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Advancing education and support around death, dying and bereavement: hospices, schools and health promoting palliative care

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Doctor of Philosophy

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2015

Declaration

I hereby declare that

- a. This thesis has been composed by myself.
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Sally Paul

January 2015

Abstract

Background: This thesis stemmed from my experience as a hospice social worker. In this role I was aware that children were often excluded from conversation, education and support about death, dying and bereavement and was keen to explore how the Hospice team could address this issue. My practice experience paralleled UK policy making on end-of-life care, which argued for discourse on death, dying and bereavement to be promoted in the community to help prevent negative end-of-life and bereavement experiences (Scottish Government 2008; Department of Health 2008; Department of Health 2010). In Scotland, engaging with schools to equip children with skills and knowledge to cope with death and bereavement has been emphasised (Scottish Government 2010). These policy movements recognise the significance of public health approaches to end-of-life care, which focus on the multi-dimensional (physical, psychological and social) nature of problems and required solutions. Recently, such approaches have been gaining recognition concerning their contribution to end-of-life care. It has been suggested that hospices are well situated to promote such activities due to their expertise in end-of-life care (Salau et al. 2007).

Aim and objectives: This thesis aimed to explore, implement and evaluate models of best practice in which hospices and schools can work in partnership to promote education and support around death, dying and bereavement from a health promotion perspective. It specifically sought to increase understanding about current practice in primary schools related to death, dying and bereavement and develop practice knowledge about the role of the Hospice in working with school communities to enhance such work.

Methods: The research was facilitated in two primary schools in Scotland, using collaborative inquiry within an action research methodology. It was conducted over three phases. Phase one (preparation and scoping) involved a literature review, visits to other hospices and focus groups with hospice staff. Phase two (exploration) included a series of interviews and focus groups with children aged 9 – 12 years, parents and schools staff to develop collaborative inquiry and engage in a process of

change. Phase three (planning and developing) comprised of deciding and advancing models of practice.

Findings: Practice innovations were identified at each school that were of relevance to the school curriculum, the relationship between hospices and school communities, and the relationship between hospices and the wider society more generally. These innovations can be understood as health promoting palliative care activities, as defined by Kellehear (2005), due to the process in which they were designed and their focus on developing capacity to respond to death, dying and bereavement.

Conclusion: The action research process identified the significance of sharing and transferring knowledge across and between hospice and school communities. It demonstrated that hospices have unique capacity to develop conversation, education and support around death, dying and bereavement in school communities. In order to fulfil this potential role, this will require a reorientation of service delivery that focuses on wider training, support, awareness raising and advocacy. The study has also demonstrated that action research is well situated to develop health promoting palliative care activities according to the shared goals of participation, ownership and empowerment.

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Dedicated to

Anthony Paul

(26th June 1944 – 25th March 2011)

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Chapter 1: Introduction

This thesis provides an account of an action research study, undertaken to explore and develop practice between a hospice and two primary schools. It is the product of research carried out as part of my role as a hospice social worker and PhD student. In this chapter I discuss the context for this research, exploring how it is shaped by my profession, current practice and the palliative care research agenda. I introduce the aim and research questions, outline the structure of the thesis, and explain the significance of this study in relation to the potential role of the hospice in the community and the emerging field of public health approaches to palliative care.

1.1 A note about language

This thesis is written in first person to bring to the fore how I engaged with the research process. This is in keeping with the theoretical perspective of action research, discussed in chapter four.

For the most part, I refer to the people who took part in this study as participants. This research aimed to develop collaborative inquiry, so that participants were co-researchers along the research journey. Participation, however, was influenced by a variety of factors and the degree to which people became co-researchers varied at different times in the study. Participant is therefore used as a generic term, with focus placed, throughout this thesis, on the extent to which collaborative inquiry was established.

I use the term child or children to distinguish those research participants under the age of 12. I recognise that this term carries certain images and associations, impacted by how childhood is understood and defined. This is discussed in more depth in chapter two. I use the term child, however, for ease of reading and because the research was based in primary schools where child is the term most commonly used.

The research was funded and supported by Strathcarron Hospice. The management team agreed that the identity of the Hospice could be made known in this thesis.

1.2 The research context

In 2007, I began working as a social worker at Strathcarron Hospice. Strathcarron Hospice (referred to as the Hospice thereafter) provides specialist palliative care to a catchment area of almost a third of a million people across a rural area of Scotland. Palliative care as defined by the World Health Organisation is

‘an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.’
(WHO 2011)

This requires working with individuals and their families both during and after the illness. The Hospice employs a team of over 150 staff, supported by over 350 volunteers. Staff include: a Pharmacist; a Chaplain; Social Workers; Consultants; Doctors; Nurses; a Physiotherapist; Complementary Therapists; an Occupational Therapist; Lymphoedema Nurses; Community Nurse Specialists; Fundraisers; and administrative support. Services include: in-patient care; community care; hospice at home; day hospice; bereavement support; complementary therapy; physical therapy; occupational therapy; patient and family support; lymphoedema; pharmacy; and the department of education, practice development and research. It supports two acute hospitals and the local primary care trust. Currently the Hospice receives 38% of its funding from the National Health Service (NHS). It needs to raise an additional £3.5 million to deliver its services.

My initial role was a newly created position that involved coordinating the organisation’s plans for setting up a children’s bereavement service, as well as completing other social work tasks within the setting. It was an exciting opportunity, and my senior and I spent a great deal of time liaising with the local community and service providers to design and facilitate the service. Referrals were much greater than anticipated and, six months after I started, we were already holding bereavement groups for children and their parent/carers two (sometimes three) nights per week. Three years into my post, the Hospice management team invited staff to put forward potential research ideas. The children’s service was beginning to build reputation for

its work in the community and we were receiving increasing numbers of referrals from other professionals as well as requests from schools and social work agencies to provide bereavement training. I had run over 20 groups and, although each group involved different challenges, I was keen to develop my skills and knowledge further. My experience of working with the children meant I was becoming increasingly aware of an apparent taboo surrounding death, dying and bereavement, which often resulted in children being excluded from important conversations about significant aspects of their lives. There were some occasions when children were referred for specialist bereavement support unnecessarily. This was due to reticence of the adults to communicate with the child about bereavement issues, referring them on to us when sometimes they had not even asked the child how they were feeling. Broad and Fletcher (1993) argue that the right time for practitioner research is when an experienced professional is ready for a new challenge that involves reflecting on their work and moving forward to find out more. I recognised the significance of providing a bereavement service. I was keen, however, to engage with the social work task from a proactive standpoint, seeking to prevent negative bereavement experiences by developing capacity within children's existing communities to manage death, dying and bereavement.

My experiences of the children's bereavement service happened alongside policy movements in the UK, which called for discourse and education around death, dying and bereavement to be promoted (Scottish Government 2008; Department of Health 2008; Department of Health 2010). These documents acknowledge that a reticence to discuss end-of-life care and bereavement impacts negatively on related experiences. In Scotland, schools were identified as an important target to ensure that children develop the skills and capacity to talk about, and cope with, death, dying and bereavement (Scottish Government 2010). I thus put forward an idea that involved researching possible interventions for working proactively with children in the school setting. The aim of this was to develop practice that would demystify and normalise death, dying and bereavement so that teachers and children are better prepared for and more able to talk about loss. I had felt that developing work in this area could potentially allow some children to receive appropriate support and

acknowledgement about their loss from professionals already in their immediate community, not pathologising bereavement as an experience that only specialists can address.

1.2.1 Towards a PhD: working across disciplines

Becoming a competent consumer and producer of empirical research was important to me. The education I received during my professional social work training emphasised evidence-based practice and reflexivity as integral to both best practice and safe practice. Social work is often subject to criticism. High profile cases such as the ‘Victoria Climbié’ (Laming 2003) and ‘Baby Peter’ case (LSCB 2009) continue to bring the profession into focus, making it apparent that social work practice should be founded on the best available research. Government reports, such as *Changing Lives, 21st Century Review of Social Work in Scotland* (Scottish Executive 2006) and *Options of Excellence in England* (Department of Health and Department of Education and Skills 2005) reiterate this focus, highlighting the ability of research to improve evidence-based policy and practice. A variety of measures have been undertaken to give emphasis to the importance of social work research and build capacity in the profession. This has included: the implementation of the new social work degree, which Orme and Powell (2007) state aimed to situate the professional requirements of the social work profession alongside academic requirements of university education; and the launch of the Joint University Council Social Work Education Committee (JSWEC) research strategy, which Bywaters (2007) highlights aims to both improve the quality of social work research and increase the capacity and skills of social work academics to do so. Such measures identify a link between research and professionalism. They assume that knowledge generated through research can challenge current practice and policies, which D’Cruz and Jones (2004) assert ensures practice that is relevant and useful. A number of authors recognise, however, that there deficit in terms of the research produced in social work as well as its usage by practitioners (Orme and Shemmings 2010; Steyaert et al. 2011). Consequently, Shaw (2005) argues that there is a need to build research capacity within the profession that seeks to promote critical practice and develop the social work research base, giving strength to the profession.

Steyaert and colleagues (2011) recognise the importance of research across disciplines for its contribution to effective and efficient practice. According to Orme and Shemmings (2010), research *for* and *on* social work can be generated by a number of disciplines to help social workers understand the people, service, policies and legislations they work with and for. Research *by* social workers involves knowledge generation *from* practice. The knowledge base that social work rests on is thus diverse, crossing a number of disciplines. This parallels research in palliative care, which Addington-Hall and colleagues (2009) argue must be multi-disciplinary. This involves drawing on a range of research methodologies, and on researchers from different academic backgrounds, to meet the aims of palliative care, which attempt to address the physical, psychosocial and spiritual needs of patients and their families. The number of different professionals and lay people working at the Hospice is testament to the diverse training and expertise that is brought together: if these skills and experiences are needed in practice, then they are equally needed in education and research.

The Hospice has always offered research opportunities. Such practice is in keeping with the modern hospice movement, which Hockley (1997) asserts is renowned for combining practice, research, education and training across a multi-disciplinary team to enhance the lives of service users. Historically, these research positions have only been available to doctors completing a Doctor of Medicine (M.D.). This time, however, the management team decided that they wanted to encourage other professions to try research. I was aware of both the debates surrounding social work research and movements in palliative care policy making and I was keen to contribute to these agendas. Moreover, I enjoyed research and, as my research training was limited, I was keen to develop my skills. I thus suggested that my research proposal was completed as part of a PhD across both social sciences and medicine. This was in recognition of the multi-disciplinary aspects of both palliative care and social work. I felt that to choose one profession would both disadvantage the research and my learning. This idea was accepted and, in September 2010, my post was filled for three years with the agreement that I continued practising at least

one day a week at the Hospice to both assist with the heavy work load and maintain a presence in the Hospice.

1.3 Practice-led research

Mitchell and colleagues (2010) argue that a pivotal aspect of practitioner research is the role of the practitioner in shaping the focus of the research which is linked to practical benefits. Gredig (2011) asserts that practitioner research should ‘enlarge and refine the knowledge base upon which professional [...] action rests’ (p.55), claiming that the process of development is the key to linking research and practice. Although there are no specific methods linked to practitioner research, it is often identified as using participatory and emancipatory styles of research (Fuller and Petch 1995; Corby 2006; Hockley et al. 2013). For example, Hockley and colleagues (2013) recognise the importance of adopting a flexible approach to research methodologies in palliative care, yet advocate participatory approaches to research, specifically action research, as a way to both confront assumptions about care of patients and families and advance end-of-life care. The values and aims of participatory research run parallel to the values and ethics of social work practice.

I have described that engaging with the social work task to advance practice was important to me. It was also important to my organisation, which was keen to see specific practice innovations developed as a result of funding the research. D’Cruz and Jones (2004) highlight the ethical and political dimensions of social work and they assert that the social work researcher ‘is a practitioner like any other social worker who aims to bring about social change’ (p.32). Furthermore, Shaw and Gould (2001) suggest social work researchers ‘should be judged by the extent to which they promote social work inquiry, marked by rigour, range, variety, depth and progression’ (p.4). My aim here is not to outline practitioner research as a distinctive or superior genre of research, but to emphasise its focus on change and development. For me, this has impacted on how I designed my research, prompting me to opt for an action research approach. This will be discussed in more depth in the methodology section of this thesis. It is important to highlight here, however, that similar to social work, action research has been regarded by a variety of authors as a

political activity (Williamson 2010; Coghlan and Brannick 2001; McKernan 1996). It enables plans for change to come from the people who will deliver or are the recipients of change. It is operational field research that deals with everyday issues of practice to increase effectiveness, 'theories are not validated independently of practice and then applied [...] they are validated through practice' (McKernan 1996, p.4). Similar to arguments for defining social work research, the process of development is a significant factor for how action research should be recognised and assessed. It is a research approach that resonates with my commitment to social work research as both a PhD student and a hospice social work practitioner committed to improving practice. I thus arrived at this PhD with a twin rationale to contribute to theory and practice.

1.4 Research aim and questions

This study aims to explore practice between a Hospice and schools that engages children in education and support around death, dying and bereavement. Five research questions were posed to achieve this aim:

1. What are the challenges and opportunities for discussing, teaching and supporting death, dying and bereavement experiences with children in primary schools in Scotland?
2. Is there a role for primary schools and hospices to work together to develop discussion, education and support around death, dying and bereavement with children?
3. If so, what actions can be successfully implemented?
4. How do these actions relate to the principles and practice of health promoting palliative care and hospice service provision?
5. What can be learned from the action research process?

1.5 Structure of the thesis

Sommer (2009) notes that the structure of a thesis built on action research is likely to look different to a more conventional thesis. Winter and Munn-Giddings (2001) argue that this is partly due to the focus of action research on learning and change, not on constructing interpretations or descriptions (Sommer 2009; Winter and Munn-Giddings 2001). Writing this thesis was thus a journey in itself. It has taken numerous drafts and restructures in an attempt to capture the extent to which learning and change took place within both me, as a practitioner, and the organisations in which I was working.

The thesis is comprised of eight chapters, which are summarised below.

Chapter 1: Introduction

This chapter outlines the context of the research, discussing the characteristics of the organisation funding this research and my role within this organisation as a social worker and researcher. I also highlight my commitment to social work and palliative care research and practice, describing how my professional training and experience has impacted on the research design.

Chapter 2: Literature review

The literature review provides a critical summary and analysis of the theoretical concepts relevant to my practice experiences. I specifically address the concept of a taboo around death, dying and bereavement, going on to explore how this relates to ideas around children and childhood.

Chapter 3: Policy and practice development

This chapter gives an overview of UK policy making, which recognises a need to renegotiate the place of death, dying and bereavement in modern society. I discuss the current emphasis on public health approaches to end-of-life care, in particular health promoting palliative care, which have been identified as a way forward to

promote openness around death, dying and bereavement and empower communities to adapt and cope.

Chapter 4: Methodology

This chapter discusses action research as a methodology for advancing practice, arguing it is the methodology most suited to this research. I introduce the theoretical framework on which this is based and consider the significance of reflexivity. I describe the research design, explaining how participating schools were recruited, what methods were used and how data was collected and analysed. I finish by discussing ethical considerations and how these were managed.

Chapters 5 and 6: Investigating and developing practice with the Roman Catholic primary school (RCPS) and investigating and developing practice with the non-denominational primary school (NDPS)

These two chapters provide an account of the action research process at the two primary schools involved in the research. I reflect on the different phases of the research, exploring how collaborative inquiry was established to engage in change processes.

Chapter 7: Discussion

This chapter combines the findings from the previous chapters. It critiques the different practice innovations initiated at each school and explores their significance in relation to the role of the Hospice working with primary schools and the literature. I relate the innovations to health promoting palliative care and suggest that they are in keeping with its principles and goal of developing community capacity in end-of-life care and bereavement. The second half of this chapter reviews the action research approach, discussing its strengths and limitations in the context of this study.

Chapter 8: Conclusion

This chapter summarises the findings from the previous chapters by directly responding to the research aim and questions discussed in chapter two. It also discusses the implications of the findings, providing recommendations for future research, teaching, policy and practice. It closes by reflecting on my own research experience and how I feel I have developed as both a researcher and practitioner.

1.6 Significance of the study

This study is significant for a number of reasons:

- Practice that engages children on issues concerning death, dying and bereavement is underdeveloped. This research specifically illustrates how to develop practice in this area that meets the needs of children and school communities.
- Given that the population is expected to live longer with a range of progressive illnesses, end-of-life care providers will not be able to meet this growing demand and there is therefore a need to develop community capacity. This study directly explores developing capacity in the community to ensure that children are better able to cope with death, dying and bereavement.
- The research actively engages with the task and role of the Hospice in working with school communities. This does not involve evaluating pre-existing services/roles, but an investigation of how the Hospice should practice in the community.

Chapter 2: Literature review

In the previous chapter I discussed how this research originally emerged due to my social work practice in a hospice, particularly through my involvement with the children's bereavement service. During this time I was increasingly aware of a perceived taboo surrounding discussions connected to death, dying and bereavement, specifically with regard to children, who were at times actively excluded from important information. These experiences were strengthened by both end-of-life care policy and current media attention that identify a taboo around death, dying and bereavement in contemporary society. This chapter introduces the broad theoretical concepts which underpin this thesis and which are relevant to these experiences and perceptions. These theoretical concepts can be presented as belonging to one of three general areas, which include: ideas around the taboo of death, dying and bereavement; ideas on children and childhood; and finally ideas relating to children, death, dying and bereavement. It will be argued that the prominent theme throughout the literature is a debate about the extent to which death is regarded as a taboo subject. Moreover, it will be suggested that discourses around death, dying and childhood are framed by ideas about what is considered acceptable and unacceptable behaviour and attitudes in current social settings. Children's involvement in death, dying and bereavement is therefore framed in particular historical and culturally specific ways. I will begin with a brief discussion of taboo before going on to look in more detail at the literature as it relates to death, dying and bereavement, children and childhood, and children and death.

