourses about staff being the experts in hospice care may also influence how staff worked with, and listened to volunteers. Whilst Morris et al. (2012) and Naylor et al. (2013) highlight the importance of volunteers in connecting hospices to the community and the outside world, I suggest that this connection is of little value if hospices are not open to listening to, and using the volunteers' feedback.

Figure 7.6 Circle of feedback with rigid system
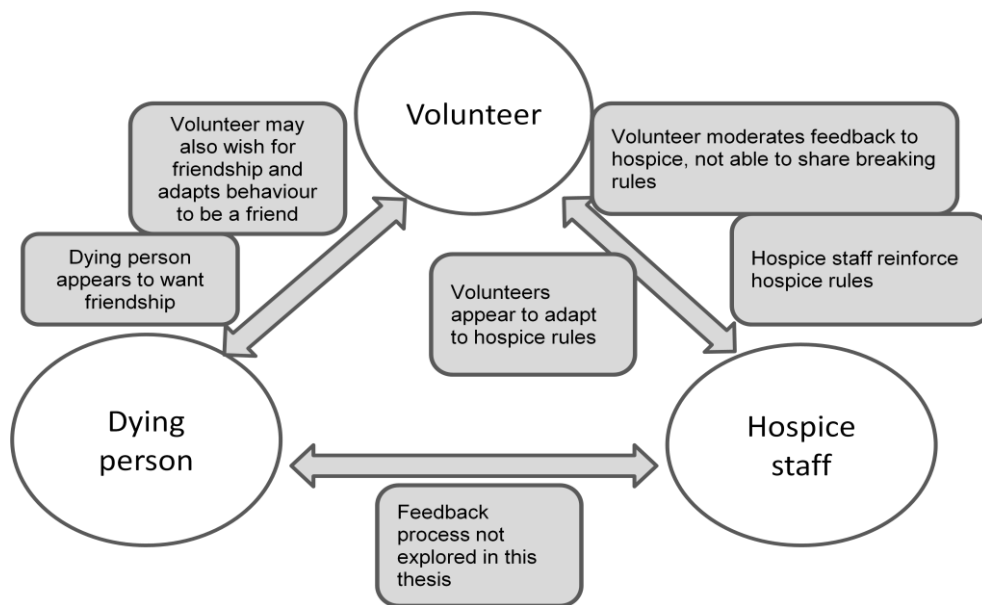
The professional beliefs in the previous section provide some explanation as to why hospice staff might hold such rigid positions in trying to uphold rules, which they may perceive as required to protect vulnerable volunteers and dying people. To resolve this, hospices may need to consider how they could develop a more flexible approach: listening and responding to feedback, and developing ways of working with volunteers which promote autonomy. Figure 7.7 below describes a model of feedback between staff and volunteers which could promote change in how relationships with dying people are discussed openly.

Figure 7.7 Cycle of feedback in a responsive system
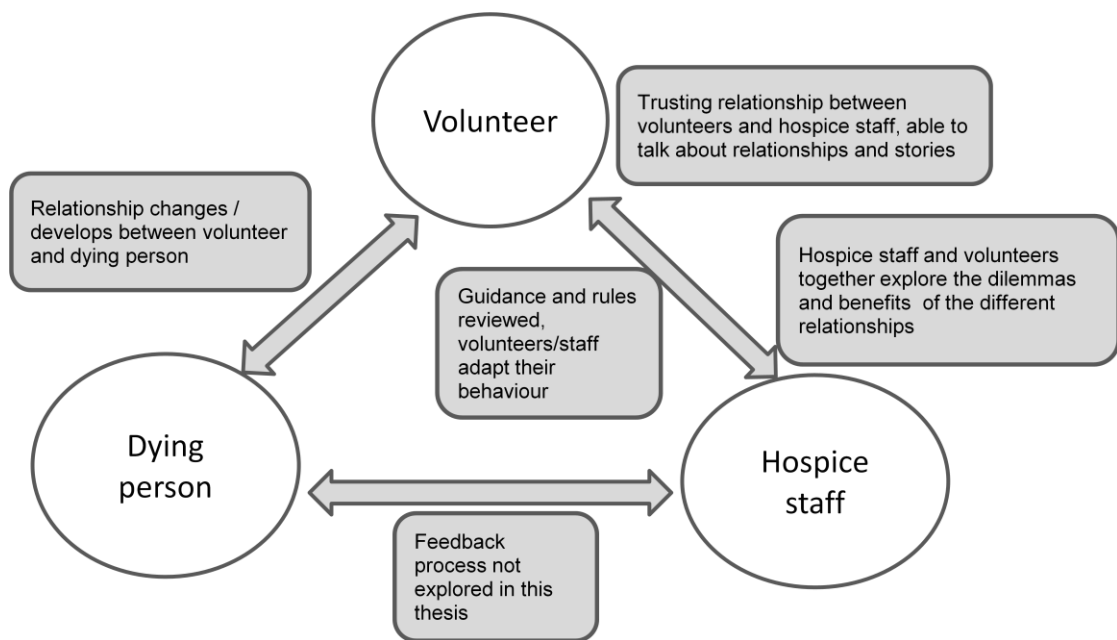
This approach might encourage volunteers to explore the type of friendship that would suit both the person they are visiting and themselves. Such flexibility and autonomy was apparent in the study by McKee et al. (2010, p.108) where volunteers had flexibility and autonomy to become "friends with skills" and resulted in positive experiences for those volunteers.