2.1 Literature review methodology

This literature review was structured and targeted to capture as much as possible of the relevant literature. It includes research on death and dying in Western societies as well as non-empirical discussion papers. Literature was identified using a simple library catalogue search as well as searching seven bibliographic databases: ProQuest, JSTOR, ERIC, ScienceDirect, EBSCO, JISC journal archives and Medline. The search terms used in both this chapter and chapter three are highlighted in Appendix 1. Publication dates were initially selected from 1990 to

2013. It was thought this period would provide the most relevant literature. As the search was iterative, however, key literature emerged prior to these times that are also included. Papers were selected first on the basis of the title, then on the abstract, and then on reading the full papers.

2.2 Defining taboo

It is argued that the term taboo was first introduced to the English Language in 1777, by Captain Cook (Schoemaker and Tetlock 2012; Steiner 1956). Allan and Burrige (2006) discuss how it was used with reference to how the Polynesians used the word 'tabu' to describe things that 'were not to be done, entered, seen or touched' relating to foods, improper sexual relations, theft and murder (p.4). The term was later adopted by anthropologists such as Margaret Mead, who, also describing the Polynesians, discussed taboo in relation to any enforced prohibitions supported by religion, spiritual forces or 'which carry no penalties beyond the anxiety and embarrassment arising from a breach of strongly entrenched custom' (in Steiner 1956, p.146). Based on these early definitions, Schoemaker and Tetlock (2012) argue that the term taboo became used to understand, describe and define group norms and role identities which develop a 'shared and meaningful social order' (p.8). The usage of the term taboo has remained largely unchanged since Cook's first description. This can be seen by the current definition provided by The Oxford English Dictionary whereby taboo is

'a social or religious custom prohibiting or restricting a particular practice or forbidding association with a particular person, place, or thing.'

Like earlier definitions, it identifies taboo as related to specific types of behaviour defined by what is customary and acceptable within a given context. Walters (1991) provides a helpful extension of this definition by relating taboo to the significance of social practices as opposed to something enforced by legislative frameworks:

'taboo refers to something prohibited, forbidden by custom rather than law.' (p.295)

Taboos are thus more flexible than laws. Steiner (1956) and Schoemaker and Tetlock (2012) note that this draws attention to the concept of taboos as changing over time, caused by a variety of factors including changes in values, technological advances and so on, as opposed to static and enduring. This emphasises the importance of social context in defining what is a taboo and what is not. It also highlights the idea of restricting behaviour according to embedded beliefs and values that are upheld during a certain time and space. It would appear then that a taboo is a way of prescribing behaviour within a particular social context.

Given the link between taboo and the prescription of behaviour it can be argued that a taboo is a form of social control that maintains a status quo through controlling certain behaviours and legitimising others. Allan and Burridge (2006) assert that shared taboos can also be a sign of social cohesion. Based on this assumption, anything which is maintained as a taboo necessarily involves groups behaving in similar ways, representing unity, consistency and shared values. Nevertheless, as Steiner (1956) highlights, a taboo is concerned with ‘social mechanisms of obedience [and] specific and restrictive behaviour in dangerous situations’ (p. 20). Freud (1912) argued that exposing oneself to something which is a taboo involves mixed emotions and, although violating a taboo might be exciting, it is equally scary due to the perceived consequences of that violation. A person can be rendered free from this danger by avoiding it or not dealing with it, thus reinforcing something which is deemed the taboo (ibid). Upholding or conforming to a taboo is therefore linked to protection of self and of society as a whole. Schoemaker and Tetlock (2012) assert that the avoidance of taboo subjects, due to fear, leaves people underprepared when they are faced with connected situations. They further argue that violating a taboo results in: moral outrage, such as contempt, anger and disgust; sanctions, such as fines punishment, public humiliation and so on; or calls for moral cleansings which result in the ‘violators recommitting to prescribed values through symbolic acts’ (p.9). They also argue that many taboos are connected to values which are held so sacred that they cannot be violated. These include ‘the sanctity of life and the human body, the need to protect children and their innocence, or the need to improve the environment for future generations’ (p.9). If this is the case, it immediately

highlights a connection between taboo and death, due to death threatening both the sanctity of life and the human body. This means that the acknowledgment of and response to death, dying and bereavement, in association with self or others, may be socially unacceptable due to its challenge to the sacredness of life; death then cannot be banned but it might be avoided through social practices that are deemed acceptable, for example, the focus placed on ‘fighting’ a incurable cancer diagnosis as opposed to ‘accepting’ and/or ‘living with’ such a diagnosis.

2.3 Death, dying and bereavement: a contested taboo

The above discussion highlights the usage of the term taboo as a concept which is connected with actions that are forbidden, unmentionable, restricted or prohibited according to social customs. This understanding of the term taboo draws attention to the public (social) aspects associated with death, dying and bereavement as opposed to personal experiences. The concept of death, dying and bereavement as a taboo within current Western societies is disputed within the social sciences. Jupp and Howarth (1997) assert that, since antiquity, death has had a strong presence in philosophy, theology and the arts, and in the UK, anthropology and medicine have always considered death as a crucial area of study. Aside from medical sociology, however, death was largely absent from the social sciences until the middle of the twentieth century. It was at this time that ‘death as a taboo’ thesis began to emerge. This was largely through the influential work of Geoffrey Gorer (1955, 1965) and Philippe Ariès (1974, 1981). Gorer claimed that death had replaced sex as the taboo subject of the twentieth century, becoming ‘an aspect of human experience that is treated as inherently shameful or abhorrent, so that it can never be discussed or referred to openly’ (1955, p.171). Similarly, Ariès (1974) claimed that death had become forbidden in modern society due to the high value placed on happiness and romantic love, which are undermined by the death of someone you love. Both Gorer and Ariès asserted that this taboo was a result of influences in modern medicine, secularisation and individualism. Modern medicine, with its focus on prolonging life, meant that death became managed by professionals and, for the most part, kept hidden, contained and privatised in medical institutions. Previously, death had been something which was a visible part of society, managed by the community or church.

Current society was therefore denied access to certain aspects of death, dying and bereavement, meaning that individuals became less experienced and less able to navigate their way through related experiences. Likewise, the process of secularisation and individualisation is argued as providing a diversity of approaches to managing death and dying, leaving people ‘uncertain, socially unsupported and vulnerable when it comes to dealing with their own death’ (Mellor and Shilling 1993, p.417). The work of Gorer and Ariès is often discussed in association with arguments which claim Western societies are fundamentally ‘death-denying’ (Becker 1973; Illich 1976; Feifel 1959). This term goes beyond identifying a taboo around death, dying and bereavement, and claims that societies refuse to admit the existence of death in both others and the self.

From the 1970’s onwards there has been a proliferation of interest in death, dying and bereavement across both the social sciences and popular discourse, and, since the 1980’s, the ‘death as a taboo’ thesis has been strongly challenged. For example, Walter (1991), Kellehear (1984) and Seale (1998), assert that the ‘taboo of death’ is questionable within current Western societies. These scholars raise a variety of important factors identifying how today’s societies are far from ‘death-denying’ but have adapted to acknowledge and manage the changing face of death, dying and bereavement. Furthermore, the interest in death, dying and bereavement across academia and in popular discourse has been asserted by Mellor (1993) as providing impetus to the argument that death is not a taboo but something which is recognised and addressed. This is confirmed by Sayer (2010), who notes that death is perhaps hidden and individualised, but not taboo. Despite the contested nature of theoretical debates surrounding the taboo of death, dying and bereavement, a number of key areas emerge relating to how these issues are conceptualised. These broadly connect to medical, religious, psychological and social understandings, which both challenge and facilitate the death taboo thesis. Although these areas overlap to varying extents, they provide a framework to explore current theory on the perceived taboo of death, dying and bereavement.

2.3.1 The idea of medical death

The 'medical death' acknowledges how developments in medicine have influenced the taboo of death, dying and bereavement in relation to conceptualising the 'dying person', 'the dead person' and the 'grieving person'. Prior to the middle of the twentieth century, Conway (2007) and Kellehear (2007) contend that death tended to happen quickly, at home and usually via infectious diseases, such as polio, tetanus and tuberculosis, that affected all age groups. People who were dying and/or dead were therefore a much more visible aspect of everyday life, and Illich (1976) argues there existed 'a constant awareness of the gaping grave' (p.177). Over the last 80 years medicine has made important advances, meaning that healthcare professionals now have the ability to prolong life in ways that had previously not been considered. Death is currently more predictable and more technically managed and Elias (1985) claims that the awareness of death is 'overlaid by the endeavour to postpone it more and more with the aid of medicine' (p.46). Advances in medical science have thus been criticised for contributing to the taboo of death by forbidding dying through prolonging life. It is maintained by several authors that healthcare professionals focus so much on extending life that death is therefore seen as an unnatural process and something that can be prevented and avoided (Gallagher 2001; Gorer 1955). In this context, death, dying and the experience of bereavement are unmentionable, as they draw attention to the limitations in medical science and human bodies.

The above discussion relates to what Walter (1991, p.302) describes as the 'limited taboo' thesis. This connects the taboo of death, dying and bereavement with particular professionals who find death difficult to deal with, not society as a whole. Illness that cannot be cured or controlled is often seen as a failure of the medical profession as they are dedicated to keeping people alive and, as a result, this professional group may avoid talking directly with patients about death (ibid). Similarly, Zimmerman (2007) highlights that although 'death denial' is debated within the social sciences it remains a key argument within the medical literature. She suggests that this concept is used by health professionals to label patients who will not participate in the acknowledgement and planning of their death as they present a barrier to what is deemed good practice in palliative care. They thus fail to

see denial as a way of ‘individual psychological coping’ (p. 299). Moreover, Kellehear (1984) highlights that patients who collude with professionals by not talking about death and/or remain ‘cheerful’ in the face of death perhaps do so according to the value prescriptions of that organisation and the accepted social norms. He asserts that denial is thus influenced by medical professionals and may not reflect the actual experience of individual patients. Death-denial is:

‘an interactional ritual which has characterised organisationally: (a) problems of poor communication between the modern doctor and his patient and (b) the spread of stigma of death as another form of medical handicap which creates an ambiguous social status for its holder.’ (Kellehear 1984, p.717)

The taboo of death in this situation is thus defined by its setting. It is not homogenous to all public life, but a product of certain beliefs and values which are only applicable within certain social situations.

Advances in medicine mean that death and dying are now linked primarily with serious illness and ageing. Holloway (2007) asserts that medical treatment and the ability to both prevent illness and prolong life until old age mean that death has potentially become ‘a fragmented phenomenon’ made up of a number of smaller deaths (p.43). These include ‘social death’, when the person no longer exists as a social being, ‘personal death’, which involves ‘the loss of personhood’, and ‘biological death’ (ibid, p.44). The different aspects of death thus provide focus to debates around who controls death as well as the impact of multiple deaths. This, in turn, raises a number of ethical questions which are frequently voiced in public domains, such as debates on euthanasia and assisted suicide. Kellehear (1984) argues that because most people now die when they are old, this has resulted in dying being included as part of life’s stages. It is therefore a concept present in the public arena, giving new meaning to the idea of ‘a public death’ (ibid, p.717). This does not mean, however, that society readily accepts ageing, then dying, then death, and then bereavement as part of the life course. Ageing is strongly connected with social isolation and experiences of loss such as the loss of role, independence, mental and physical ability and so on. Exley (2004) refers to those dying in old age as the ‘disadvantaged dying’ as they are potentially ‘invisible’ in both health services, due

to a lack of terminal diagnosis that prompts medical attention, and society more broadly (p.120). The experience of ageing, dying or bereavement means you are therefore moved to a lower status and uniquely isolated. Moreover, McConnell and colleagues (2012) argue that if death is associated with ageing it can be avoided and managed by prizing youth and health and stigmatising ageing, claiming we are a youth obsessed culture. This focus on youth and health is commonly shown in the public domain through the popularity of advertising which focuses on the latest beauty treatments to minimise the visible effects of old age.

Furthermore, Kellehear (1984) asserts that societies cope with their fears organisationally, by developing medical treatments, hospital care and so on. This challenges the assumption that medicine is only responsible for creating a 'death taboo'. For example, the hospice movement and palliative care more broadly arose in recognition of the reality that dying people were often ignored in hospitals as there was nothing that could be done for them and they were thus dying in pain and alone. Lawton (2000) critiques the hospice movement for contributing to keeping death behind closed doors, yet it could also be argued as responding to the taboo of death by rejecting the accepted social norm of that time and choosing to prioritise the health of those who are dying. This highlights that although death is perhaps hidden in buildings and managed by professionals, it is undoubtedly acknowledged and responded to organisationally and socially. Conversely however, Gorer (1955) asserts that a preoccupation with managing and preventing death has resulted in a preoccupation with risks associated with death. This situation is arguably ever present today through the increase in public health measures, such as compulsory immunisation for children, smoking bans, public awareness campaigns on health eating and so on. Public health thus tells us that if we have the right immunisation at the right time, eat a healthy 'five-a-day', stop smoking, wear our seatbelts and so on, we can limit risks leading to a premature death. Although this enables people to feel that they have more control over their own lives and bodies, death is kept at a distance and notions of immortality are strengthened. Moreover, the dominance of medicalised healthcare is seen by Illich (1976) as becoming an obstacle to a supportive and healthy social life. There is now a push to put death back into the

community, which will be discussed in the next chapter, however, Illich (1976) argues that the dominance of medicalised health deprives individuals of the opportunities to control their own physical and emotional health. This results in deskilling society's ability to cope with suffering. It also means that death has become a speciality that only medical professionals are equipped with the skills to manage. Societies therefore increasingly rely on these professionals to manage all aspects of physical, emotional and social care, thus removing opportunities to develop experience and coping strategies.

2.3.2 The idea of religious death

The move towards secularisation and the declining role that organised religion now plays in the majority of people's lives is related to contributing to the taboo of death, dying and bereavement. As Clark (1993) highlights:

‘following the collapse of grand narratives, particularly those associated with formal religions, individuals in modern societies must share their own identities and systems of meaning within a private sphere of social relations.’ (p.4)

In pre-modern cultures, religion provided communities with an established framework through which to respond to death and grief. Gorer (1965) notes that this included prescribing rules of behaviour such as how to dress, what to do and how to treat mourners. Mellor and Shilling (1993) suggest that religion thus prompted and promoted ‘a multiplicity of collective, ritual acts intended to minimise the possible threat of death to the continuance of the social order’ (p.415). These accepted religious responses, behaviours and language enabled symbolic meanings of death to be articulated; the demise of these traditions has resulted in death rituals becoming more privatised. For example, funeral services today are much more personal and attended by those who knew the person well, rather than an entire religious community. Holloway (2007) asserts that such services recognise the importance and significance of the individual, including their unique contribution to life through eulogies for example, as opposed to a focus on religious meaning-making. Moreover, Mellor and Shilling (1993) argue that the move towards secularisation has resulted in a lack of prescription around acceptable behaviour, meaning that there is

currently no ‘analogous secular recognition of the fact that human beings mourn in response to grief’ (p.111). This means that the mourning experience receives little acknowledgement in current society, which may serve to both pathologise the grief experience and isolate those who are bereaved. Similarly, Elias (1985) argues that secularisation has prompted a shift towards informality, which has meant that the previous traditional patterns of behaviour have ‘become suspect and embarrassing’ (p.27). This means that people have no particular framework for approaching someone who is dying and/or mourning and, instead of relying on traditional approaches assigned by religious practice, they become immobilised and do nothing. This process of secularisation has consequently been argued as resulting in removing traditional support mechanisms and guidance about what is and what is not appropriate behaviour.

Religion has also been criticised for being ‘death-denying’ in the sense that, in most religions, death is considered a new beginning to another kind of life. Gorer (1965) argues, however, that religion also provides an established belief system which gives death and life more meaning. The increase in secularisation means that most people lack both ritual and spiritual systems of belief to help aid them through life, death and grief (ibid). Walter (1994) argues that there is currently a revival of death whereby ritual has been replaced by discourse, with emphasis placed on individual experiences of a good death. Thus, although religion can be asserted as giving death more meaning, discourse replaces this by focusing on choice, autonomy and the memories of the life that was lived and the lives that are left behind. This relates to Kellehear’s (1984) argument that societies accommodate themselves to secularisation by dealing with death in ways that are more appropriate to current belief systems. Death and grief have thus become a private matter that must be negotiated according to one’s individual beliefs, culture and coping strategies.

2.3.3 The idea of psychological death

The term ‘psychological’ death is related to the move towards individualism during the renaissance period and a new focus on the individual autonomy of self and identity. This has been linked with the shift towards secularisation, which

emphasises the importance of individual interpretations. Individualism has been asserted by Kellehear (1984) as 'contributing to the conflict and disruption of institutional pressures towards conformity' (p.717). This is highlighted in the quest to make death more individual, resulting in a person being faced with more choices and decisions about their death, or that of others, than ever before (ibid). This can be a confusing area to navigate, specifically when, as has been referred to previously, people today have less experience of managing these situations due to the privatisation of certain aspects relating to death, dying and bereavement. Kellehear (1984) also argues that individualism identifies the rights of individuals to choose. In a medical environment, where historically healthcare professionals have held all of the information and power relating to symptom control, pain management and cessation of care, this raises interesting questions in terms of access to choice and how 'a good death' and 'good grief' are conceptualised. In relation to the taboo of death, dying and bereavement, individualism both challenges the taboo, by encouraging the pursuit of individual priorities, and facilitates the taboo, by causing a crisis of ownership around who is responsible for managing death: the medical profession or the individual. This debate is currently being highlighted in the UK by attempts to legalise assisted suicide, which have so far been rejected. This identifies a clear conflict around an individual's right to choose death and the power of the state to challenge this.

The concept of individualism necessarily involves individuals participating in a process of meaning-making, attempting to understand their perception, place and purpose in the world. Mellor (1993) and Mellor and Shilling (1993) have expanded on Giddens' (1990, 1991) theory of self-identity in relation to individualism and death, dying and bereavement. Giddens (1991) argues that

'Death remains the great extrinsic factor of human existence [...]. Death becomes the point zero: it is nothing more or less than the moment at which human control over human existence finds an outer limit.' (p.162)

Death thus has the ability to threaten a person's understanding of, and control over, their world. It is consequently a challenge to what Giddens' (1990, 1991) refers to as

ontological security, that is, the sense of order and continuity in relation to a person's life events and how a person can make meaning from these events. Death may challenge this process of meaning-making and how an individual negotiates their place in the world. As Mellor (1993) highlights:

‘The essential confrontation with death, one's own death or the death of others, has the potential to open individuals up to dread, because it can cause them to call into question the meaningfulness and reality of the social frameworks in which they participate, shattering their ontological security.’ (p.13)

This line of argument is continued by Seale (1998), who argues that death poses a threat for individuals by making life meaningless. Thus, the image of death in someone else is closely bound up in the image of our self. Seeing death and bereavement present in the lives of others highlights the inevitability of one's own death, or that of someone who is important, potentially challenging how one conceptualises one's self. Elias (1985) argues that the death of another thus ‘shakes the defensive fantasies that people are apt to build up like a wall against the idea of their own death’ (p.10). He goes on to assert that, rather than deal with this threat, people ignore it, thus developing personal boundaries as a form of self-protection. This may lead to a lack of exposure to death as well as an inability to give dying and bereaved people the support they need. This argument is potentially strengthened due to advances in medicine. Kellehear (1998) claims that deaths which do not occur in old age can now be viewed as ‘premature’ or ‘meaningless’ (p.716). Thus, being reminded that someone who is of a similar age and at a similar life stage is dying or bereaved can prompt feelings of fear and insecurity around loss of self. This is enhanced by the focus on youth, ability and achievements in current social and cultural life, which Seale (1998) argues requires turning away from death and embracing life and youth.

Kellehear (1984) asserts that the fear of death is not universal and consequently only applicable to certain groups of individuals and/or communities. He argues that the above argument is psychological in its context and can therefore not be applied to societies in general. Death is thus not a social taboo, but a taboo for particular individuals who rely on the concept of a prolonged life to give their own life

meaning and direction. Likewise, understanding and responding to grief has also become more psychological despite being a universal experience that is individually and socially encountered. A variety of grief theories exist which, although they emphasise the commonality of human experience and feelings, focus on grief as a psychological problem, mediated through factors specific to an individual. Kellehear (2007) highlights that less attention is given to the experience of grief in its more positive aspects in the search for ‘meaning-making’ and that ‘the legacies of loss often increase compassion, empathy and social sensitivity and promote greater dreams, commitment and social visions for changes in personal as well as social and political life’ (p.76).

2.3.1 The idea of social death

As discussed, a number of authors comment that experiences of death were previously more common and thus considered a community affair (Ariès 1974; Gorer 1965; Silverman 2000; Kellehear 2007). As such, death was ‘normalised’, considered part of life and society: a social phenomenon which prompted communal responses (Ariès 1974). Most people now die in institutions such as hospitals, care homes and hospices (ONS 2009). There is some evidence that numbers for people dying at home may be increasing again (ONS 2012). Nevertheless, as Walter and colleagues highlighted in 1995, most people get

‘through many years without either ourselves being seriously ill or someone we love dying, death is generally absent from private personal experience yet is very much institutionalised in public institutions’. (p.581)

The idea of ‘social death’ thus suggests that current society copes with death through creating institutions and professions that help and support people, yet equally keep death hidden in buildings, and Kellehear (2005) argues that death is now a private, medical matter rather than a routine and universal human experience. The list of professionals that support the dying and bereaved is vast and includes doctors, nurses, social workers, funeral directors, clergy, spiritual leaders, police, paramedics, bereavement counsellors, and so on. These professionals are deemed ‘qualified’ to deal with the multiple aspects associated with death and grief from looking after the

dying person, the dead body and the grieving person. People today are therefore less likely to come into contact with dead or dying people unless through a specific choice. Although the professionals responsible for managing death operate in the public domain, traditional community support systems have been replaced by a 'professional' team. Elias' (1985) view that, in the past, communities supported each other better due to the frequent exposure to death, better community networks and religious affiliation has been criticised for being overly romantic. Furthermore, Reith and Payne (2009) argue that death and dying is fundamentally a social event as it impacts on existing social relationships, social institutions and social experiences. Nevertheless, Jackson and Colwell (2002) contend that dying and dead people are generally removed from their usual environment, which reinforces the idea that death and dying is a medical event which must be handled by those qualified to do so.

As death has become less common, so too has the experience of grief. Ariès (1974) maintains that grief is subsequently seen as a sign of 'mental instability' rather than a normal reaction to loss. Moreover, Gorer (1965) argues that, as a result, people attempt to avoid mourning and the grieving person is kept separate through fear and shame; death thus becomes a private and personal experience rather than a communal one. A survey conducted by the Scottish Partnership for Palliative Care (SPPC) highlighted that 70% of people feel that as a society we do not discuss death and dying (SPPC 2003). This reluctance to acknowledge death and loss has been argued by Monroe and colleagues (2007, p.65) to make people feel more isolated and afraid when faced with related experiences such as bereavement or life-limiting illnesses, thus compounding negative end-of-life experiences. Yet, Blauner (1966) argues that longer life expectancies and larger populations enable people to come to adapt better to somebody dying. Seale (1998) highlights that, previously, death caused a threat to social order, where the death of someone in an important social role, such as 'healer, hunter or tool maker', had a huge impact on the community (p.51). He goes on to argue that the social role that people now play is potentially easier to fill by someone or something else. For example, Blauner (1995) notes that if a father dies in old age his children may cope with his loss by having already taken on roles as a possible parent, husband or wife, and there is thus no need for elaborate

rites of passage. This example, however, draws attention to the potential social isolation of the dying and the bereaved: the father may be aware that his role in the family has potentially changed and, due to his age and decreasing abilities, feels he is a possible burden to his family. Equally, the bereaved wife may not wish to share her grief with the family due to feeling that they already have enough to cope with in their own families. This situation potentially forbids either the husband or wife from talking about death and bereavement due to feeling like they will upset the status quo and/or draw attention to their own vulnerabilities, thus identifying a taboo.

A main challenge to the 'death as a taboo' thesis is the frequency with which death appears in the media. Holloway (2007) argues that there has been a dramatic shift in boundaries between public and private lives' (p. 15), citing the popularity of live documentary television as an example of this. In current social life the media plays a huge role in everyday lives, with most people having access to a mobile phone, television, newspaper or the internet, all of which grant them instant access to recent news as well as other people's thoughts and emotions. Internet applications such as Twitter and Facebook, for example, are commonly used as platforms to share feelings with a wider public forum and this had not been possible before. Such tools allow people to post memorial messages and keep friends updated on how they are doing, thus gaining support and encouragement from all over the world. Death in the news, however, only allows certain types of deaths. In this arena death is omnipresent, and Walter and colleagues (1995) assert that the media has generated a public discourse on death, dying and bereavement which is far more accessible than medicine. They also note that, aside from public figures, death in the media follows certain rules; someone who dies of a heart attack at home will not make news but someone who is murdered or who dies in a fire will. The death of a private person is therefore only publicly visible when the circumstances of the death are extraordinary. Moreover, they discuss how reporting in the media always includes an investigation of private emotion from people connected to the deceased, such as family members, friends, colleagues, neighbours and/or acquaintances. They argue therefore that death in the media is 'not emotional avoidance but emotional invigilation, not

depersonalisation but an active reporting of the personal' (p.585). This gives strength to the argument that death is not forbidden in the social, but embraced.

Holloway (2007) argues that such widespread media representations of death which emphasise 'the commonality of human experience' can also serve to keep death at a distance (p.14). Depictions of death in the media can assist people in keeping death 'outside themselves and their experiences, inured to images which, if they consider fully their meaning, might lead to feelings that they do not wish to confront' (Holloway 2007, p.14). Likewise, Gorer (1995) asserts that while natural death has become 'smothered in prudery', violent death has played an ever-growing part in what is offered to mass audiences (p.174). These depictions, he argues, ignore social and physical limitations, but offer 'substitute gratifications' (p.174). Media representations very rarely follow up with how families are doing 'long term'. Instead, they focus on the dramatic incident as it is happening. Although this may offer some measure of identification between those at home and those on TV, the emotions that are depicted last only as long as public interest remains. These emotions are not commonly seen as enduring, which theories on grief tell us is often the case. Likewise, the media tends to highlight sudden and/or tragic events and grief is potentially sensationalised in a way that serves to distance viewers, rather than providing them with a framework to identify and validate their own feelings ("How can I feel like this when they are going through that?"). The media is thus a forum that may facilitate and challenge the death taboo. It enables escapism from one's own grief experiences, providing an outlet for emotions to be expressed removed from personal experience, that both encourages talk about death ("They are talking about death, therefore it must be acceptable to do so.") and discourages talk about death ("It's acceptable to talk about death and grief in relation to other people, not me.").

2.4 Children and childhood

Children are a diverse group. Their experiences and perceptions are affected by age, gender, ethnicity, class, disability, cognitive ability, and so on. They are also viewed by Hill and Tisdall (1997) as being 'greatly impacted by the attitudes, ideas and

expectations of both the immediate and wider social context' (p.3). Interestingly, theoretical discussion on children mirrors that of death. Like death, children are discussed by Jenks (2005) as being 'omnipresent in human society both across space and through time' (p.52). Yet, as highlighted by Cree (2010), prior to the 1980s, the study of children and the concept of childhood as a discrete area of interest was absent from the social sciences, featuring predominately in psychology or discussion and research on the family, community or education. James and Prout (2004) note the study of children was not marked so much by its absence but by its silence. This suggests that there exist significant gaps in knowledge about how we understand the experiences of children in society and the concept of childhood more broadly. Furthermore, similar to the taboo of death, it was also the historian Philippe Ariès (1962) who is recognised for drawing attention to the notion of childhood as a social construct that is historically variable over time. According to Ariès, childhood as a separate category did not exist until the eighteenth century, which he asserted was due to not associating status with age or maturity. Although his work has been subsequently critiqued by a number of scholars, Tisdall and colleagues (2009) note that his work served to put childhood as a focus of study, encouraging a more critical look at how childhood is conceptualised and how these conceptualisations impact relationships, structures and service provision.

Who is deemed a child and what constitutes childhood is a matter of debate. Undoubtedly childhood begins at birth; however, recognising when childhood ends and adulthood begins is contested. Historical and cross-cultural comparisons highlight the variety of ways in which childhood is constructed, influenced by different and changing boundaries between child and adult, rituals and rights associated with transition to adulthood, and expectations (Hill and Tisdall 1997; Cree 2010; Cunningham 2006). For example, the influence of legislation is significant in recognising the importance of different ages across and within countries. Cunningham (2006) highlights that UK legislation denotes when we can buy alcohol, have sex, drive and vote, all of which are possible markers defining a transition from child to competent adult. Such markers are not consistent, i.e. the age at which you can have sex is sixteen whereas to buy alcohol you need to be eighteen, and these

ages have shifted over time. This is highlighted by the recent decision in Scotland to lower the voting age to sixteen for the Scottish Referendum on Independence. This is based on arguments that sixteen year-olds are now considered to have the right and competence to make decisions about their country. Frost and Steins (1989) assert that constructing childhood is essentially political, highlighting it is the most governed aspect of daily life, and such shifts can easily be viewed as political as they may help to gain more votes for the party proposing the change. Nevertheless, this example also illustrates how the construction of child and childhood is not static, but subject to revision.

As previously mentioned, prior to the 1980s psychology dominated our conceptualisation of children. This included theories on childhood development such as Piaget (1929) and Erikson (1995), which remain helpful in distinguishing children's needs as distinct from those of adults. These traditional theories of and research on children became subject to criticism as they viewed childhood as a fixed and natural process, determined by biological and psychological facts: children were what Tisdall and Punch (2012) call 'human becomings' rather than 'human beings' (p.250). Qvortrup (1994) argues that, in this context, adulthood is thus 'regarded as the goal and endpoint of individual development or perhaps even the very meaning of a person's childhood' (p. 2). This means that childhood was predominately understood as a preparatory stage, with children portrayed as dependent, irrational, incompetent or incapable, failing to take into account the social context and agency of children. Cree (2010) asserts that the individualising approach in psychology contributed to obscuring how 'the issues and problems which children and young people face may be structural in origin (such as class, poverty, or inequality) rather than rooted in individual personality or developmental stage' (p.84). Social scientists have thus argued for an alternative understanding of children committed to the view that childhood is not a predictable, limited, universal or natural process, but is shaped by a variety of environmental and social factors. Moran-Ellis (2010) notes that this places emphasis on understanding the lives of children based on their own experiences, meanings and interpretations. Hill and Tisdall (1997) argue that this view of childhood recognises that 'the interests, feelings, behaviours and

personalities of individual children are crucially affected by, and in turn affect, their relationships with parents, other family members, peers, teachers, and other professionals and wider society' (p.1). This means recognising the rights and agency of children. Rather than a view that children are passive recipients of adult values, models and knowledge, they are seen as active in contributing to the world in which they live. Despite this focus on the social construction of childhood, the terms child and childhood retain usefulness as concepts that draw attention to growth and transition and highlight difference. In other words, childhood is a time for social, physical and intellectual development and children do have different needs than adults. Frost and Stein (1989), in contrast, ask why we need to define children as other, not people. This is a poignant argument. The language chosen to describe children, such as kids, young people, teenagers, adolescents, youths and so on, all carry with them different images and associations. The discussion around the influence of language and environmental factors draws attention to James and Prout (2004), who call for research with children that works to find a relation to both children's own activity and to the social processes that constrain children's lives.

The rise of the study of childhood paralleled movements in legislation and policy-making, which emphasised that children should be social actors in their own lives. In the UK, this includes the Children Act (1989), the Children (Scotland) Act (1995), and more recently the Children and Families Act (2014) and the Children and Young People (Scotland) Act (2014). The United Nations (UN) Convention on the Rights of the Child has been the leading international force in advocating for the rights of children and, in 1989, it passed fifty-four articles which covered the protection, participation and provision of rights for children. Hill and Tisdall (1997) identify that policy and legislation relating to children identifies a tension between their rights and needs: 'on the one hand they are dependent and vulnerable; on the other hand they are people with capacities and viewpoints to be respected' (p.19). Such legislation and policy is therefore both liberating and controlling. Nevertheless, it has been asserted by Tisdall and Punch (2012) that such policy developments, coupled with the reconceptualisation of childhood, have led to research in the UK which prioritises the voices of children to reflect better their experiences and

perspectives. This has led to the development of new methods for working with children, which ensure that they are kept central to the research process. This focus recognises that the interests, feelings, behaviours and personalities of children also affect their relationship with adults and society in general. Current discourses on children are thus shaped by children's own experiences and academic knowledge, but also by social practices and institutions.

James and Prout (2004) note that the construction of childhood involves 'an actively negotiated set of social relationships within which the early years of human life are constituted' (p. 7). This acknowledges that children's experiences are not only affected by their own interests, personalities and desires, but also by the ways in which childhood is conceptualised within particular households, communities and societies (Hill and Tisdall 1997). It highlights the significance of power relationships between children and their environment in shaping their experiences. Today, childhood is often portrayed in terms of more democratic relationships between adults and children, which Jenson and McKee (2003) assert corresponds with the assumption that children's power has increased. The power relations that exist between adults and children, however, have been argued by Hill and Tisdall (1997) as important in impacting the scope for children to modify or resist social influences. This is relevant when we consider the taboo of death, dying and bereavement, which could be possibly viewed as influencing children's attitudes towards these issues through a variety of environments and structures.

2.5 Children, death, dying and bereavement and a contested taboo

I have illustrated that there is no settled agreement on the taboo of death, dying and bereavement in Western societies. Noticeably, children were, for the most part, missing from key discussion papers associated with this, thus demonstrating a gap in conceptualising how children interact with the contested taboo surrounding death, dying and bereavement. This is significant, given that death and bereavement are universal experiences that all children will experience at some point in their lives. Adams and Deveau (1995) suggest that, where life expectancy is long, children may

actually have limited experience of death until older age, thus limiting their exposure to and understanding of death. They go on to assert that, similar to the experience of adult, this lack of exposure has not provided children with the tools and experiences they need to help cope when a death occurs. Nevertheless, in the UK, 78% of children will have experienced the death of a second degree relative or close friend by the age of sixteen (Harrison and Harrington 2001). Four to seven percent of these children will have experienced the death of a parent (Ribbens McCarthy 2006).

According to Ariès (1974), prior to ‘the eighteenth century no portrayal of a deathbed scene failed to include children’ (p.12). This suggests that children were commonly included in information and rituals surrounding death, dying and bereavement, similar to the rest of society more broadly. Due to this Elias (1984) argued that children were better able to cope with death and bereavement. Furthermore, literature including children in the debates around the taboo of death, dying and bereavement commonly referred to children’s exclusion from such experiences as a manifestation of such a taboo. This is highlighted by Elias (1984) who writes:

‘nothing is more characteristic of the present day attitude to death than the reluctance of adults to make children acquainted with the facts of death. This is a symptom of the repression of death on the individual and social places.’ (p.18).