7.5 **An alternative approach – a flexible hospice system**

Whilst this chapter has focused on the potential impact of a rigid hospice system on volunteers' experiences, it is important not to ignore how powerful the stories were in illustrating how volunteer participants appeared able to manage their relationships with dying people, which could inform new positive stories about dying and death, as well as those that told of hospices which appeared to encourage volunteers to be autonomous and to use their common sense. Such stories illustrate how volunteers gained confidence through their experiences of being with dying people and reduced their own fears about death, and how the support of the hospice played a role in helping them to do this.

It has been suggested that volunteers could be part of the solution to the increasing demand faced by hospices and part of the solution to improve social action and enhance community resilience in line with a health promotion approach to palliative care (Abel et al., 2011; Department of Health, 2011; Garber and Leadbeater, 2010; The Commission into the Future of Hospice Care, 2013). Other voluntary and statutory organisations in the UK are already demonstrating how community volunteers can play a significant social role supporting people at the end of life (Gardiner and Barnes, 2016; Naylor et al., 2013; Smith et al., 2018).

However, constraining volunteers within a rigid system may also have an impact on the wider community system, as volunteers feel constrained from telling new stories about their experiences, and I suggest they may also feel constrained from taking action outside the hospice system. The literature reviewed demonstrated how volunteers not part of a rigid hospice system such as those described by Kumar (2013), Naylor et al.(2013), McKee et al. (2010), Gardiner and Barnes (2016) and Grant et al. (2011), all appear to have more flexibility and appear less constrained than the volunteers interviewed in this thesis.

My findings demonstrate that a professional rule-bound system does not fit a model of visiting, which is based on friendship and companionship and that such a rigid system could also increase volunteers' reliance on healthcare professionals, thus requiring more resources and increasing pressure on the hospice system. In addition, the findings suggest that volunteers who feel constrained and lack autonomy are more likely to continue to promote the idea that death remains in the realm of healthcare professionals, rather than assisting in its acceptance as a social experience, as suggested by Sévigny et al. (2010) and Kellehear (2013).

Therefore, the findings demonstrate that a hospice system with rigid rules, constrains volunteers from sharing positive stories about death and dying and at times seeking support from family and friends. Whilst hospices and volunteers need to comply with national laws or regulations, I suggest that volunteers could be helped by staff to distinguish between information, which might contravene such regulations, and stories and experiences which may be shared with friends and families. This would enable volunteers to use their own network of support, with the hospice there as back-up if their own support proves insufficient.

The findings demonstrate that community hospice volunteering has the potential to influence societal discourses about death and provide support to dying people in the community. However, for this to be sustaining, hospices may need to reconsider how such services are managed. Whilst some volunteer participants felt the hospice allowed them autonomy and flexibility to use their discretion, others felt constrained and frustrated by the rigidity of hospice rules.

This lack of flexibility highlights two problems for hospices. First, as demonstrated in this thesis, it would suggest that for these volunteer participants, hospice staff missed opportunities to hear and respond to feedback from volunteers about their experiences, and how they managed relationships with the dying person and the eventual death of that person. This feedback could help staff understand the social role the volunteer fulfils and the value of friendship, rather than perpetuate a belief that volunteering and friendship are not compatible. Campbell (1991) suggests that organisations which are open to ideas and feedback from its people are more likely to be open to improvement and change. This lack of feedback seen in this research, denies the hospice system the opportunity to make adjustments towards working in a different way, potentially improving the experience both for the volunteers and the people they were visiting. A lack of feedback with the community may also inhibit changes that could happen within the community.

Second, these volunteer participants appear to have better experiences when they have some autonomy and flexibility. This was also observed in the studies by Walshe et al. (2016) and Ipsos MORI (2012). Likewise, Guirguis-Younger and Grafanaki (2008) highlight that it is the flexibility that may attract people to volunteer, and denying them this may not only result in a poor experience, but could lead them to stop volunteering for a hospice. Similarly volunteer schemes that have developed outside of the hospice system appear to have developed at a greater scale with more flexibility than those that are part of a rigid system

Therefore if community hospice volunteering were to be viewed as a different system to a professionally regulated system, this might free community from the constraints of a professional system. To demonstrate this, I have positioned volunteer home visiting as a separate system, but still connected to the hospice system, as my findings suggest that volunteers benefit from the advice, support and guidance of hospice staff in improving their confidence in being with dying people and included the importance of feedback to the wider systems (see Figure 7.8).

Figure 7.8 Proposed model of community hospice volunteering
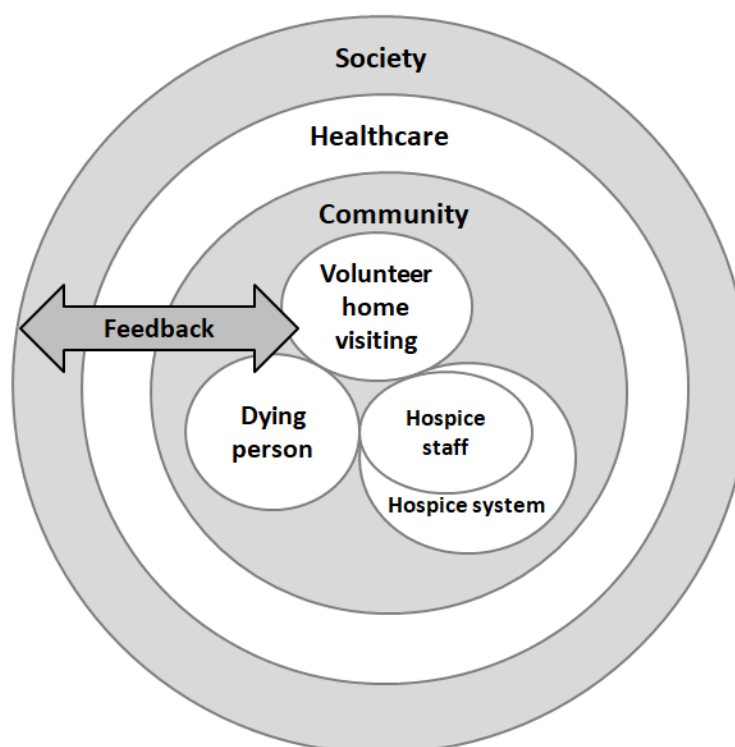
Community hospice volunteering might be better to be more closely aligned to informal volunteering, with flexible rules and boundaries negotiated between the volunteer and the person they are visiting. This proposal challenges recommendations that volunteering needs to become more professionalised, with increasing training and supervision (The Commission into the Future of Hospice Care, 2013).