Thus, the exclusion of children from rituals associated with death is argued as exemplifying the taboo within wider society. These arguments suggest that children’s attitudes towards death, dying and bereavement parallel those in the wider society. Moreover, Jackson and Colwell (2002) assert that the death taboo has been accepted and maintained in order to protect children by reducing their fear of death. This is related to a fear from adults around harming children or destroying the innocence of childhood through approaching these issues. These discussions fail, however, to acknowledge the individual agency of children in defining and redefining their own attitudes towards death, dying and bereavement, reflecting the reality that although children were present their voices were absent. Nevertheless, there is a vast amount of literature that does focus on the importance of talking to

children about death and supporting them through bereavement. This body of knowledge suggests that children's attitudes, understanding and experiences of death, dying and bereavement are largely shaped by biological and social factors. I will discuss these two aspects both in terms of how they influence children's attitudes towards death, dying and bereavement and relate to the contested taboo.

2.5.1 Death and biological factors

There is a vast amount of literature exploring the ways in which children comprehend death. A 'mature' view of death is seen to reflect an understanding of the universality, irreversibility, non-functionality and causality of death (Smith and Hunter 2008; Speece and Brent 1984). Most discussion in relation to how children master these areas of knowledge is informed by developmental approaches and a vast amount of research and literature exists in this area. Piaget's theory of cognitive development (1954) and Nagy's (in Bluebond-Langer 1977) research on children's development of death-related concepts were key in developing the theoretical basis for conceptualising how children understand death.

Piaget (1954) identified four sequential phases in a child's development, which reflect their changing understanding of the world. This includes: a sensory-motor stage whereby children up to two years of age know the world through actions and sensory information; a pre-operational stage which involves children aged two to seven in egocentric thinking; a concrete operational stage whereby children aged seven to twelve are able to take into account the perspectives of others but remain tied to their immediate experience; and a formal operational stage from age twelve onwards, where abstract reasoning begins and children are able to reason and speculate. Based on this understanding of children's cognitive development, children are also viewed as understanding death in different stages. For example, younger children should not be able to fully grasp the concept of death as permanent due to their focus on senses; they will thus be more aware of the feeling of separation rather than a concrete understanding of the finality of death. By two to seven years of age, children should begin to understand this finality; however, they are unable to grasp the causality and universality of death due to their limited ability to think

outside of their world. By the concrete operational stage, children are able to fully understand the causes and processes of death and how this impacts others, and from age twelve onwards children are able to think more abstractly about what death might mean for them and their future.

Similar to Piaget's stages, Nagy (1948) also argued that children develop ideas about death in three concrete stages, which correlate with particular biological stages of development. She asserts that it is only by the age of nine or ten that children understand death as inevitable and irreversible. She argues that prior to this children view death as a departure, where life continues under different circumstances, but by the age of seven they have grasped the irreversibility but not inevitability of death. This work parallels Piaget's work, as does most literature and research on development, which identify that between the ages of five and eight children will have developed a concrete understanding of death and dying (for example, Lindsay and Elsegood 1996; Silverman 2000). Such research thus suggests that the age and stage of a child is an important factor in understanding death.

In reviewing developmental approaches it is clear that there is no consensus around what age a child actually obtains a mature and complete understanding of death, and there is a significant age bracket in which children are considered to be undergoing a 'natural' process of learning. Developmental approaches focus on a linear model of learning that does not take into account the social, economic and cultural background of children. For example, a child's age may not actually correspond with their developmental age due to a number of factors that include social and cultural factors, learning disabilities and so on. These criticisms are reflected in more recent work such as Christ's (2000), which identifies that cognitive, emotional and social aspects of development are important in shaping a child's response to death. This highlights Corr's (1995) argument that children develop differently through life experience, personality, patterns of communication and environment. Theory connected to ages and stage can only offer, therefore, a limited understanding of children's understanding of and attitudes toward death.

Prescribing ages to knowledge acquisition may influence wider opinion on talking about death with children. For example, if a six-year-old wants to know how her father died, based on developmental theory an adult may feel that children are incapable of understanding the truth. They may therefore not give the child any information or access to rituals surround the death, thus failing to take into account the needs and experience of that particular child. This potentially contributes to creating a taboo around involving children in death, dying and bereavement by prohibiting or avoiding behaviours connected to engaging children in these issues. Moreover, although developmental approaches are helpful, they presume that knowledge flows one way, from adult to child, and is therefore not an iterative process. This serves to disempower children by identifying adults with all the answers and does not suggest that children may have a lot to teach adults.

2.5.2 Death and social factors

Social and environmental factors, such as structures, communities and family, influence how a child experiences the world and therefore undoubtedly impact on how children understand and perceive death, dying and bereavement. As discussed previously, literature focused on the taboo of death, dying and bereavement frequently discussed a fear from adults around discussing death, dying and bereavement in relation to harming children and/or destroying the innocence of childhood. Yet, literature and research relating to childhood bereavement and death education identify the importance of being open and honest about these issues (Worden 1996; Monroe and Kraus 2005; Silverman 2000). For example, Smith and Hunter (2008) highlight that when adults try to protect children from death, this can foster confusion, ignorance and a lack of trust. This mirrors children's experience of loss more broadly, such as through divorce, becoming looked after and accommodated, and so on. Research in these areas identifies a strong desire from children to be kept informed and involved; for example, Robinson and colleagues (2003) research on experiences of parental divorce found that children coped best when they have a narrative of events. Despite focusing on informing and including children, literature on childhood bereavement also tells us that there still prevails a discomfort from adults to discuss death with children, with Adams and Deveau

(1995) asserting that the majority of adults view death as morbid and harmful to children. As a result, a number of authors note that children are commonly denied access to information and rituals about death, dying and bereavement, which impacts on their ability to cope when someone dies (Smith and Hunter 2008; Monroe and Kraus 2005). Likewise, it has also been identified that adults often think discussing death will encourage children to think about it, thus causing unnecessary angst (Puolimatka and Solasaari 2006; Jackson and Colwell 2001). This fear from adults has been identified by Jackson and Colwell (2001) as paralleling fears which were commonly expressed about sex education, thus linking to Gorer's (1955) argument that death has replaced sex as the new taboo subject for both adults and children. It would thus appear that children are perceived by the majority of adults to be in need of protection when it comes to talking about issues relating to death, dying and bereavement. Adams and Deveau (1995) argue that attitudes to death are partly shaped by exposure to death, but also by our views about the world and our place in it. If children are not allowed access to information or rituals surrounding death, dying and bereavement, then they are unable to develop a full understanding of what death means. Consequently, children's needs are often ignored and death is introduced not as a normal experience but as abnormal. This is important, given that Silverman (2000) argues that adults undoubtedly play a key role in shaping children's perceptions of death.

It would appear that adults limit children's exposure to death, dying and bereavement through an attempt to protect them. This relates to Hill and Tisdalls' (1997) argument around adults constraining children's choices and access to information 'ostensibly in the interests of children, but this can too readily become a rationalisation for marginalising children for the convenience of adults' (p.20). Silverman (2000) highlights that adults avoid talking about and involving children in issues related to death and dying as it is something that they find anxiety-provoking and challenging even though the child maybe asking for such information. This potentially contributes to a possible taboo around death, dying and bereavement, as children learn from adults that these issues are not something that is talked about. The use of euphemistic language around death strengthens this point further. Terms

such as 'passed away', 'lost', 'gone', 'kicked the bucket' are commonly used when discussing death, which McConnell and colleagues (2012) assert attempts to conceal and soften the reality of death. My practice experience confirms that such terms are frequently used with children, however, due to developmental understandings, younger children do not always understand what these terms mean and actually believe that the person is 'lost' or 'gone' and may therefore return. A lack of clear information may make the grieving process more difficult for children. Moreover, it further strengthens the idea that death is unmentionable. It would therefore appear that both developmental and social factors influence adult opinion of children's ability and appropriateness to be included in such discussion and experiences which, in turn, impacts the extent to which children have exposure and information relating to these issues.

Children will inevitably come into contact with death either directly or indirectly. Rowling (2003) argues that images of death that are presented in the media offer a distorted view of death by frequently portraying it as violent, traumatic and tragic rather than a normal. Observing death in the media is therefore particularly relevant to children whose first experience of death may be via computer games, films and television. Such representations may themselves establish misconceptions about death and dying experiences. This is potentially compounded by children's view of their role within the family and community. For example, due to their status as child they may feel unable to ask questions that clarify their understanding concerning issues related to death, dying and bereavement. Moreover, they may also feel unable to discuss these issues due to messages they are receiving from adults about death as an unnatural process which is unspeakable and upsetting. Based on this understanding, if death, dying and bereavement is a taboo topic within contemporary society, related accepted behaviours will potentially pass from adult to child and continue across generations.

Ward and associates (1996) note that the avoidance of death, dying and bereavement is contradictory to research which argues that both adults and children have the ability to deal with any crisis depending on their preparation for it. Undoubtedly childhood is a time for social, physical and intellectual development and this

suggests that what children learn will be important for their future reactions. Lazar and Tonrey-Purta (1991) highlight that many children do think about death without having direct experience of it. Left to their own devices, however, they may ‘construct imaginative and elaborate explanations that are not grounded in reality’ (Adams and Deveau 1995, p.55). It is important therefore to assist children in learning constructive attitudes toward death and effective responses to death-related problems. Rowling (2003) argues that families and schools have an important role to play in challenging negative views connected with death, dying and bereavement, both normalising and educating children in related experiences of death and grief. Such information assists to ‘lessen feelings of insecurity, loneliness and self-consciousness when young people experience loss’ (ibid, p.1). Moreover, Jackson and Colwell (2002) assert that introducing death, dying and bereavement to children as part of their education on human growth and the lifecycle normalises the experience of death as well as creating an open discourse. Children, however, are viewed as a particularly neglected and problematic group with regards to death and grief education owing to their status as ‘child’ and potential vulnerability (Wass 2004, Jackson and Colwell 2001). In this context, the taboo concerning death, dying and bereavement is thus potentially more pronounced in relation to children, and hence potentially more damaging.

2.6 Conclusion

My original perception of the taboo around death, dying and bereavement, prior to coming to this research, was that a taboo did exist and that this taboo was particularly impacting on children. This was an opinion derived largely from my experiences of working with bereaved people as well as the attention that is currently being given to public attitudes towards death and dying in end-of-life care policy making (discussed in chapter three). Nevertheless, I now believe that the idea of death as a taboo is oversimplified. Due to medical, psychological, spiritual and social influences, ‘death is both absent and present in contemporary society’ (Holloway 2007, p.20). The wider theoretical discussions surrounding the contested taboo of death, dying and bereavement are significant to children’s attitudes towards death. Although there is no conceptual body of knowledge that relates the death taboo specifically to this

group, children's current exclusion in issues related to death, dying and bereavement are commonly discussed as a symbol that the taboo does exist. The lack of research in this area is representative of the lack of research more broadly on the experience of individual differences, such as cultures, class, age and gender, in relation to the fear and management of death, which has been identified as an area for further investigation (Kellehear 1984, Holloway 2007). This also demonstrates the complexities between public and private experiences. Walter and colleagues (1995) note that public situations are undoubtedly governed by social rules, just as private situations are impacted by personal experiences, values and beliefs. Experiences and understandings of death, dying and bereavement are thus contradictory, and the diversity of approaches and influences means that a taboo cannot be contained within a certain framework and is likely to be contested. In relation to children, death, dying and bereavement gives expression to the relationship between children as both autonomous individuals and members of a given society. Knowledge and experience of death and dying are therefore influenced by debates of both developmental approaches and sociological understandings and experiences. To understand the taboo of death, dying and bereavement in children's lives thus requires looking at the beliefs and behaviours of children, of the adults who surround them and the wider society, thus highlighting the significance of negotiating the space between public and private experiences. This systematic approach is one that informed my action research practice.

Chapter 3: Policy and practice development

Recent end-of-life care policy making in the UK recognises a need to renegotiate the place of death, dying and bereavement in contemporary society. This is due both to changing demographics and a perceived public reluctance to acknowledge these issues, which is identified as negatively influencing related experiences. In this chapter of the thesis I will outline these policy developments highlighting the recent focus on public health approaches to end-of-life care, specifically health promoting palliative care, which have been identified as a way forward to develop meaningful care for the majority of people. The gaps in this area of practice development will be described, showing that there is a need to carry out research that explores practice development between hospice and school communities. Because this research is located in Scotland, I have drawn mainly on Scottish legislation and social statistics; however, the discussion of health promoting palliative care in relation to work with schools is undoubtedly broader.

3.1 Death in Scotland

In Scotland, over 55,000 people die each year, usually over the age of 65 and often following a period of, possibly prolonged, illness and/or frailty (Scottish Government 2008). This figure is expected to rise, meaning that people will be increasingly living longer with a range of progressive illnesses, which will have significant implications for the range and amount of care that will be required (Scottish Executive 2005). Current palliative care and end-of-life service provision will not be able to meet this growing demand and developing capacity to provide equitable care and support for this population is therefore necessary. Cohen and Deliens (2012) note that this is an issue for most developed countries, where increasing life expectancies over the last century have contributed to an ageing population. This means that people will live longer and the period that people live with disabilities or health problems will increase. Moreover, the numbers of deaths per year are expected to rise, meaning that more people will be living with grief. In Scotland, the need to develop services that reflect these changing demographics has been addressed in a variety of recent policy- making. This includes: *Delivering for health*

(Scottish Executive 2005), *All our futures: Planning for a Scotland with an ageing population* (Scottish Government 2007), *Better health, better care* (Scottish Government 2007), *Living and dying well* (Scottish Government 2008), *Living and dying well: building on progress* (Scottish Government 2011). These developments reflect parallel movements happening in the rest of the UK. *The end of life care strategy* (Department of Health 2008) in England and Wales, *Living matters, dying matters* (Department of Health 2010) in Northern Ireland, along with *Living and dying well* (Scottish Government 2008) in Scotland, have been particularly important in relation to setting out a strategy for developing better palliative and end-of-life care. These documents highlight the significance of a person-centred and holistic approach to end-of-life care, based on need rather than diagnosis, and which focuses on continuity of care and choice in how that care is delivered. Moreover, they also identify a need to bring discourse and education around death, dying and bereavement into the community, acknowledging the associated reticence as impacting negatively on end-of-life care and bereavement experiences. These government documents thus identify a taboo around death, dying and bereavement as a barrier to providing quality and equitable end-of-life care.

Since the introduction of *Living and dying well* (Scottish Government 2008) and *The end of life care strategy* (Department of Health, 2008), a variety of advances have been made that specifically focus on creating an open discourse on death, dying and bereavement. In 2009, 'Dying Matters', a national coalition to promote greater public awareness and discussion of issues relating to death, dying and bereavement was developed. Led by the National Council for Palliative Care (NPCP), it aims for a 'fundamental change in society in which dying, death and bereavement are seen and accepted as the natural part of everybody's life cycle' (dyingmatters 2011). A 'Dying Matters' awareness week has been introduced, which has been identified as providing end-of-life care services with a defined opportunity to open up discourse on death, dying and bereavement (Paul and Sallnow 2013). In December 2014 'Dying Matters' launched a '*Being There*' campaign to raise the needs of people experiencing bereavement. It also provides a variety of tools and resources to facilitate discourse and, although based in England and Wales, it is primarily web-

based, potentially broadening its impact. In Scotland, a short-life working group was set up, specifically addressing palliative and end-of-life care from a public health and health promotion perspective to facilitate a wider discussion of death, dying and bereavement across society. In 2011, this led to the establishment of the ‘Good Life, Good Death, Good Grief Alliance’, which seeks to provide a network and resources to raise public awareness and promote community involvement in death, dying and bereavement (goodlifedeathgrief 2012). These developments identify the significance of public health approaches to end-of-life care in both breaking down barriers to discussing death, dying and bereavement as well as involving the community in addressing end-of-life care issues. Such methods are recognised in a report by DEMOS, a British cross-party think-tank, which asks for a ‘‘Big Society’ response to a dying population in which civic, mutual and self-help solutions play a much greater role’ (Leadbeater and Garber 2010, p.16). These ideas are strengthened by a developing literature and practice base, which recognises end-of-life care as a public health issue and identifies associated approaches as an effective way to improve and develop sustainable and meaningful care.

3.2 Public health approaches to end-of-life care

Issues related to death, dying and bereavement have previously been excluded from public health discourse. Public health describes a variety of actions taken to improve the health of groups of people rather than interventions aimed at improving the health of a specific individual. Peterson and Lupton (1997) assert that public health is thus a broad term focused on ‘the health of populations rather than individuals’ (p.2). Baum (2008) notes that it has been applied to different actions over time, but focuses on improving the health of communities through change. It has been asserted that public health activities are historically life-affirming, avoiding death and dying by focusing on preventing and controlling illness, disease, injury and premature death (Kellehear and Young 2007; Lupton 1995). The avoidance of death from public health frameworks has thus been argued by Lupton (1995) as categorising death in a way that avoids ‘direct confrontation with its reality’ by emphasising and eliminating risks connected with ill health and death (p.64). Public health therefore implicitly reinforces ‘negative attitudes towards death, dying, and loss as help-less, hope-less,

experiences that are not amenable to ideas and efforts towards prevention, harm reduction, support and healthiness' (Kellehear 2007, p.77).

Public health measures have always been implemented by societies to control disease and create healthier and safer cities. Examples consist of:

'the Roman baths, Roman laws governing burial of the dead and regulating dangerous animals and unsound goods, the regulation of prostitution in Ancient Rome and Greece, inoculation against smallpox in India and China before the Christian era, the isolation of people with leprosy in Europe in the middle ages and the quarantining of ships by the Venetians.' (Baum 2008, p.20)

Traditional public health measures relied on legislation, sanitary reforms and medicine. For example, in the nineteenth century the 1848 Public Health Act was introduced, which enabled local authorities to improve unsanitary conditions and demanded adequate drainage and sanitation (Kearns 1988, in Baum 2008). These measures were in response to the death toll caused primarily by communicable diseases such as cholera, tuberculosis and malaria. In the twentieth century, specifically the 1950s to 1970s, developments in medicine resulted in clinically orientated public health interventions which involved immunisation, screening and treatment. Cohens and Deliens (2012) argue that during this time emphasis was placed on the medical profession and the cure and treatment of disease, which was criticised for resulting in an individualistic approach to health that ignored social and economic aspects. They go on to assert that this era paved the way for the 'new' public health, which places less emphasis on the biomedical approach and 'aimed to focus on equity and on attempting to break down barriers between professional groups and lay people' (ibid, p.11).

Public health models today recognise that the traditional 'top down' public health measures from governments not only frequently fail, but ignore the role of community knowledge (Kellehear and Sallnow 2012). The move to a 'new' public health therefore involves a variety of methods and concepts that stress the importance of equity of care, participation and empowerment, based on 'the assumption that social and environmental factors influence ill health' (Baum 2008,

p.31). According to Cohen and Deliens (2012) equity of care relates to the differences that public health can make at a population level as opposed to individual patients. Participation involves breaking down barriers between professional and lay knowledge and recognising that this knowledge is culturally and temporally specific. Baum (2008) argues that empowerment is increased when people are given information about how their environment and behaviour impacts on their health at all stages of their life and autonomy to control their own health.

It is perhaps important here to define what is meant by the term 'health'. The most common definition of health is prescribed by the World Health Organisation (WHO), whereby health is 'a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity' (WHO 2006). This definition has been used since 1948 but, given the rise of chronic disease, has been critiqued for its focus on 'complete' health, which has been argued as focusing on the importance of medicine and leaves people with chronic disease, illness or disability as perpetually ill (Jadad and O'Grady 2008; Huber et al. 2011). Huber and colleagues suggest redefining health as 'the ability to adapt and self-manage in the face of social, physical and emotional challenges' (2011, p.1). This definition of health places much more focus on the individual within the context of their life space and hence, I would argue, sits more comfortably within the field of social work. Social work has always been concerned with valuing difference, recognising the whole person within their experience, values, social networks and environment (Sheldon 2000; Healy 2005). In this sense, health is a multi-faceted term defined by the individual according to their unique situation and perspective. Based on Huber and colleagues' definition of health, the new public health involves a diverse range of approaches that enable and equip populations of people to adapt and cope with physical, social and emotional experiences through all life's stages. Public health approaches, according to Peterson and Lupton (1997) include: 'health promotion and health education, social marketing, epidemiology, biostatistics, diagnostic screening, immunisation, community participation, health public policy, intersectoral collaboration, ecology, health advocacy and health economics' (p.5). Combining these 'new' public health approaches with palliative and end-of-life care has been

recognised by a variety of authors as offering a powerful way to achieve meaningful end-of-life care for the majority of people (Stjernswärd et al. 2007; Kellehear 1999; Conway 2007). From a 'new' public health perspective, end-of-life care should thus work to promote openness and challenge stigmas related to death, dying and bereavement as well as empower communities to draw on their own resources and community supports to adapt and cope. Conway (2008) argues that this relies on principles of health promotion and offers a framework to support those experiencing life-limiting illness through encouraging and developing sustainable social support and care.

Despite this positive framework that the 'new' public health sits within, namely around equity of care, participation, empowerment and autonomy, it is nevertheless a political activity. As Peterson and Lupton (1997) highlight,

'Medical, scientific, epidemiological and social and scientific knowledge are routinely employed as 'truths' to construct public health 'problems' and to find problems for dealing with them' (p.8).

Professional expertise therefore remains privileged over lay expertise and the discourse of public health serves to determine the type of society we should live in through maximising and motivating the public (ibid). In relation to end-of-life care, as highlighted previously, people are living longer, usually with progressive illnesses, and current service provision will not be able to meet these demands. Employing public health approaches to palliative care could thus be argued as 'persuading people to conform to the goals of the state and other agencies' (Petersen and Lupton 1997, p.12), that is, managing future deficits in end-of-life service provision. Nevertheless, current health and social care most often attend to presenting 'end-of-life' problems; adopting public health approaches invites governments, service providers, community groups and lay people to consider end-of-life care issues before they are presented. For example, the work of Murray and colleagues (2005) on illness trajectories identifies that specific diseases often have common patterns of experiences, symptoms and needs. They assert that there is a need to have realistic dialogue about these illness trajectories to both improve quality

of life for patients and their families, but also to develop appropriate service provision. Taken from a public health perspective, which would involve knowledge sharing and promoting autonomy, this has implications for end-of-life care at both a personal and community level. Public health frameworks thus provide a way to conceptualise and respond to problems and opportunities which confront communities dealing with death, dying and bereavement.

3.2.1 Health promoting palliative care

Lupton (1995) claims that health promotion is a central feature of the 'new' public health. Health promotion is argued by Bennett and Murphy (1997) as recognising health as a multidimensional concept involving physical, social and emotional aspects. They assert it is a concept 'premised on the understanding that the behaviours in which we engage and the circumstances in which we live impact on our health, and that appropriate changes will improve health' (p.7). The ideological principles behind health promotion are thus based on a holistic view of health, which Scriven and colleagues (1996) argue deems inequalities unacceptable, with people being empowered to make healthy decisions as opposed to compliance to a set-out regime. To work in a health promoting way therefore means focusing on health, not illness, empowering individuals with knowledge to make healthy, positive choices. According to Naidoo and Wills (1998), this does not involve one discreet intervention, but rather a variety of interventions, which are adopted dependent on the concepts and models of health that are being used.

In 1986, the World Health Organisation (WHO) produced the Ottawa Charter for Health Promotion. Five strategies were identified to support and maintain health that included building public health policy, creating supportive environments, strengthening community actions, developing personal skills and reorienting health services (WHO 1986, p.2). In 1999, Allan Kellehear explicitly applied the WHO principles of health promotion to palliative care (Kellehear 1999). The notion of health promoting palliative care thus emerged, broadening out the remit of palliative care providers from the personal, i.e. supporting individual families, to the

community. According to Street (2007), palliative care from a health promotion perspective is

‘not only directed at the care of individuals [...] but is also concerned with the social and community environment [and] public policies and community services [which] enable communities to cope with the inevitability of death and consciously support loss, grief, dying and bereavement, especially in the most vulnerable community members.’ (p.105)

Kellehear (1999) asserts that health promoting palliative care seeks to alter ‘community attitudes to a wide range of ideas that have attracted, and continue to attract, negative imagery and discriminating behaviour from others’ (p.78). It can be done via a variety of activities including research, education, community development and political action (Kellehear 1999; Kellehear and O'Connor 2008), which have been argued as challenging the current focus of palliative care ‘on clinical bedside care based on individualistic approaches’ (Haraldsdottir et al. 2010, p.130). Health promoting palliative care is thus a holistic approach that recognises and builds on existing strengths and skills within the wider community. It involves exploring and developing ways in which individuals and communities can cope and manage issues relating to end-of-life care, as appropriate to their unique experience and environment.

It has been argued that the ignorance and confusion that surrounds the needs of people living with incurable illness or bereavement is an important target for education, which seeks to place issues related to death and dying as a normal part of life (Kellehear and O'Connor 2008; Salau et al. 2007). Education on death, dying and bereavement has been highlighted as a method of harm reduction as it is associated with a number of benefits that relate to emotional wellbeing . For example, education on death and dying has been identified as enabling and preparing people to manage individual experiences of, and support those impacted by, death and loss (Kellehear and O'Connor 2008). It has also been asserted as equipping people with the tools and language to address difficult aspects of loss and death (Jackson and Colwell 2001; McGovern and Barry 2000) and providing people with

an opportunity to clarify values, meanings and attitudes towards death (Feifel 1977). Education is a key feature of health promotion, seeking to

‘enhance positive health and to prevent or diminish ill health, through influencing beliefs, attitudes and behaviour. The stimulation of a healthful environment – social and political as well as physical – is an important objective.’ (Downie et al. 1996, p.49)

Peterson and Lupton (1997) argue that this focus highlights how health promotion is a ‘moral enterprise’ attempting to prescribe how we should conduct our lives and bodies (p.174). They go on to assert that this can reinforce intolerance towards difference, i.e. those who do not conform to the knowledge being shared. Based on this argument, health promoting palliative care is necessarily based on a certain set of values and beliefs which seek to influence behaviour. This revolves around the underlying philosophy that it is beneficial to address end-of-life care issues at both an individual and community level, which may isolate and/or stigmatise those who do not consign themselves to this set of values, i.e. those who do not want to talk about death or loss. An example of this perhaps relates to Zimmerman’s (2007) point, discussed in the previous chapter, whereby patients who do not want to talk about their prognosis with healthcare professionals are labelled as ‘death-denying’. This concept of health promotion as a moral enterprise draws attention to the importance of transparent and reflective practice. Peterson and Lupton (1997) argue therefore that evaluation, which acknowledges the interaction between knowledge and power, should be a significant aspect of any health promoting activities. Health promoting palliative care practices should therefore seek to acknowledge diversity and difference, promoting choice rather than prescribing certain actions or behaviours.

Health promotion, and indeed the ‘new’ public health more broadly, is multi-disciplinary. It places emphasis on cooperative relationships between state institutions, voluntary and private agencies, professionals, bureaucrats and ordinary citizens, and involves action from all parties (Peterson and Lupton 1996). Moreover, Kellehear (2005) asserts that, although health promotion is only one public health approach, it is usable in small settings. This affirms that end-of-life care providers are in a position to initiate and/or provide leadership in health promotion activities

through developing community partnerships, which aim to establish sustainable activities addressing issues surrounding death, dying and bereavement (Street 2007, Kellehear and O'Connor 2008). Likewise, *Supporting people to live and die well: a framework social care at end of life* (NEoLCP 2010) recognises that social care services are 'predominantly located in community settings' and have a significant role in 'promoting supportive communities through engagement with a wide range of community services' (NEoLCP 2010, p.30). Nevertheless, in Kellehear's more recent book, *Compassionate cities* (2005), he notes that the practice of introducing health promoting palliative care occurs largely within clinical healthcare settings. This indicates that health promoting palliative care activities can be defined by the boundaries of an institution/organisation as opposed to working with communities more broadly. It has been argued that a reason for this is that palliative care organisations lack time, funding and training/understanding of health promotion activities (Kellehear 2005; Rosenberg and Yates 2010). This analysis corresponds with my knowledge and awareness of current UK projects, specifically those working with children, which use the hospice as a 'specialist' sight from which to facilitate activities for the community (Hartley 2009; Turner 2010). Although these projects are undoubtedly worthwhile they still situate palliative care professionals as central to the activity.

As a guide to understanding 'genuine' health promoting palliative care initiatives, Kellehear (2005) offers a 'Big Seven Checklist', in which projects must be able to answer questions one or two or three, and all questions from four to seven (Kellehear 2005, p.156). The seven questions are:

1. In what way does the project help prevent social difficulties around death, dying, loss or care?
2. In what way do they harm-minimise difficulties we may not be able to prevent around death, dying, loss or care?
3. In what ways can these activities be understood as early interventions along the journey of death, dying, loss or care?

4. In what ways do these activities alter/change a setting or environment for the better in terms of our present or future responses to death, dying, loss or care?
5. In what way are the proposed activities participatory – borne, partnered and nurtured by community member?
6. How sustainable will the activities or programmes be without your future input?
7. How can we evaluate their success of usefulness so that we can justify their presence, their funding and their ongoing support? (Kellehear 2005, p.156)

This checklist highlights community ownership, collaboration and participation as essential to a health promoting approach to palliative care. The importance of local activities, designed around the community's needs, led, but not owned by, palliative care professionals is emphasised (Haraldsdottir et al. 2010). Peterson and Lupton (1997) identify that there is very little analysis of power relations in 'new' public health frameworks. This is surprising given the focus on and concepts of empowerment and voluntary actions from individuals (ibid). It is also more significant for health promoting palliative care, which is likely to be involved with groups of people who may be deemed as vulnerable, such as the elderly, children and/or people who are ill. An awareness of power in this context is therefore extremely important. Likewise, health promotion is frequently acknowledged for failing to recognise the impact of class, gender, ethnicity and so on, having more success with people who are economically advantaged (Petersen and Lupton 1997; Baum and Harris 2006). Lupton (1995) argues that a critical approach to health promotion therefore involves looking at 'whose voices are being heard and privileged' (p.49). This draws attention to the importance of working *with* communities, to engage them in a process of identifying and addressing end-of-life care issues pertinent to their own specific needs, i.e. transferring power rather than maintaining it.

3.2.2 Health promoting palliative care and the role of hospices

Since the mid-1960s, the hospice movement has had a considerable impact on care of the dying (Hockley 1997). It emphasises a holistic approach that seeks to place the service users' lived experience at the centre and stresses the importance of multi-disciplinary collaboration (ibid). With the establishment of St Christopher's Hospice by Dame Cicely Saunders in 1967, the hospice movement began to include teaching and research as part of its remit to improve experiences for people who are dying and their families. Consequently, palliative treatment began to emerge as a specialist form of care (ibid), the grassroots of which affirms life and regards dying as a normal process (WHO 2011). The rise of the hospice movement has been considered positive, enabling dying people to share their final moments with family as opposed to behind curtains in hospitals (Kellehear 2007). In the UK, Reith and Payne (2009) highlight that hospice care is widely available, having developed through advancing Saunders's original model. Hospices are often referred to as a gold standard service for the care of the dying, but Stjernswärd and colleagues (2007) identify that hospices have been criticised for failing to reach the majority of those needing palliative care. In response to this, initiatives such as the Liverpool Care Pathway have attempted to roll out the model of hospice care to improve care for those that are imminently dying (Ellershaw et al. 2010). Many people living with dying and/or loss primarily spend their time in their communities and only a short amount of time in healthcare settings. Hospices have been criticised for neglecting concepts of community involvement and social networks in death and loss, focusing on individual and interpersonal levels of care (Conway 2007; Abel et al. 2011). Moreover, it has been asserted that they have become over-medicalised, managing certain kinds of deaths 'because the community cannot accommodate them either practically or symbolically' (Lawton 1998, p.123). It has therefore been argued that the hospice movement has contributed to keeping death behind closed doors, 'subject to intrusions and greater interpersonal and professional surveillance as a price for the social support and legitimacy' (Kellehear 2007, p.73). The associated multidisciplinary support services empower dying and bereaved people, but simultaneously 'make their own presence a precondition for that empowerment' (Foote and Franke in Kellehear 2007, p.73). It has been argued that this runs contrary to the original philosophy of hospice care, in neglecting the task of

promoting health at the end of life through an open and healthy discourse about death and dying (Haraltdottir et al. 2010).

Adopting public health approaches to palliative care has been asserted as involving a reorientation of service delivery that requires a move back to the origins of the modern hospice movement (Conway 2008). As discussed previously, the demand for end-of-life care is forecast to rise, which will place increasing strain on current hospice services. This changing landscape will mean that, in order to meet these challenges, hospices will have to ‘address difficult questions about how to demonstrate the best use of their expertise, experience and public support to meet increasing and wider ranging needs’ (Calanzani et al. 2013, p.3). Kellehear (2005) argues that a health promoting palliative care approach recognises the limits of direct service provision and potentially offers a way to reform organisational policy and behaviour that is more sensitive to the needs of people living with incurable illness and bereavement. Conway (2008) identifies two models of health promotion approaches to palliative care. These include a reform model that focuses on pain control and bereavement support, and a reorientation model that focuses on community development. He asserts that the latter suggests a ‘possible reorientation of palliative care to community needs and sources of sustainable social support and care’ (Conway 2008, p.407). Rosenberg (2012) notes that this involves promoting skills and developing learning that proactively prepares people for all life’s stages, emphasising social and collective responsibility for providing end of life care. Brown and Walter (2013) claim that the social work profession is well positioned to develop such models of care due its values, culture and experience. Likewise, Payne (2014) argues that models of community social work offer a broad focus for intervention to support those who are disadvantaged or oppressed.

In the UK, there are over 220 services providing free palliative care to adults, including both independent hospice and in-patient units attached to hospitals (HtH 2013). Eighty percent of adult hospice care is provided by independent hospices and less than a third of hospice funding is covered by the Government, the remainder derived from donations, legacies and trading (Calanzani et al. 2013). The organisation and practice can vary across hospice care providers. Nevertheless, a

survey conducted by a colleague and me identified that public health approaches to palliative care are a priority for the majority of UK end-of-life care service providers, and there is currently a diverse range of initiatives taking place (Paul and Sallnow 2013). This work is poorly disseminated and further research and guidance is needed to develop this area further (ibid). In response to these findings a spectrum for community engagement was developed, which sought to offer conceptual clarity around the role of hospices in working with communities (Sallnow and Paul 2014). Nonetheless, although there has been an increased literature and policy focus on such approaches to palliative care over the last decade, and practice examples exist worldwide, it remains an area that is still under-reported and under-researched.

3.2.3 Health promoting palliative care: schools and hospices

Children are a particular target for health promoting palliative care in that they are a population whose needs around death, dying and bereavement are often missed. The literature, discussed in chapter two, acknowledges how children, as a group, are excluded from knowledge relating to these issues and thus recognises how societal and existing structures potentially serve to exclude children from a significant aspect of life. Central to this idea is the concept of children as active citizens; children have rights to information about important and everyday parts of life, but these rights are often not acted upon. The underlying premise being that, if children are given opportunities to be better informed about death and dying, they will be more prepared to cope in the face of illness and/or bereavement and better able to support those around them. Moreover, it has been argued that ‘childhood is a key site for attempts to influence behaviour, since this is the time when it is thought many habits are formed that have far-reaching consequences’ (Hill and Tisdall 1997, p.139). Health promotion strategies directed at children are thus frequently focused on preventing later ill health in adulthood (ibid). This identifies that health promoting palliative care also has an important role to play with children.