7.6 Conclusion

In this chapter I have argued how community hospice volunteering can provide experiences for volunteers which can transform how they think about death and dying and could challenge dominant discourses that, as a society, we are frightened of death. But the context of a rigid hospice system, and wider discourses about regulation, may be having a considerable impact on the experiences of community volunteers.

I have demonstrated how personal, professional and organisational beliefs may influence volunteers to respond differently to rules. In addition, a lack of feedback between the hospice and the volunteers means the hospice is missing an opportunity to hear their stories and initiate changes to improve the volunteers' experiences and the hospice system.

An alternative approach could require hospices to improve their understanding of the importance of the social role that volunteers fulfil and that home visiting need not be constrained by professional rules. Instead they could work with volunteers in a system that promotes feedback, autonomy and the flexibility enabling volunteers to be able to support people at home with confidence.

8 Conclusion

This chapter draws together the main points in this thesis and draws overall conclusions, clarifying the new knowledge that I have identified. I consider the implications for hospices using volunteers to provide companionship to dying people at home, and conclude with my recommendations for future areas of research and a final summary of this thesis.

This thesis asks: '*How community hospice volunteering with people at the end of life impacts on volunteers' experiences and their attitudes to death and dying'*. My interest relates to national recommendations for hospices to use more volunteers to extend their reach into their communities. I was curious to know how hospice volunteers felt about being with dying people, and I was also increasingly aware that there were pressures for volunteers to be more 'professional', which could be in conflict with a community role that may be more related to friendship.

This thesis demonstrates how for these volunteer participants: visiting dying people in the community provided experiences which transformed how they thought about life and coped with dying and death. However, knowledge not seen before in the reviewed literature was the impact on the volunteer participants' experiences of working with a professional rule-bound hospice system within a heavily regulated society, and how volunteers in this research made sense of and came to terms with these regulations. This was vividly demonstrated by those who perceived that they could not be 'a volunteer and a friend' and expressed concerns about getting 'too close' and 'being professional'. This thesis also gives greater insight into why volunteers might not comply with rules, an issue I highlight in the reviewed literature. These insights demonstrate the influence of personal, professional and organisational beliefs and what the rule meant to the volunteer participant, as well as their relationship with the dying person and the hospice staff, and the feedback they received from hospice staff.

The findings indicate that some volunteers in this research did not comply with rules because the rules did not fit with their experiences. However, because of the lack of open feedback between staff and volunteers there appeared to be little opportunity for this dilemma to be explored: instead, volunteer participants ignored the rules and would agree between themselves not to mention it. The respect volunteers had for hospices' expertise also may have contributed to the volunteers' lack of challenge to hospices when hospice rules did not fit with their experiences.

Participants in this research found they learnt to cope with multiple losses, and a finding not seen before in the reviewed literature was how some people followed the example set by doctors and nurses when coping with multiple deaths, an example which helped them cope with the death and 'move on'. Their stories could, therefore, provide a new narrative that death need not be frightening and could counter a dominant narrative that, as a society, people are scared of death. However, the findings also demonstrate that some volunteer participants felt that such stories should not be shared outside the hospice and this could risk perpetuating the medicalisation of death.

The findings in this thesis demonstrate the problems caused by a rigid hospice system which does not respond to feedback and is resistant to change. Such a system appears to lead to a poor experience for some volunteers and denies the hospice the opportunity to learn from volunteers and to adapt their system to provide a better experience for those volunteers.

My thesis makes a case for hospices to develop a flexible and responsive approach to home visiting which is more closely aligned to informal volunteering, encouraging volunteer autonomy, where rules and boundaries are negotiated between the volunteer and the dying person. Without this shift in emphasis, volunteers may continue to feel constrained by rules, and perhaps become increasingly dependent upon hospice staff, rather than be able to support each other in their own communities. To help this shift, I suggest that hospices need to learn from their volunteers and other organisations to understand and value the social role a volunteer fulfils and the importance of friendship. As I highlight in Chapter 2, the increasing demand on hospices, alongside people's preferences to be cared for and to die in their own homes requires solutions which include increasing the involvement of communities in caring for the dying, and moving away from simply a clinical model of dying which sits in the realm of healthcare professionals.

8.1 Strengths and contributions of the thesis

This thesis shows how a narrative approach to data collection and analysis can successfully elicit stories from the volunteers about their experiences. Volunteers were able to speak about aspects that had not previously been found in the reviewed literature; for example about what their relationships with dying people and hospice staff meant to them, how they made sense of those experiences, as well as their perspectives about coping with rules. This approach also ensures the stories from the volunteers are held together and not fragmented, ensuring their voices are a strong part of the findings.