Principles of health promoting palliative care parallel movements across Scottish school communities. The Schools (Health Promotion and Nutrition) (Scotland) Act (2007) endeavoured to ensure that all schools in Scotland are health promoting. In

May 2008 guidance was released to make relevant the concept of health promoting schools within the new 'Curriculum for Excellence'. As such, health promoting schools should

'adopt a whole-school approach to integrating health promotion into every aspect of school life. Through effective partnership working with pupils, all teachers and other staff, parents and the wider community, the health promoting school: promotes the mental, emotional, social and physical health and wellbeing of all children and young people; and works with partners to identify and meet the health needs of the whole school and its wider community.' (Scottish Government 2008, p.6)

The purpose of the 'Curriculum for Excellence' is encapsulated in the four capacities that seek to enable each child or young person to be a successful learner, a confident individual, a responsible citizen and an effective contributor (LTS 2011). Each local authority is responsible for developing its own curriculum to achieve these aims across eight different curriculum areas. These include: expressive arts, health and wellbeing, languages, mathematics, religious and moral education, sciences, social studies and technologies. It thus places an emphasis on health and wellbeing as an area of learning throughout the student's schooling, with the main focus being that children will 'develop the knowledge and understanding, skills, capabilities and attributes necessary for physical, mental, emotional, social and physical wellbeing now and in the future' (Scottish Government 2008, p.7). This focus is directly applicable to the concept of health promoting palliative care.

As discussed previously, in response to *Living and dying well* (Scottish Government 2008) a short-life working group was set up to address end-of-life care from a public health and health promotion perspective. Their report, *Addressing palliative and end of life care from a public health and health promotion perspective*, was published in March 2010 and made ten recommendations. Recommendation ten included:

'Engage with educational establishments, planners and practitioners to ensure that children and young people develop the attributes, capabilities and capacities which will enable them to be comfortable and confident in talking about and dealing with death, dying and bereavement, and to ensure that appropriate

educational resources and support to facilitate this are available.’
(Scottish Government 2010, p.5)

This situates Scottish schools as an important target for public health approaches to end-of-life care and recognises the possible role of such approaches in challenging taboos related to death, dying and bereavement. The report gives three examples of health promoting initiatives within schools. These include: a creative arts project at a hospice in England; a bereavement project in Scotland that provided a schools resource pack, support and a staff member to facilitate ‘bereavement’ art work with pupils; and a resiliency project called ‘Bounce Back’ developed in Australia. It was not clear if the latter project had been implemented or it was a suggested plan only. It was also unclear if the focus of the latter two initiatives was on all children or only children who had experienced bereavement. The report also highlights that limited research is available on health promotion projects in Scotland and emphasises that ‘any work encouraging a wider discussion of death, dying and bereavement [...] should aim to find ways to bring these issues into schools in sensitive and supportive ways’ (p.18).

Rowling (2003) argues that external agencies have either a preventative or intervention role in relation to death, dying and loss in a school community. A prevention model would involve activities designed to educate and support children so that they are better able to cope with loss, and intervention involves responding to crisis and/or offering support once bereavement has been experienced (ibid). Moreover, it is claimed that agencies need to work in both ways to establish comprehensive ways of working (Stokes et al. 1999). These approaches parallel Conway’s (2008) two models for a health promotion approach to palliative care; a reform model and a reorientation model. The reform model, like an intervention model, focuses on direct support, such as symptom control and bereavement support. A reorientation and/or prevention model focuses on development, which involves awareness raising and enabling community support. Both the reorientation and preventative approach, however, are still considered a relatively new way of working (Conway 2008; Rowling 2003). Rowling (2003) argues that bringing death and dying into the curriculum from a preventative, health promotion perspective depends

on a number of factors that include: curriculum priorities; the skills, comfort and motivation of teaching professionals; the learning environment; and the learning context. Although Jackson and Colwell (2002) assert that death and dying can be incorporated 'normally' in all aspects of the curriculum, there is a variety of literature on death education that notes that teachers often lack the confidence to do so (Rowling 2003; Crase and Crase 1979; Adams and Deveau 1995; Dubow et al. 1993). Crase and Crase (1979) highlight that death education for children necessarily involves self-development of teachers and cooperation with parents as well as effective communication with children. It is therefore essential that external agencies with an intervention role create strong, supportive, enabling relationships, led by the needs of the schools.

A survey of UK palliative care services found that working with schools was the most common type of work done in the community, identified by 73% of respondents (Paul and Sallnow 2013). This involved both intervention work, 'providing bereavement support with individuals and staff' and preventative work, 'engaging pupils in conversations on palliative care, death, dying and bereavement' (ibid, p.3). This suggests that working with schools is on the agenda of palliative care services and is deemed to be something worthwhile. There is, however, a lack of literature and research documentation sharing this work. In the process of preparing this chapter, I found only seven projects describing work with schools. Five of these were in England and two in Scotland. Only one of these projects was written up in academic literature, the others were discussed in either poster abstracts or as short segments in an email bulletin from Hospice UK (a national charity for hospice care).

The St Christopher's Hospice Schools Project, based in London, appears to be the most documented in the literature (Hartley 2009, 2012; Scottish Government 2010). It was established in 2004/5 and involves groups of pupils visiting the hospice over a period of four weeks to meet day care patients and join them in working towards a project theme decided in week one, usually via creative arts or performance. The hospice also provides a guidance and information pack which shares the work and plan of the project with the aim of enabling other hospices to see the potential in

becoming centres of death education (Hartley and Kraus 2008; Hartley 2012). Anecdotally, this appears to be the best known schools project amongst the hospice community. Two schools projects discussed in the literature were based on this model, one in England and one in Scotland. An additional project between hospices and schools that used a similar approach was also identified; however, this was not explicitly related to the St Christopher's Schools Project. These three projects worked with primary-aged school children and appeared to focus on education and awareness-raising on both the role of the hospices and end-of-life care. Two of the projects described in the literature discussed work with older children. One was an ongoing project between art students from a local college and day care patients. The other was a ten-week project between a hospice, the National Council for Palliative Care and a school designed to engage hospice day care patients and 6th form students in intergenerational discussions about death, dying and bereavement. It is unclear if the latter project was a one-off or a sustainable programme. The remaining project in England involved providing bereavement training to teachers, whole school presentations and workshops with the school or individual groups, as well as visits to the hospice. It was unclear who initiated this work and whether or not the bereavement training was proactive or reactive. The project in Scotland involved a hospice working with a school to promote healthy eating (Haraldsdottir et al. 2010). No further information was provided. This review identifies that although such work is deemed a priority by hospices there is an array of approaches being tried, most of which appear to be hospice-led rather than community-led. Although this may be due to each project reflecting local community need, it represents swampy ground for any new hospice wanting to develop work with schools.

In relation to bereavement, the Childhood Bereavement Network (CBN) has been significant in recognising that the support needs of children can be met through a health promoting approach. Their *Grief Matters for Children Campaign* attempts to promote the capacities of communities to support one another and assist in viewing death, loss and grief as a normal part of life. In June 2013, they also embarked on *The Elephant's Tea Party*, which is an annual event aiming 'to help teachers give children the emotional literacy and life skills needed to equip them for bereavement

now and in later life' (CBN 2012). Although the findings of these activities are not documented they are in line with health promotion concepts, which recognise a vision for society where 'communities of all kinds are empowered to provide effective support to those dealing with death, dying, bereavement and loss' (Scottish Government 2010, p.3). 'Dying Matters' and 'Good Life, Good Death, Good Grief' include on their website a section for schools, which discusses a number of strategies for incorporating issues around death and dying across the curriculum. There is however limited information on whether this has been taken forward.

Hartley (2012) argues that although The St Christopher's Schools Project is primarily driven by the hospice, it meets key requirements for schools in terms of teaching about loss and bereavement. This is confirmed by both 'Dying Matters' and 'Good Life, Good Death, Good Grief', and highlights that there is scope for developing health promoting palliative care with schools that meets both hospice and school agendas. Kellehear (1999) argues that, for health promoting palliative care to be developed effectively with school communities, partnerships that involve health education, death education, social supports, interpersonal reorientation and policy development are required. The literature relating to school projects is often focused on describing activities and anecdotal evidence from participants. It is thus limited in describing how these projects specifically relate to health promoting palliative care. There is also limited research on why the existing school projects were setup, who initiated the process, and for what purpose. This is significant, given that health promotion advocates involving all those participating in activities as integral to their design and success. Given this limited research and literature base it is therefore unclear to what extent the activities were health promoting. This is representative of literature on health promoting palliative care more broadly, which confirms that there is a need for conceptual clarity that enables service providers to understand the principles of health promotion and how this is potentially different from direct service provision (Paul and Sallnow 2013; Rosenberg 2012). It reflects a lack of literature in general about the introduction of health promoting palliative care practice to the UK, which is perhaps representative of a developing theoretical and

practice model. There is thus a need for more research that involves working in partnership with school communities to develop this area.

3.3 Conclusion

There is a current drive to develop public health approaches to end-of-life care, namely health promoting palliative care, based on current thinking and responses to death and dying, as well as policies that recommend action to generate awareness about related issues. Public health approaches offer a meaningful contribution to palliative care that has significant potential for optimising end-of-life care. This includes both challenging stigma associated with death, dying and bereavement (Kellehear 2009) and encouraging sustainable community support and care (Conway 2008). Health promoting palliative care is an approach which requires reorientation of normal service provision towards a broader focus on community participation and empowerment as opposed to a purely reactive response to need. It encourages practice that shares professional knowledge and experience to educate and enable communities to meet the social care needs of its members. It is an approach to end-of-life care that attempts to ‘support individual strengths through communal capacity and partnerships that normalise dying and celebrate life’ (Street 2007, p.105). Schools have been identified as a suitable site for health promoting palliative care initiatives and there exists a general consensus across both literature and research that it is beneficial for children to talk and learn about death. This involves working from children’s rights perspectives, whereby children are considered active citizens entitled to information and support about important aspects of life.

The ‘Curriculum for Excellence’ was introduced into schools in August 2010. It is still undergoing a period of change and growth where schools may potentially be more able to incorporate new methods of working and build upon health promotion principles in line with their curriculum agenda. Health promoting palliative care is, however, a sensitive area and as such may provide a number of additional challenges. There is a very limited research base of health promoting palliative care initiatives in Scotland and therefore, if such concepts are continued to be established and endorsed by the Scottish Government, there is a need to develop this research base further.

Moreover, for a school/hospice programme to be both effective and sustainable it needs to be suited to the context of both agencies, taking into account educational targets, pragmatic and financial resources, and the emotional sensitivity of the area. There is currently no evidence prior to the PhD study that explores developing work between hospice and school communities that engages children in education and conversation on death, dying and bereavement from a health promotion perspective.

Chapter 4: Methodology

This chapter focuses on the research design and methods and the rationale for both. I begin by reviewing the overall aims of the research, discussing action research as a methodology that focuses on practice development. I will discuss the underlying ontological and epistemological assumptions and theoretical perspectives that informed this research approach. I will then outline the research context and the research methods used, highlighting the ethical issues that were considered prior to and during the research process. Due to the nature of action research, how the research was conducted was adapted according to the participation of those involved in the research process. This will be discussed in more depth in chapters five and six.

4.1 Research aim and questions

The aim of this research was the exploration and development of practice between a hospice and schools that seeks to engage children in conversation and education on death, dying and bereavement. This necessitated employing a research approach that encompassed change as part of its focus, taking forward theoretical discussions on how the contested taboo of death, dying and bereavement is understood and experienced in relation to children and advancing practice knowledge on how hospices and schools can work together. The following questions provided the initial focus for the research:

1. How is the social taboo about death, dying and bereavement understood and experienced in relation to children in Scotland?
2. In what ways might the principles and practice of health promoting palliative care encourage and facilitate a new approach to death, dying and bereavement for children in Scotland?
3. Is there a role for hospices and primary schools working together in seeking to achieve this?

4. If so, what models of practice between hospices and primary schools can be developed?
5. What can we build on and what are the challenges and obstacles?

These questions were shaped by my own practice experience within the Hospice, by the literature review and by current policy and practice in other agencies (outlined in chapter three). These questions assisted in determining my original research design, thus enabling me to write a research proposal that could be submitted for ethical approval at both the university and the sites where the research was conducted. Action research is, however, an iterative process, led by the needs and input of the research participants. This means that the research aims, questions and the overall design of the research had to be negotiated throughout the research process. My original ideas were thus challenged, re-evaluated and adapted. This was due not only to the action research process itself, but also to the influence of my developing knowledge of research design and methods, which is a necessary feature of any PhD study. The above research questions therefore evolved as the research progressed and can now best be described as:

1. What are the challenges and opportunities for discussing, teaching and supporting death, dying and bereavement experiences with children in primary schools in Scotland?
2. Is there a role for primary schools and hospices to work together to develop discussion, education and support around death, dying and bereavement with children?
3. If so, what actions can be successfully implemented?
4. How do these actions relate to the principles and practice of health promoting palliative care and hospice service provision?
5. What can be learned from the action research process?

How the focus of these questions changed is discussed in chapter seven, which reviews and reflects on the overall action research process.

4.2 An action research methodology: a research approach to practice development

Whitehead and McNiff (2006) state that methodology refers to ‘a theory of how we do things’ (p.23). It thus relates to how the researcher conceptualises the research process and the assumptions and perspectives that they bring. There are various methodological approaches to research design including experimental research, survey research, phenomenological research, grounded theory, feminist research and so on. Silverman (2000) argues that methodologies are not true or false, but guided by how useful they are to the research. Likewise, Blaikie (2000) states that all research approaches should be built on the foundation of the research questions. He goes on to discuss three main types of research questions, which are grouped into ‘what’, ‘why’ and ‘how’ questions. This research sought to investigate *what* and *why* something happens to facilitate an exploration of *how* the situation could be developed. In order to answer the initial research questions and meet the aim of this research an action research methodology was chosen. Several authors assert that action research aims to both increase knowledge, experience and understanding of a current situation and engage in a process of change (Winter and Munn-Giddings 2001; Creswell 2007; Coghlan and Brannick 2001). It is a political activity, focused on involving those who are fundamental to the issues being researched as central to defining and developing what needs to be changed as part of the research process. The concept of developing and implementing new practice is a fundamental aim of this research. Although other research methodologies could have been chosen, action research addresses the aim of this research in ways that other methodologies would not allow by emphasising that research acts as a basis for, and an agent of, change. I will outline some of the underlying principles of action research before going on to identify why I specifically chose action research as a methodology for this research.

4.2.1 Defining action research

Action research does not belong to a single academic discipline, but has emerged over time from a broad range of fields, inspired by different epistemological and philosophical stances. Kurt Lewin, a social psychologist, is considered one of the founders of action research in his work conducted in organisational and experimental psychology. He developed a spiral of steps for both generating knowledge about a social system while attempting to change it (Lewin 1952). This cycle consisted of four major stages: plan, act, observe, and reflect (ibid). McNiff (1992) notes that Lewin stressed democratic collaboration and participation in completing these stages and promoted action research on the basis that workers would be more effective if they were involved in shaping the context of their work. Action research has, since then, been developed by a range of disciplines, including education, community development, health and social care. Both Hart and Bond (1995) and Carr and Kemmis (1986) argue that this is mostly due to the value of action research in directly linking research, theory and practice. Nevertheless, there is some debate in the literature concerning where action research is situated within the philosophy of social science (Brydon-Miller et al. 2003; Cassell and Johnson 2006).

A number of strands of action research now exist, each providing a different focus on how the research should be conceptualised. These include participatory action research, collaborative inquiry, emancipatory research, action learning, contextual action research, insider action research, external action research and so on. Due to this variety of approaches, a number of authors suggest that action research is shrouded in mystery and contradictions (Coghlan and Brannick 2001; Healy 2005; Hart and Bond 1995). Attempts have been made to categorise these variations in order to better articulate the range of approaches that they offer. McKernan (1996) offers three main typologies of action research, which include: scientific-technical; practical-deliberative; and critical- emancipatory. Variations of these typologies have also been offered, for example by Hart and Bond (1995) and Cassell and Johnson, (2006), yet, I would argue that those proposed by McKernan (1996) provide a broad framework within which other variations can be included. Scientific-technical action research aims at increased effectiveness in performance through

changes in social practices. The researcher is relied on as an outside expert and the research thus relies on positivist principles to improve workplace efficiency (ibid). Practical-deliberative action research involves ‘transformations of the consciousness of participants as well as change in social practices. The researcher acts as a research consultant, engaging in dialogue to encourage both the cooperation of participants and self-reflection’ (Zuber-Skerritt 1991 in Rolfe et al. 2001, p.160). Critical-emancipatory action research is concerned with the researcher empowering participants involved in the research process to enable them to challenge existing social structures and practices that cause disadvantage. Gray (2009) also offers a broad discussion on the common features of the different action research approaches. He argues that common features include:

‘research subjects are themselves researchers or involved in democratic partnerships with a researcher; research is seen as an agent of change; [and] data are generated from the direct experiences of research participants’ (p.313).

Furthermore, it is asserted that what makes action research distinctive is the iterative cycle of problem identification involved in the series of a spiral of steps (Cassell and Johnson 2006; O’Brien 2001). If a methodology is understood as a ‘strategy or plan of action [...] that shapes our choice and use of particular methods and links them to desired outcomes’ (Crotty 1998, p.7), it is from this basis that I would argue that action research is a methodology. Through facilitating this spiral of steps, action research provides a framework from which to choose and utilise research methods.

Action research is grounded in practice development and its purpose is not to describe or interpret the world, but to change it. Coghlan and Brannick (2001) argue that action research is therefore a powerful conceptual tool for uncovering truth on which action can be taken. Action research is thus committed to both theoretical and practical knowledge development. Noffke and Somekh (2009) assert that it offers a means of generating knowledge as well as personal and professional development, through enabling participants to understand themselves and their work better. Nevertheless, Brydon-Miller and colleagues (2003) note that how theory is generated is unclear if not contradictory. Friedman and Rodgers (2009) assert that this

confusion is partly due to the lack of attention given to theory in action research projects, with most authors focusing on processes of investigation and practice developments rather than elaborating on the techniques used to gather and analyse data. They argue that

‘empowering clients to make practical and sustainable changes means co-creating a shared knowledge of the causal conditions of their social world and its attendant difficulties, and that this knowledge is theoretical’ (2009, p.44).

Likewise, as Dick and colleagues (2009) highlight, when people act,

‘they choose the actions that they think will produce the outcomes they want. In other words, before they act they have a theory, perhaps informal, connecting actions and outcomes.’ (p.7)

Theory in action research is grounded in enabling participants to explore a collective understanding of their current situation and to make changes that improve it. Noffke (2009) states that it attempts to bridge ‘theory and practice but also generate new ways of understanding practice’ (in Noffke and Somekh 2009, p.10). In most traditional research approaches, the researcher starts with a hypothesis that is then tested out. This assumes that there is a linear connection between theory and practice. Carr and Kemmis (1986) assert however that action research assumes that all practice has theory embedded in it. This means that theories are not ‘validated independently of practice’ but ‘evaluated through practice’ (McKernan 1996, p.4). Zuber-Skerritt (2011) states that the aim of theory in action research then is not to predict or control behaviour, but to understand social practices, conditions and processes and to change them if they inhibit or obstruct the desired outcome.

4.2.2 The action research framework

As discussed previously, action research is usually conducted through a spiral of steps composed of planning, action and evaluation/critical reflection of the action in order to learn and to plan subsequent events (see Figure 1). It is therefore an iterative process of problem identification that can start at any point in the cycle based on the researcher’s existing relationship and knowledge of both the organisation and the issues concerned. Unlike some methodologies, action research does not distinguish

between qualitative or quantitative methods. Hockley and Froggatt (2006) highlight that action research differs from quantitative and qualitative research paradigms in three ways: ‘in its understanding and use of knowledge; its relationships with research participants; and the introduction of change into the research process’ (p.836). Action research thus recognises that there is more than one way of knowing and can employ a variety of methods that are suited to both the task at hand and the community in which it is happening. Action research is consequently full of choices and, despite the framework which the cycle of steps provides, it can be described as a messy, iterative process. This is highlighted by Kemmis and Wilkinson (1998), who note that ‘initial plans quickly become obsolete in the light of learning from experience. In reality the process is much more likely to be fluid, open and responsive’ (p.21). Action research is therefore not a rigid method of inquiry, but shaped by the community in which it is happening. It is a developmental process in which the participants contribute to resolving the issues in question, which Zuber-Skerritt (2011) claims requires creativity and flexibility.

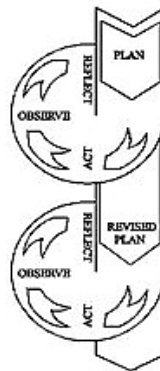


Figure 1: The action research cycle (Kemmis and Wilkinson 1998, p.35)

Hockley and Froggatt (2006) argue that the extent to which people participate in action research depends on the context of the research setting. Different organisations may be more open to collaborative working than others for reasons such as pragmatic concerns, including a lack of time and resources to free people to participate, and existing hierarchical structures that warrant some voices more important than others. O’Brien (2001) asserts that this is a challenge to action researchers. He notes that a balance has to be achieved, which involves being both

flexible to the needs of the organisation in which the research is happening as well as a systematic inquiry informed by theoretical considerations. The role of the researcher is thus different in action research compared with more traditional research paradigms, as the researcher moves from the role of expert to that of an enabler who is involved directly in the research process (Cassell and Johnson 2006; Rolfe et al. 2001). Kemmis and Wilkinson (1998) argue that a successful action research project, from this perspective, is not judged according to whether the cycle of steps have been followed faithfully, but instead, whether there is 'a strong and authentic sense of development and evolution in their practices, their understandings of their practices and the situation in which they practice' (p.21). This places emphasis on transparency of the research process, which is linked to issues around validity, reliability and generalisation. These terms have been argued particularly relevant to social science research and highlighted as key criteria for assessing any research (Frankfort-Nachmias and Nachmias 1996; Blaikie 2000). In relation to action research however, Coghlan and Brannick (2001) state that these terms do not apply. Instead they argue that action research is based on describing what happened, making sense of the choices and experiences, and extrapolating usable knowledge or theory from what happened. This requires exposing the research process to critique, making all research decisions transparent so that the research process is seen as credible and robust by audiences. Similarly, Reason (2006) argues that action research is concerned with how experiences are understood in the wider context of theoretical debates and the ways in which the inquiry affects the community in which it is based. He relates this to the extent to which the research has

'helped to support and develop an effective community of inquiry, whether questions of power have been addressed, whether the inquiry has been emancipatory and deepened the experiential basis of understanding' (p.193).

An important assessment criterion for action research is therefore not what works, but the extent to which the research process serves to empower, facilitate and enable change and knowledge generation in the research setting.

4.2.3 Action research and the aims of this research

A number of reasons underpinned my choice of an action research methodology. Firstly, Carr and Kemmis (1986) argue that action research is integral to professional work owing to its symbiotic relationship with theory and practice. McNiff (1992) asserts that action research often begins with dissatisfaction about current practice that prompts the researcher and/or organisation to explore better ways of working. Alston and Bowles (2003) note that these factors are particularly relevant to social work practitioners. I have discussed previously that this research arose as a result of my practice experience and dissatisfaction around requests to provide pre-bereavement/bereavement support to children when people/professionals already involved in the child's life had not even discussed the subject with them prior to making a referral. I was keen to explore and develop more proactive work that sort to normalise, rather than pathologise, death and bereavement. Moreover, the Hospice that funded this research had certain expectations in terms of what it would like to see for its investment. Although the management team recognised the importance of research in informing practice they were also committed to action and stipulated that they would like to see practice developed as a research outcome. I felt that action research would potentially serve to meet both the needs of the funders and my professional commitment to practice development.

Action research actively seeks to impact and shape practice through working in partnership with key stakeholders. It is therefore essentially concerned with democratic forms of decision-making within organisations and communities and is about research 'with' people, not 'on' people (Reason and Bradbury 2008). As the focus of this research was on exploring and developing practice, I felt it was necessary that knowledge was co-created with the intention of empowering those involved to make changes as they see fit. This would mean that any practice developments were inclusive and responsive to the needs of participants rather than my own and/or that of the organisation. This is consistent with the principles and values of social work, which Hughes (2011) highlights 'place as much emphasis on how we work with people as on what work we do' (p.2). It is also a key feature of health promoting palliative care, as discussed in chapter three, which Conway (2008)

argues is fundamentally about working in partnership to discover ‘what can be done most appropriately to share power and knowledge’ between communities and palliative care providers on end-of-life care issues (p.412). Furthermore, I was also aware that the Hospice and schools operate within different boundaries, structures and procedures, which would undoubtedly impact on any practice developments. I felt that the participatory nature of action research would provide opportunities for such issues to be negotiated and explored.

Action research is often associated with critical theory in its ability ‘to inform social actions, particularly ones directed at the readdress of social inequalities’ (Noffke in Noffke and Somekh 2009, p.11). Gray (2009) claims that action research aims ‘to bring people with divergent views and perceptions together, so that they can collectively formulate a joint construction’ (p.318). As discussed in chapters one and two, readdressing the power imbalance between children’s and adults’ ability to access information and education on death, dying and bereavement was a motivation towards undertaking this research. Discussion around how children can be included in research is increasing. Gokah (2006) argues that this is often based on the concept that, if children are excluded from research that is either about or involves them, the data generated would be the result of an adult perception of what children want and/or need. Punch (2002) states that the ways the researcher perceives the status of children undoubtedly influences the choice of research design and methods. She outlines three main viewpoints, which include: those that see children and adults as the same; those that see children as different to adults; and those that see children as similar to adults with different competencies. Although each viewpoint has its own strengths and weaknesses, I primarily take the latter viewpoint, as I believe that children are active beings and, with age-appropriate information and support, have rights to information and education about significant aspects of their lives, including loss, death and bereavement. This view also means that involving children in this research was incredibly important for me, allowing them the opportunity to express their views, be listened to and responded to. I felt that an action research methodology would ensure a platform for both involving and listening to children and initiating change. Although other methodologies, such as feminist research, also

have this focus, unlike action research, they are less likely to be committed to readdressing power imbalances by changing practice.

4.2.3.1 Action research and the use of self

The above discussion clearly identifies how my role as a practising social worker and beliefs around the importance of including children in research and conversation about death shaped this research design. From this standpoint, I wanted to use action research to create a space with school communities whereby I could challenge opinion that may run contrary to this belief. Gray (2009) argues that the action researcher is ‘a catalyst for achieving change by stimulating people to review their practices and to accept the need for change’ (p.323). Likewise, Hockley and colleagues (2013) assert that the:

‘Action researcher themselves are part of the change mechanism; their research therefore is not value-free, but will inevitably be tied up with their own previous experience alongside that of co-researchers.’ (p.9)

The researcher is then firmly situated within the research process, of which relationships are fundamental. Action research thus challenges research approaches that rely on researcher neutrality and objectivity by situating the researcher in an active position as a vehicle for facilitating, not directing, change. Reflexive practice is thus intrinsic to action research to allow the action researcher to explore how they engage with both the research and the research participants. Cree and colleagues (2002) argue this is significant in addressing issues of influence and bias.

Reinharz (1997) discusses how ‘the self we create in the field is a product of the norms of the social setting and the ways in which the “research subjects” interact with the selves the researcher brings to the field’ (1997, p.3). He categorizes three major groups of ‘selves’ that include the research-based self, the brought self and the situationally created self (1997, p.5), all of which need to be acknowledged and explored. The concept is significant to this thesis. As a researcher: I am sponsored by a hospice; I have a clear goal of pursuing a PhD qualification that has included specific training as well as necessitating specific requirements from the research process; and I am a temporary member of the school communities. As a brought

self: I am a woman, I speak with an English accent; I have personal and professional experience of death and dying; I am social work trained; I dress and look a certain way; I believe that children should be included in conversations about death, dying and bereavement; and I bring vast experience of working with children in a group context. Both my 'researcher' and 'brought' self will influence how I understand and use action research. Moreover, they will impact on how the research participants interact and engage with me and how I situationally create my sense of self within the action research process. Reinharz (1997) argues that this, in turn, impacts the type of knowledge that is shared and created. This relates to Finlay's (2003) concept of research as being 'co-constituted – a joint product of participants, researcher and their relationship' (p.5). I have attempted to employ reflexive practice through this study, seeking to question my academic and personal assumptions of the research process, as well as my use of self. It is specifically addressed as part of my data analysis framework (see section 4.4.5), as well as being aided by meetings with supervisors and a reflective log kept during the action research process.

4.3 Ontological, epistemological and theoretical framework

The above methodology is influenced by the ontological, epistemological and theoretical perspectives that I bring to this study. Such perspectives also provide a foundation for the choice of research methods. Crotty (1998) argues that these perspectives also influence both the researcher/participant relationship and how the findings of the research are communicated. I employed an extended epistemology, using critical inquiry as a theoretical framework from which to design and facilitate an action research approach to data collection. I will outline the reasons for this choice below, showing how these decisions were affected by the research process, my professional and personal value base in terms of how to work with research participants, and a commitment to developing practice.

4.3.1 Ontological and epistemological perspectives

Blaikie (2000) describes ontology as 'concerned with the nature of social reality' (p.92). It is therefore interested with what does or can exist (ibid). Carter and Little

(2007) define epistemology as ‘the theory of knowledge’ (p.1317) and is focused on what kinds of knowledge are possible, i.e. how do we know what we know. When I initially proposed this research, I rejected the use of realist ontologies and objectivist epistemologies. Crotty (1998) argues that such assumptions rely on the concept that truth exists independently of experience and falls into the positivism theoretical perspective that research can obtain an objective truth. My initial aim had been to explore how children experience the taboo of death, dying and bereavement, and it was clear from the literature review that such experiences are influenced by historical and cultural influences and are therefore far from objective. Moreover, I have discussed the ways in which the researcher role in an action research paradigm is that of enabler rather than objective facilitator, which challenges the positivist view point that research is value-free. I thus argued for the use of an idealist ontology and constructionist epistemology to inform my research design. These assumptions are founded on the premise that truth is a representation of the human mind, based on social realities of shared meanings and the construction of meaning in different ways depending on an individual’s engagement with the world (Crotty 1998; Blaikie 2000). They place emphasis on the ways in which knowledge is created via interpretation and how meaning can be shaped via social experiences. I believed that this approach suggested that ‘meaning-making’ is an evolving process that is malleable and open to change, thus suited to my research aim. As I progressed through the process of data collection, however, I became dissatisfied with these accounts of knowledge production. I began to be aware that placing my own assumptions of how knowledge is created was in opposition to participatory working that is an essential feature of an action research methodology. How could I operate in a truly participatory manner if I held predetermined ideas on what knowledge counted as truth?

A key reason for embarking on this research was based on my practice experience, which I would argue validates and recognises knowledge created through practice. This also became apparent at certain stages in the research, particularly relating to how participants created knowledge about the research area. For example, a teacher I interviewed decided she wanted to teach a lesson on loss, change and bereavement.

It was planned that all participating teachers would meet to discuss their thoughts on what they wanted to do and/or change. This teacher, however, wanted to skip this stage as she was aware that some children in her class had recent bereavement experiences which she had not addressed. As a result, she wanted to do something quickly and wondered if I had any material. I lent her some books and we arranged to talk the following week. When I went into the school to meet with her she had already facilitated the lesson, and reported that the experience “was great. I’d definitely do it again. I’ve been telling all the other teachers they should do it too”. Although this demonstrated to me the constructionist view of knowledge creation, which Creswell (2007) describes as being negotiated and transformed through social practices, it also emphasised how the practice of experimenting with new ways of working had influenced the teacher’s knowledge construction. I thus began to question the use of a constructionist view point and turned to the work of Peter Reason and John Heron, who argue for the use of an extended epistemology in action research (Reason 2006; Heron and Reason 1997). They assert that constructionism fails to account for experiential knowing, and contend that an extended epistemology which encompasses different ways of knowing is much more relevant. This includes experiential, presentational, propositional and practical ways of knowing. Experiential knowing is based on knowledge from direct face-to-face encounters with a person, place or thing. Presentational knowing grows out of experiential knowing and is evident through forms of imagery such as music and verbal art forms. Propositional knowing is knowledge in conceptual terms and is expressed in informative statements and theories. Practical knowing is based on how to do something, demonstrated by a skill or competence (Heron and Reason 1997). An extended epistemology thus validates different ways of knowing that allows participants to engage with the research according to how they view and prioritise knowledge construction.

4.3.2 Theoretical perspective

Guba and Lincoln (1994) claim that theoretical perspectives represent a world view that describes the nature of the world and the individuals place within it. This research employs a critical inquiry perspective, which maintains ‘a view of theory

that has the central task of emancipating people from the positivist ‘domination’ of thought through their own understandings and actions’ (Carr and Kemmis 1986, p.130). Lather (1986) argues that critical inquiry is ‘a fundamentally dialogic and mutually educative enterprise’ (p.268). Fay (1975) argues that it emphasises participatory and interdisciplinary research and is a response to the experiences, desires and needs of oppressed people. Winter and Munn-Giddings (2001) assert that understanding situations to bring about change is a defining feature of action research. Consequently, several authors assert that action research should derive from a critical-emancipatory paradigm (Carr and Kemmis 1986; Houston 2010; Hockley et al. 2013).

Critical theory is perhaps primarily associated with the work of Jürgen Habermas (1971, 1972), who argues that, from a critical standpoint, researchers should be engaged with emancipatory action to expose inequality and disadvantage in the interests of human autonomy. Similarly, Fay (1975, 1987) emphasises the need for social science research to identify and expose false consciousness and develop a plan of action surrounding how people can affect positive change. The critical inquiry tradition has therefore been asserted by Crotty (1998) as challenging the scientific establishment and its claims to objectivity and methods of operation. Here, researchers often tend to maintain a spectator, outsider perspective and any theory generated is thus the researcher’s theory about other people. From a critical inquiry perspective, the purpose of research is aimed not just at advancing knowledge in the research area, but also at developing an intervention that attempts to change the social world. It is concerned with not only how things are, but also with how they might be. The researcher thus positions them self from a value standpoint, involved in a process that attempts to both explore and/or understand situations and seek out alternatives. This involves working in partnership with others to discover indicators of disadvantage and the solutions for readdressing such disadvantage.

A critical inquiry perspective was chosen because of the underlying purpose of this study to empower participants to change practice and challenge barriers that prevent children’s inclusion in conversation and education on death, dying and bereavement. Furthermore, I was aware from the onset of this study that the research aim and

questions clearly identified my views on children's involvement in relation to the research area. An emancipatory focus was therefore central to this research, as it involved attempting to address power imbalances between children and adults through promoting the rights of children to have access to information about significant aspects of their lives. Critical inquiry is also potentially in line with health promoting palliative care, which aims to develop community capacity in end-of-life care and bereavement that ultimately enables choice around care and support, rather than be confined to established organisational structures and services. As McKernan (1996) highlights in relation to action research, this involves 'lifting of the oppressive situation: the treating of blockages and barriers to effective action; in short, the improvement of life quality in the research setting' (p.53). Moreover, critical theory has been argued by Houston (2010) as being particularly suited to social work research as it focuses on 'the interplay between real selves, real narratives, real institutions and real worlds' (p.88). It is consequently a perspective that is essentially collaborative and practical, both aspects of which were integral to the aims of this research and an action research methodology.

4.4 Research design

I have discussed how the research aim and questions led me to use an action research methodology, employing an extended epistemology and a critical inquiry framework to inform the research design and data collection. I will now describe how the research was designed, describing the research context and an overview of the action research process. I will outline the research context, paying particular attention to issues around units of study and research sites, data collection methods and analysis. I will also discuss the ethical issues that were considered and how this shaped the research design and process.