The use of systems theory provides a framework which emphasises the importance of the context, beliefs, meaning and feedback in influencing behaviour, with which I explore and make sense of the volunteers' experiences. This generates new perspectives about the lack of feedback between volunteers and staff which could be said to be preventing change and may be perpetuating poor experiences for some volunteers, a consequence of which may inhibiting the development of community resilience and the development of a health promotion model of palliative care.

Whilst this thesis has particular relevance to community hospice volunteers, the insight gained into why volunteers respond differently to rules has relevance for the wider hospice, voluntary and statutory working with volunteers. Understanding that volunteers' responses to rules will be affected by their own backgrounds and beliefs and how that impacts upon their relationships with dying people and other people they visit, as well as the importance of feedback between volunteers and staff, could help staff to work differently with volunteers.

The process of research has increased my understanding of how powerful the hospice system can be in relation to volunteers, and how the dominant discourse about the expertise of hospice staff can mean that volunteers may feel their own experiences or opinions are not valued.

8.2 **Limitations**

The study was limited by the specificity of the geographical area of the research, which excluded potential participants and limited access to individuals' stories. The volunteers' stories show only one side of a volunteer-patient relationship and included neither the patients' stories nor the stories from hospice staff including those managing volunteers. The data includes little information about the context of each volunteer participant, further information about their family, background and beliefs could have increased my understanding of their different responses. Whilst friendship was seen as important to volunteer participants, this thesis has only heard the volunteer participants' perceptions, and those being visited may have a different view of the type of relationship they would like, an area that would benefit from further exploration. In, addition understanding the perspectives of those managing volunteers, whether they be paid staff or volunteers, could give further insight into how feedback between volunteers and those managing them could be improved.

Whilst a narrative approach facilitated a breadth of different stories and experiences, some areas may have benefited for more in-depth exploration. For example, I would have been interested to hear more about how volunteers learned about coping with death from the example set by doctors or nurses, and to understand the training and support that volunteers found helpful. In addition, understanding more about the volunteers' beliefs about illness, death, volunteering and regulation would have added greater insight into why volunteers responded differently. However, these aspects may have detracted from stories that were important to the volunteer to tell, and so could be the focus of further research.

Chapter 5 highlights the challenges for me in researching a topic known to me, in an area where I was known, particularly in my own hospice. I am aware my own role as researcher and CEO will have influenced the research process and my interest in rules and systems may have meant that I missed other narrative threads in the stories told. However, I have tried to be transparent about my perspective throughout this thesis.

8.3 **Implications for hospices and other organisations**

Whilst volunteering has always been part of the hospice movement, this thesis highlights the potentially adverse impact of developing community home visiting within a hospice system that is overly constrained by professional rules. Therefore, I argue that there are two areas that hospices need to consider which would address the dilemmas raised by this thesis. First, there is a strong case for hospices to consider how to develop and manage community services alongside their heavily regulated care services, and whether community hospice volunteering could be recognised as a different system from the formal professional hospice system. This could be developed into a more flexible informal system which promotes volunteer autonomy.

Second, hospices need to address the rigidity and lack of feedback seen in this thesis between the volunteers and hospice staff. The rigid application of rules and the lack of autonomy and flexibility, has led to a poor experience for some of the volunteers interviewed. Therefore, to improve staff-volunteer relationships, I suggest that hospice staff may benefit from more specific training on understanding the importance of a social befriending volunteer role, and how to work with volunteers, where relationships between staff and volunteers are built on foundations of trust, collaboration and feedback, giving more opportunities for staff to understand the volunteers' experiences and beliefs in a relationship which encourages autonomy.

The findings in this thesis may also be applicable to other statutory, voluntary and private organisations working with community volunteers, particularly those working with people at the end of life. If community volunteering is seen as way of enhancing social action and developing compassionate communities, organisations need to promote volunteer autonomy and flexibility.

8.4 Areas for future research

To build on the findings of this thesis, further knowledge is required to develop community hospice volunteering. This thesis has highlighted the lack of quantitative data about current community hospice volunteering. A quantitative survey sent to all hospices and palliative care organisations specifically about community volunteers visiting dying people, and how they are being managed and coordinated, would give a better understanding of the scale of the work being done. These data could inform further qualitative research and could include hearing the stories of hospice staff, those coordinating community hospice volunteers and the dying people that are being visited. This would generate a richness of stories and enable all the voices to be heard, providing a deeper understanding about relationships from the dying person's and hospice staff's perspective.

Research which specifically explores the understanding, perspectives and beliefs of hospice staff could help to inform the training and support that staff might need in order to work with volunteers who may be working more informally. This could include research into the different experiences and outcomes of community hospice volunteer schemes run and coordinated by paid staff or volunteers. Future qualitative research could include volunteers and dying people from different cultural groups, which would allow a more inclusive perspective about the social support needed at home across different communities. Finally, research that compares the experiences of hospice community volunteers with other organisations that work with community volunteers more informally and flexibly may bring new knowledge about different ways of working with volunteers.

8.5 **Final summary**

This thesis demonstrates how, for these volunteer participants; visiting dying people in the community can provide transformative experiences in terms of how volunteers think about life and learn to cope with multiple deaths. However, the evidence in this thesis suggests that a volunteer community service based on companionship and friendship does not necessarily fit with a rigid, heavily regulated hospice system, however well-meaning that regulation is. An alternative approach could be considered, where hospices work from the premise that home visiting need not be constrained by professional rules. Instead, hospices could work with volunteers in a system which promotes feedback, autonomy and flexibility equipping them to support dying people at home. Such an approach could be applicable to other organisations working with volunteers and is more likely to enable individual and community resilience and promote a health promotion model of palliative care.

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10 Appendices

Appendix 1 Literature Searches

Database	Search Terms	Date	Found
Web of Science	volunteer* AND hospice or palliative or "palliative care"	1945-2016	429
PubMed	(volunteer workers[MeSH Terms]) AND hospice[MeSH Terms]	1974-2015	296
Ovid	hospice care and volunteers voluntary worker/ or volunteer/ AND hospice/ or hospice care/ or hospice nursing/	1946-2016	229
CINAHL	(MH "Hospice and Palliative Nursing") OR (MH "Hospices") OR "hospice" OR (MH "Hospice Care") OR (MH "National Association for Home Care & Hospice") OR (MH "Hospice (Saba CCC)") OR (MH "Hospice and Palliative Nurses Association") OR (MH "Palliative Care") OR (MH "Terminal Care") AND (MH "Volunteer Workers") OR (MH "Volunteer Experiences")	1981 2015	415
MEDLINE	(MM "Hospice and Palliative Care Nursing") OR (MM "Hospice Care") OR (MM "Hospices") AND (MM "Volunteers")	1976-2015	264
PsycINFO	MM "Hospice" MM "Hospice" AND MM "Volunteers"	1999-2015	170
PsycArticles	(DE "Hospice") OR (DE "Palliative Care") AND DE "Volunteers"	1999-2015	31
AMED, CINAHL, MEDLINE, PsycARTICLES, PsycINFO	volunteer*+hospice* + communit*	1978-2016	460
	volunteer*+palliative + communit*	1984-2016	385
Total			**2679**

Appendix 2 Ethical approval letter

Applicant: Barbara Gale
Supervisors: Dr Amanda Bingley
Department: DHR

LANCASTER UNIVERSITY

21 February 2014

Dear Barbara and Amanda,

Re: Understanding the hospice volunteering: volunteers' stories about supporting people at the end of life in their own communities

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 University Research Ethics Committee (UREC), 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 (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 the Research Ethics Officer, Debbie Knight (01542 592605 ethics@lancaster.ac.uk) if you have any queries or require further information.

Yours sincerely,

SC.Tay

Sarah Taylor
Secretary, University Research Ethics Committee

Cc Fiona Aiken, University Secretary, (Chair, UREC); Professor Paul Bates (Chair, FHMREC)

Research Support Office
Research and Enterprise Services

Lancaster University
Bowland Main
Lancaster LA1 4YT
United Kingdom

Tel: +44 (0) 1524 592002
Fax: +44 (0) 1524 593229
Web: http://www.lancs.ac.uk

Appendix 3 Participant consent form

Study Title: Understanding hospice volunteering: volunteers' stories about supporting people at the end of life in their own communities

I am asking if you would like to take part in a research project, the aim of this study is to help me understand what it like to be a hospice volunteer in your own community when you are supporting people who are facing death. Before you consent to participating in the study I ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to me as the principal investigator, Barbara Gale.

Please initial box after each statement

1. I confirm that I have read the information sheet 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 legal rights being affected.	
6. I understand that once my data has been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication.	
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published	
8. I consent to information and quotations from my interview being used in reports, conferences and training events.	
9. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will/may need to share this information with his/her research supervisor.	
10. I consent to Barbara Gale keeping written anonymised transcriptions of the interview for 10 years after the thesis has been assessed.	
11. I consent to take part in the above study	

Name of Participant_____ **Signature**_____ **Date** _____

Name of Researcher _____**Signature** _____**Date** _____

Appendix 4 Confidentiality Agreement

For the Transcription of Qualitative Data

Study Title: Understanding hospice volunteering: volunteers' stories about supporting people at the end of life in their own communities

Researcher: This research is being undertaken by Barbara Gale, who is conducting this research as a student on the PhD in Palliative Care programme at Lancaster University, Lancaster, United Kingdom.

The aim of this study is to help us understand what it like to be a Hospice Volunteer in the community when supporting people who are facing death.

As a transcriber of this research, I understand that I will be hearing recordings of confidential interviews. The information on these recordings has been revealed by interviewees who agreed to participate in this research on the condition that their interviews would remain strictly confidential. I understand that I have a responsibility to honour this confidentially agreement.

I, _____ **agree:**
                       (print full name in block capitals)

- **not** to share any information on these recordings, about any party, with anyone except the Researcher of this project. Any violation of this and the terms detailed below would constitute a serious breach of ethical standards and Data Protection Act and I confirm that I will adhere to the agreement in full
- to ensure that material provided for transcription is held securely and can only be accessed via password using the encrypted memory stick supplied
- **not** to store any audio and electronic files held and relevant to the above study on my own PC but to use the encrypted memory stick supplied
- to return transcribed material to the researcher when completed using the encrypted memory stick supplied

Your signature _____

Date _____

Appendix 5 Advert for UK Hospice Online

Research Study:

Understanding hospice volunteering: volunteers' stories about supporting people at the end of life in their own communities

Request to all Volunteer Services Managers

As part of my PhD studies with the Faculty of Health & Medicine at Lancaster University I am doing some research about hospice volunteering in the community.

I am looking for independent Hospices in **London, central and eastern England**, that have been using volunteers for over 1 year to support people at the end of life in their local community.

I would like to interview **adult volunteers** that are working as a hospice volunteer within their own community in either a rural or urban area and are able to speak English.

I will be interviewing 15 – 20 volunteers about their stories of supporting people who are at the end of their lives in their own communities.

If you are interested in finding out more about the possibility of your volunteers participating in this study please contact me.

Barbara Gale, St Nicholas Hospice Care

b.gale@lancaster.ac.uk

01284 715575

Appendix 6 Study Leaflet

Side 1

Researcher
Barbara Gale

Barbara works at:

St Nicholas Hospice Care
Hardwick Lane
Bury St Edmunds
IP33 2QY

Research study into Hospice Volunteering in the community

Can you help ?

Faculty of **Health & Medicine**   LANCASTER UNIVERSITY

Side 2

Why is the study being done?

As part of my PhD studies with Lancaster University I am doing some research about hospice volunteering. The study has been approved by the University Ethics Committee.

What is the study called?

Understanding hospice volunteering: volunteers' stories about supporting people at the end of life in their own communities.

What is the study about?

I would like to listen to volunteers about their stories of supporting people who are seriously ill and at the end of their lives in their local communities.

Who is being interviewed?

I am interviewing adult volunteers who have visited people in either their local city or rural areas.

What will happen?

I would interview volunteers either at their local hospice or in their own home. The interview would take 1 and a half to 2 hours.

If you are interested in finding out more

Please contact me and then I can call you back to discuss the study in a little more detail.

If you telephone or email me please

Leave your name and telephone number and let me know when would be a good time to call you back.

Other information

This is quite a small study I will be interviewing 15 to 20 volunteers.

How to contact me

Telephone:
01284 715 575

E-mail:
b.gale@lancaster.ac.uk

Appendix 7 Interview letter/email to prospective participant

St Nicholas Hospice Care
Hardwick Lane
Bury St Edmunds
IP33 2QY
01284 715575
b.gale@lancaster.ac.uk

Date

Research Study:
Understanding hospice volunteering: volunteers' stories about supporting people at the end of life in their own communities

Dear (insert name of participant)

Thank you for offering to be part of my research study.

To confirm our conversation the interview will be taking place on (insert date) at (insert time).

The interview will take one and a half to two hours and will be recorded using an audio tape recorder.

As I mentioned I will explain the study and ask you to sign a consent form of which you can keep a copy.

Thank you once again for agreeing to be part of this study.

Looking forward to talking with you

Yours sincerely

Barbara Gale

Appendix 8 Participant Information Sheet

Faculty of Health & Medicine

LANCASTER UNIVERSITY

Research Study:
Understanding hospice volunteering: volunteers' stories about supporting people at the end of life in their own communities

My name is Barbara Gale and I am conducting this research as a student on the PhD in Palliative Care programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?
The aim of this study is to help us understand what it like to be a Hospice Volunteer in your own community when you are supporting people who are facing death.

Why is this research important?
Whilst hospices in many other countries use volunteers to support people at home, it is a fairly new and growing trend in England. Understanding what it is like from a volunteer's perspective may help to shape future services and ensure that volunteers have access to the right training and support.

Why have I been approached?
You have been approached because you are a volunteer in a hospice in England that uses volunteers to support people in their own community.

Do I have to take part?
No. It's completely up to you to decide whether or not you take part.

This is quite a small study I will be doing 15 to 20 interviews, therefore there is a chance that I may not be able to interview everyone who contacts me. But I will let you know as soon as I can.

What will happen if I take part?
If you decide you would like to take part, I will be asking you to tell me your story of what it is like to be a volunteer in your local community.

I will arrange to meet with you either at your hospice or I can come to your home, so that you can tell me about your experience, whichever is most convenient for you and where you might feel most at ease and able to talk without interruption.

I will ask you to sign a consent form of which you will have a copy.

The interview may take up to 1 and a half to 2 hours and with your consent will be recorded on an audio tape recorder.

Can I change my mind about being part of the research?
Even after signing the consent form you may still withdraw from the study, this can be at any time during the interview. After the interview, if you change your mind about me using your story you can withdraw it up to 14 days after the interview.

After that you can still withdraw, but once your interview has been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract your data, up to the point of publication.

Will my data be confidential?
The information you provide is confidential.

The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Identifiable information will be removed from the audio recording once it has been transferred to a computer.
- The audio recordings will be deleted after the thesis has been assessed.
- Hard copies of all paperwork with your details on will be kept in a locked cabinet.
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself will be password protected.
- At the end of the study, paper copies of the interview (which has been anonymised) will be kept securely in a locked cabinet for ten years. At the end of this period, they will be destroyed.
- 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 publications from the study, so your name will not be attached to them. The researcher will ask if you have a preference what pseudonym you would like to be used.

There are some limits to confidentiality, for example 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 speak my supervisors about this. 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 or presented at a Hospice Conference and a short general summary will be sent to all those who were interviewed.

Are there any risks?
There are no risks anticipated with participating in this study. Should you feel distressed as a result of taking part you can access support – (01XXX) XXX XXX (Local Hospice).

Are there any benefits to taking part?
Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?
This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee at Lancaster University. I have also received formal permission from you (insert Hospice CEO) for volunteers to be part of the study.

What experience do you have in interviewing?
I have worked in hospice care for many years as a nurse and currently run a hospice in Suffolk. Interviewing has been part of my work as a hospice nurse, working with families and now as a manager.

What do I do if I am interested in taking part and hearing more about the study?
Please contact me:

Barbara Gale
Email: b.gale@lancaster.ac.uk or 01284 715 575

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to me the researcher, you can contact my supervisor:

My supervisor is
Dr Amanda Bingley
Email: a.bingley@lancaster.ac.uk
Lecturer in Health Research
Faculty of Health & Medicine
Division of Health Research
Furness College
Lancaster University
Lancaster
LA1 4YG
England UK
01524 592 718

If you wish to speak to someone outside of the research team you may also contact:

Professor Paul Bates
Associate Dean for Research
Email: p.bates@lancaster.ac.uk
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YD
01524 593 718

Thank you for taking the time to read this information sheet.

Appendix 9 Interview schedule

Research Study:
Understanding hospice volunteering: volunteers' stories about supporting people at the end of life in their own communities

Revisit consent and withdrawal.

Agree pseudonym.

Setting the scene to help the participant feel at ease.

Researcher:

Could you tell me a little about yourself –
                               Your family?
                               Your work?
                               How long have you lived in (volunteer area)?

Researcher:

I would like you tell me about your story about being a community hospice volunteer, whatever experiences are important to you?

Please start wherever you like and take your time?

If appropriate researcher will use prompts about:

- Training
- Support
- Experiences about dying and death
- Their relationship with hospice staff
- Volunteer's thoughts about how this type of volunteering has impacted on other people in the community
- How they have made sense of all these experiences

Appendix 10 Mind map notes of interview
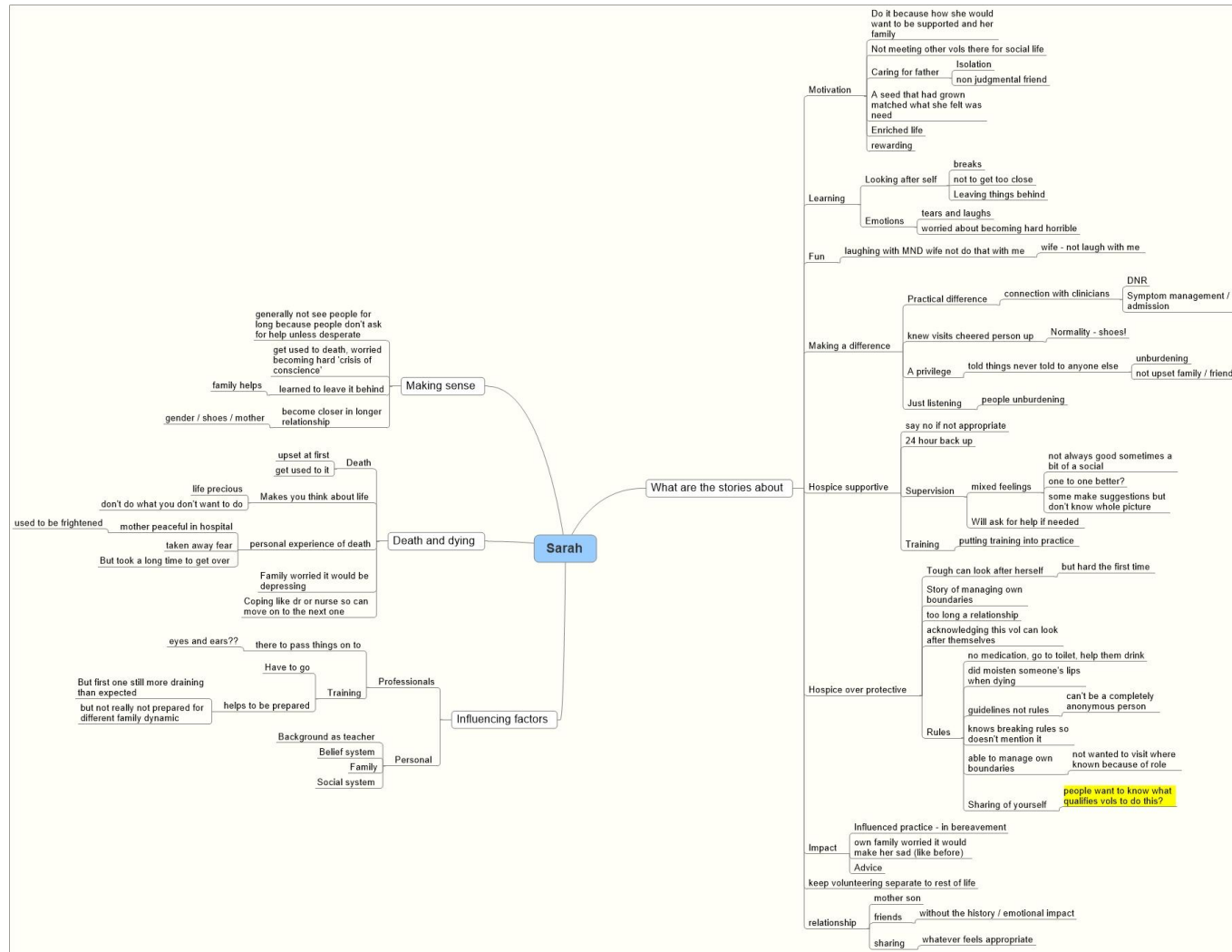
Appendix 11 ATLAS.ti examples of groups of threads

Code Family: Stories about attitudes to death and dying
Created: 2015-01-28 10:21:59 (Super)
Codes (52): [d&d - affected by death a bit] [d&d - Alzheimers inspire to do own planning for death] [d&d - Alzheimers more upsetting] [d&d - assumption family not acknowledge] [d&d - coping with the deaths] [d&d - coping with the deaths using family and hospice] [d&d - death expected] [d&d - death part of life] [d&d - evidence of experience and knowledge] [d&d - family worried it would be depressing] [d&d - getting used to death] [d&d - grateful for health] [d&d - humour] [d&d - losing a partner devastating] [d&d - made her think about it in more depth] [d&d - make the most of life] [d&d - makes you more aware] [d&d - makes you think about life] [d&d - makes you think about life an example how to cope] [d&d - no change not really thought about it] [d&d - nore accepting] [d&d - not able to discuss not her place] [d&d - not as scarey] [d&d - not depressing] [d&d - not frightened comfortable] [d&d - not phased by death] [d&d - not talked about dying not saw how hospice could help] [d&d - other deaths made him retire early] [d&d - own experience of death] [d&d - palliative care & bereavment knowledge] [d&d - people know when they are dying] [d&d - recognised dying] [d&d - sadness and normality] [d&d - surprised be people's strength getting on with it] [d&d - was fearful of being around death] [d&d - we are all the same] [experience - being there at the death] [experience - death devastating] [experience - death mix of sadness and privilege] [experience - going to the funeral meeting relatives] [experience - going to the funeral meeting relatives upsetting not known] [experience - joke so many deaths] [experience - know people are dying] [experience - not talk about life / illness] [experience - sadness and surprise] [experience - talked about dying - ending life] [experience - talking about funeral] [experience - weird being there at death] [learning - attending funeral helps say goodbye and move on] [making sense of - coping like dr or nurse] [making sense of - death, society and hospice making it more civilised] [making sense of - different types of grief]
Quotation(s): 75

Code Family: Stories about rules
Created: 2015-02-06 09:58:14 (Super)
Codes (55): [experience - deciding how to manage own boundaries] [experience - similarities relating to own experience about dementia] [experience - would like more medical information] [experience - appreciate own family] [experience - better not to say in case told off] [experience - boundaries - mix of not disclosing and sharing tel number] [experience - breaking rules talking to friends] [experience - breaking rules talking to friends can't always anonymise] [experience - can't help getting emotionally involved] [experience - challenge restrictions] [experience - checked if ok interview after death] [experience - confidentiality - everybody knows anyway] [experience - coping with constraints] [experience - frustration - solved by doing other roles] [experience - getting it wrong] [experience - getting it wrong being told off] [experience - influencing change in rules] [experience - issues of sharing telephone numbers] [experience - manager - authoritative voice] [experience - managing lone working because feel concerned] [experience - not allowed to use nursing experience] [experience - not get too close] [experience - not share own as a volutneer] [experience - not sharing of yourself] [experience - not sharing of yourself - pt insists] [experience - not understand constraints not match expereince at weekends] [experience - one sided conversation] [experience - overstepping the rules justification] [experience - permission from manager] [experience - restrictions] [experience - restrictions can't cross the line] [experience - restrictions in contradiction to feedback from patients] [experience - restrictions take getting used to] [experience - restrictions trained and explained] [experience - role express / share views] [experience - rules - left to volunteer to decide] [experience - rules some activity outside of service child bereavement] [experience - rules will do it when remember] [experience - some things need a professional] [experience - sticking to the rules] [experience - story of not being allowed to help / dysfunction] [experience - story wanting to do more frustration but needs someone to say no] [making sense of - boundaries using experience] [making sense of - chosen to stretch some boundaries] [making sense of - hospice protection, but can protect self] [making sense of - rules a bit over the top] [making sense of - rules but not challenging them] [making sense of - rules dogs need permission to visit] [making sense of - rules it's about trust] [making sense of - rules representing hospice not a friend] [making sense of - rules there to protect patient, volunteer and hospice] [making sense of - sharing because always done so] [making sense of - there for them not for you] [making sense of - why can't be a normal conversation] [making sense of - why told off and different perspectives]
Quotation(s): 82

ATLAS.ti examples of groups of threads – Continued

Code Family: Stories of friendships
Created: 2015-02-06 10:01:10 (Super)
Codes (27): [experience - became part of family invited to celebrations] [experience - become part of own family] [experience - becoming a friend] [experience - becoming a friend a new friend] [experience - comforting visits looked forward to] [experience - companionship] [experience - companionship and respite] [experience - companionship doing ADL] [experience - concern about ending relationship] [experience - conversation] [experience - described as a friend] [experience - doing as a friend not a volunteer] [experience - feeling natural] [experience - getting close] [experience - getting on] [experience - home dynamics with TV partner] [experience - looks after other people / friends] [experience - not always gel] [experience - not time to develop relationship] [experience - share stories about own families] [experience - story - care and loneliness] [experience - story of friendship] [making sense of - can't be a friend and a volunteer] [making sense of - pals] [making sense of - reflections about developing friendships with volunteers] [making sense of - relationship friendly professional] [making sense of - volunteer you look in on it]
Quotation(s): 41

Code Family: Stories about living
Created: 2015-05-22 09:49:27 (Super)
Codes (11): [d&d - death part of life] [d&d - grateful for health] [d&d - makes you think about life] [d&d - makes you think about life and make the most of it] [d&d - visiting more about living than dying] [experience - companionship doing ADL] [experience - encouraging patient to volunteer] [experience - life enhancing] [experience - listening to life stories] [experience - story - previous life] [experience - talking just natural life not illness]
Quotation(s): 20