4.4.1 Research context

I have highlighted that the remit of hospices in promoting awareness of issues related to death, dying and bereavement has been given increasing significance through UK policy making in end-of-life care. This research is situated within a Scottish context based on a number of factors. Firstly, as previously discussed this PhD is funded and

supported by Strathcarron Hospice which wishes to develop work with schools. Secondly, Scotland has different health and education systems than the rest of the UK, which would impact any connected activities. Thirdly, the literature review highlighted that there currently appears to be more projects between schools and hospices in England and Wales and this is a potentially underdeveloped area in Scotland. Moreover, 'The End of Life Care Strategy' (Department of Health 2008) in England Wales, was introduced prior to the Scottish equivalent policy, 'Living and Dying Well' (Scottish Government 2008) and a result there are more structured health promoting palliative care developments in England and Wales. This has been identified by the Scottish Government (2010) as an area that needs further research and development.

4.4.2 Study sample

Frankfort-Nachmias and Nachmias (1996) argue that units of study are a key aspect of research as they determine what aspect of the phenomenon is to be studied, thus influencing the research design. Deciding what units were to be studied within this context determined whether the research allowed a focused, in-depth understanding or a wider study that might allow for broader generalisations to be made. As noted previously, the Hospice funding this research agreed to be a research site for this study. It covers four local authorities (LA's), which includes 24 secondary schools, 133 primary schools and three independent schools. Given the amount and geographical spread of the schools, within the limits of a PhD research project it was not possible to focus on all schools in any meaningful way. Schools were therefore recruited from the LA in which the Hospice was situated. This LA covers 112 square miles and has a population of 151,570. The area contains both rural and urban communities and thus has characteristics that are similar to the other three LA's in the Hospice catchment area. Moreover, due to the Hospice being located within the same LA as the recruited schools, it enabled me to travel in between the Hospice and the schools in a relatively short space of time. This was significant given I was initially juggling both PhD research and social work practice in the Hospice.

Schools work with a wide age range of children. I felt it was of fundamental importance to include children's views in this research for reasons already discussed and, within the limits of this research, did not feel it was possible to cover all age groups in any meaningful way. I decided therefore to focus on primary school children aged nine to 12 years, i.e. those children in primary classes six (P6) and seven (P7). This was based on a number of factors. Firstly, anecdotal evidence from staff within Strathcarron Hospice identifies increased anxiety around talking to younger children due to fears around causing unnecessary upset. The hospice management team were therefore specifically interested in developing work with primary schools. Secondly, as also discussed in the literature review, children aged eight and upwards are considered as having developed a concrete understanding of death (Lindsay and Elsegood 1996; Silverman 2000; Bluebond-Langer 1977). Although younger children will be aware of death, their understanding varies according to their experiences (Christ 2000). It is not an intention of this research to cause unnecessary harm by introducing concepts to children that they are not already familiar with. Moreover, this research is not attempting to explore how children understand death but how adults engage with them on these issues, and therefore involving older primary children based on development theory suggests that the children involved will be more able to participate.

In Scotland, the majority of schools are state-funded and non-denominational (Scottish Government 2013). 14% of Scottish schools are denominational, the bulk of which are Roman Catholic, with one Jewish and three Episcopalian (ibid). This situation parallels the LA identified to recruit schools from. Within this LA, there are 50 primary schools, 43 of which are non-denominational and seven Roman Catholic. All of these schools are state-funded (ibid). In the literature review, I discussed that the impact of faith on how death, dying and bereavement is spoken about and managed can be significant. I felt it was therefore important that two primary schools of different dominations were recruited in the research to allow an opportunity to see if the role of faith was an important issue in any developed practice, as the literature might suggest. The research therefore took a micro-approach, using the Hospice and two primary schools located within one local

authority as case sites, one of which was Roman Catholic (RCPS) and one non-denominational (NDPS). Saunders (2001) argues that this approach is suited to an action research methodology. She asserts action research should be site-specific and aim to develop practice whilst achieving a deep understanding of the specific community that is the focus of the study.

4.4.3 Recruitment: schools and participants

At the time of starting this PhD there were 49 primary schools in the local authority, with an additional school opening in 2012. Out of these schools, five were located in the same town as the Hospice. The Hospice management team felt it was preferable not to involve any of these schools as it was likely that many of the children would have friends or relatives working in the Hospice, which may impact on data collection. This meant that there were 44 primary schools, seven of which were Roman Catholic, which I could contact. As there were fewer Roman Catholic schools I started to contact those schools first. Contacting schools, however, was challenging due to difficulties in accessing head teachers to discuss the research. I frequently had to rely on messages being communicated via deputies and or secretarial staff, or through emails sent to either a generic school address or, when possible, the head teacher directly. Often these emails and messages did not get returned. Over a period of two months I was able to speak directly to a head teacher or deputy head at six schools of the 44 primary schools to inform them of the research and to see if they were interested in participating. The first Roman Catholic school I spoke to agreed to participate. The first four non-denominational schools I spoke to did not want to participate for reasons which included: competing workload priorities; staff shortage; and uncertainty around the subject matter. Two schools noted that, although they did not want to be the first schools to participate in the research, they were incredibly keen to find out what the research findings were.

The schools which agreed to participate, one Roman Catholic (RCPS) and one non-denominational (NDPS), were located seven miles apart. Both head teachers discussed the research with their staff team prior to committing to take part. Once they had agreed to participate, I met with the head teacher at each school and the

Hospice Chief Executive (CEO) to negotiate how the action research process would be facilitated at each site. This also included developing a strategy for recruiting participants. As discussed previously, Winter and Munn-Giddings (2001) assert that action research aims to give a voice to those who are often culturally silenced. I therefore intended that participants in the action research process would include all those who may be impacted by possible changes to practice as opposed to those in management, who are most often the decision-makers. Participants therefore included Hospice staff across varying departments, school staff, children aged nine to 12, and parents/carers. Chapters five and six discuss how the research was negotiated and facilitated at each school.

4.4.4 The action research process

I have discussed previously that there is no one way of doing action research. It is a process of steps that can involve a variety of methods depending on the aims of each project. This section will outline the process of steps I intended to undertake, the methods used and the rationale. Although the methods used were the same in each setting, how the actual research developed was different at each site according to a variety of factors. Therefore, as noted above, how this action research process developed in each setting is discussed in more detail in the next chapters.

4.4.4.1 The research cycle

At the start of this PhD process it was intended that I would work through an initial cycle of the action research (plan, act, observe, reflect), with subsequent cycles being facilitated by teams involved in any developed practice. I therefore argued in my initial proposal that this study would include five phases. These were:

Phase one: Preparation and scoping

- Literature Review
- Visit hospices across the UK currently working with children in school settings to explore the types of work they were conducting and the aims of this work.

- Focus groups with Hospice staff
- Recruit schools
- Develop themes for interviews and focus groups from both the literature and project visits, to be facilitated in phase two.

Phase two: Exploration phase

- Interviews and focus groups seeking to develop discussion and explore ideas related to how education and support around death, dying and bereavement is experienced by children and to explore practice ideas with schools.
- Data generated from interviews and focus groups transcribed and analysed.

Phase three: Planning and developing a model(s) for possible interventions

- Exploring, deciding and developing possible practice ideas with relevant stakeholders.

Phase four: Piloting developed practice(s)

Phase five: Evaluation of the new practice(s) in parallel with stage four

As this is a PhD research project I had a defined timescale within which to work. Unfortunately, developing practice alongside school timescales meant that not all of the above phases were completed as part of this study. When I began writing this thesis, phase three was underway with practice models being developed and piloted. The intention was that these actions would be critically evaluated within existing systems at each organisation, led by the research participants involved. The remainder of this thesis therefore primarily reports on phases one, two and part of three. It describes how change was explored and what projects were decided on, but

not on the complete process of how the models of practice were developed and evaluated. Kemmis and Wilkinson (1998) note that, ideally, action research should not end with a final evaluation, but should involve continuous reflection on action, meaning that any changes to practice are continually developed and refined. Emphasis is thus placed on completing and continuing action research cycles. Nevertheless, Coghlan and Brannick (2001) state that the decision to stop is dependent on the researcher's judgement of the extent to which the project has yielded sufficient learning. Although it feels somewhat disappointing and restrictive not to complete and fully discuss all five phases of the research within this thesis, I would argue that sufficient learning was achieved to demonstrate a contribution to theory and practice in this arena. This will be discussed in greater depth in subsequent chapters. A discussion outlining the justification for choosing these methods and stages of research is carried out below. It is worth highlighting, however, that I took seven months maternity leave before completing the final chapters of thesis. As the practice ideas continued to be developed during this time I have therefore also included an overview describing what took place at each site, including my involvement and the current state of play (see Appendix 16).

4.4.4.2 Research methods

Moses and Knutesen (2007) describe research methods as problem-specific techniques. The purpose of phase two (the exploration phase) was to explore what was currently happening at each school in terms of engaging children in issues around death, dying and bereavement, identify any challenges, and explore possible approaches to meet these challenges. Likewise, phase three focused on sharing these ideas with other relevant stakeholders to decide and develop possible practice initiatives. As I was not familiar with the school settings, I felt that time needed to be spent at these phases to develop a relationship with the school community that would allow the research area to be explored and developed together. I thus decided that qualitative research methods were best suited to facilitating these phases. Silverman (2000) argues that qualitative methods seek to gain a deeper understanding of a social phenomenon through recognising and exploring varied social and cultural constructions of reality that quantitative studies may not permit.

Gerson and Horowitz (2002) assert that qualitative methods are concerned with the ways in which people interpret and give meaning to experiences, and aim to discover and develop new concepts rather than impose preconceived ideas and categories. Qualitative methods thus require that the research is systematically, strategically and rigorously conducted, but that learning is understood within the specific context in which it is situated. Creswell (2007) identifies that the ‘procedures of qualitative research [...] have been characterised as inductive, emerging, and shaped by the researcher’s experience in collecting and analysing the data’ (p.19). This compliments an action research methodology as it enables the research process to become a shared journey between the researcher and participants, whereby the researcher is not seen as external and objective to the research but as part of the process. Moreover, Noffke and Somekh (2009) argue that action research chooses and uses research methods to enable social change, whilst enabling the participants to remain experts in their own environment. By using a mixture of focus groups and interviews I felt that I could create space for participants to reflect on what was currently happening within their specific contexts, both individually and collectively, to then identify challenges and explore alternatives. Furthermore, using these qualitative methods would also enable me to develop a relationship with the participants in a way that quantitative methods, such as surveys and questionnaires, would not allow. I felt that developing relationships was significant in building trust and openness between the participants that would be needed if any practice developments were to happen.

4.4.4.3 Research methods: focus groups

Focus groups were used in phase one, two and three of the research to generate data around how children are included in conversation and education on death, dying and bereavement as well as to explore and decide possible practice developments. Focus groups are discussed by Barbour and Kitzinger (1999) as ‘group discussions exploring a specific set of issues [...] distinguished from group interviews by the explicit use of group interaction to generate data’ (p.4). They argue that the use of focus groups enables participants to both explore and share their experiences, opinions, concerns and ideas while also pursue their own priorities within the

research topic. As action research focuses on enabling participants to work together to engage in a process of change according to shared priorities, focus groups seem to be the most suited method. Given that the research area could have been a relatively unfamiliar subject to participants, I felt that the benefits of group discussion and interaction would assist participants in developing their thoughts and ideas about the research area.

Bryman (2008) claims that focus groups are a ‘popular method for researchers examining ways in which people in conjunction with one another construe the [research] topic’ (p.475). This can enable different perspectives to be expressed and heard in way that is not possible through using interviews alone. Compared to other research methods, several authors highlight that focus group participants are considered less likely to embody preconceived ideas of the facilitator, potentially generating ideas that they may not have considered (Kitzinger 1994, Barbour and Kitzinger 1999, Bloor et al 2001). Furthermore, Kitzinger (1994) considered focus groups helpful in ensuring that ‘priority is given to the respondents’ hierarchy of importance, their language and concepts, their frameworks for understanding the world’ (p.108). This is significant to this research. Given my professional experience of working with children experiencing bereavement, I have developed specific ideas around how I anticipate different people will respond to the research area. It was therefore important that I created a space to allow alternative viewpoints to come forward and be heard. Moreover, given the potential sensitivity of the subject area, I felt that focus groups would provide a less threatening environment than interviews. This was particularly so for children who did not have any previous relationship with me. Unlike interviews, in focus groups the individual is not the focal point. Emphasis is placed on group interaction, and therefore this allows people to opt in and out of conversation as they feel appropriate. This undoubtedly depends on the researcher’s ability to ensure a safe and confidential place where people feel free to talk, however, it also gives participants more control over what they do, or do not, decide to contribute to the research.

In phase one, focus groups were held with Hospice staff. In phase two, focus groups were planned with children and parents/carers who have children of primary age. I

chose not to use focus groups with teaching staff for reasons described below. The focus groups aimed to explore responses to how the social taboo about death and dying is understood and experienced and generate discussion around how practice could be developed in this area. I aimed for a minimum of six to eight participants in each group. Barbour and Kitzinger (1999) highlight the need to ‘over-recruit’ participants, given that people often drop out prior to meeting. In response to this challenge I aimed to have at least eight participants recruited for each group at the initial recruitment stage. A guide sheet was designed to focus the direction of the group discussion (Appendix 4). This did not use leading or closed questions, which Bryman (2008) highlights can inhibit reflective discussion. It also aimed at being interested, rather than intrusive, in participants’ responses. Kreuger (1998) argues this enables a natural and reflective discussion to develop. In his research with children, Hill (2006) found that they preferred to have choice in what research methods are used. This research, coupled with the sensitive nature of the research area, meant that I gave potential participants an option of whether or not they would prefer to participate in a focus group or interview. One child and one Hospice staff member opted to participate in an interview.

Time at the beginning of each focus group was spent aiming to establish an open and accepting environment. In order to take into account children’s varied social competencies and life experiences Punch (2002) argues that research with children should employ a range of different techniques and methods. The children’s group therefore involved several activities aimed at generating discussion. These included using icebreakers and games that were developed around the focus of the research and which encouraged a mixture of verbal and written feedback. The focus groups were recorded and transcribed, with permission from participants. This allowed me to focus on the group discussion, thus keeping conversation flowing as naturally as possible. Transcribing also enabled me to become extremely familiar with the data for purposes of analysis (see section 4.4.5).

Focus groups used in phase three of the research sought to encourage participants to explore, decide and develop possible practice from the ideas generated in phase two. The nature of action research involves

‘continuously negotiating between differences of perspectives, and its validity resides in the carefulness and rigour of this process [and] how far it seriously addresses the crucial issues of organisational and professional power.’ (Winter and Munn-Giddings 2001, p.21)

It was therefore intended that a cross-section of participants was included in this aspect of the research, including Hospice staff, teaching staff, parent/carers and children, in order to achieve a group consensus on developing ways forward, whilst ensure that different perspectives were given a voice. Issues of power were apparent at this stage of the research and the two schools subsequently decided to proceed quite differently, discussed in chapters five and six. As with the previous stage of the research these focus groups were recorded and transcribed, with permission from participants.

4.4.4.4 Research methods: interviews

Interviews were used with one hospice staff member during phase one of the research and school staff in phase two. Gray (2009) argues that interviews are a useful method for gathering information about an individual’s knowledge, experience, values, feelings and attitudes. They differ from focus groups in that participants are involved in a one-to-one interaction with the interviewer, and participants do not therefore have an opportunity to reflect on other participants’ thoughts, opinions and ideas. As discussed above, I had considered using focus groups as the main method for data collection in this phase, as I felt that creating a space where school staff could share and learn from other participants was significant. Interviews, however, were used for two reasons. Firstly, both head teachers felt that it would be easier to gain access to school staff if I spoke to them individually because they would be able to accommodate covering their teaching commitments. They also felt that holding focus groups outwith schools hours would inhibit participant recruitment. Secondly, I was aware from the literature review that, in 2001, over 70% of schools had a bereaved child in their school at any time (Holland 2001). This suggests that most school staff will have experience of working with a bereaved child in their classroom. Yet, Jackson and Colwell (2001) argue that discussion about death, dying and bereavement is not mainstreamed into

the classroom owing to staff feeling unskilled and anxious. I thus felt it was likely that teaching staff may, at some point, have considered the research area in terms of their role and possibly established fixed ideas on what they felt was good practice. Gray (2009) argues that interviews allow more opportunities for probing, drawing on the participants' personal and professional knowledge and experience, than other research methods. Using interviews would therefore potentially allow me to challenge any preconceived opinions that teaching staff may hold. Holstein and Gubrium (1995) term this as active interviewing term, which involves

‘the consciously active interviewer intentionally, concertedly provokes responses by indicating – even suggesting – narrative positions, resources, orientations, and precedent for the respondent to engage in’ (Holstein and Gubrium 1995, p.39).

The researcher thus activates and stimulates the interviewee and meaning is co-constructed within a given space, at a certain point in time, in relation to individual histories, experiences and viewpoints, and according to the specific relationship that exists between both parties. Although this identifies issues of power, whereby the interviewer is in a hierarchal position relating to how they guide and challenge the interviewee, it emphasises the importance of ethical and reflexive practice using the strategies detailed in section 4.2.3.1.

One interview was held in phase one of the research and 14 interviews were held in phase two. This included seven interviews with staff at RCPS, six with staff at NDPS, and one with a child. The interviews sought to investigate attitudes towards discussing death, dying and bereavement with children and explore possible initiatives between the Hospice and schools. They were semi-structured, which Mason (1996) argues allows the researcher to respond to individual responses and experiences. Robson (2002) asserts that this format of interviewing means that the researcher is able to change the wording of questions and give explanations according to the individual characteristics of each participant. I felt this was extremely important, owing to the range of expertise and experience of the different school staff. It also allowed me to ensure that the questions made sense to the participants and related to their experiences, circumstances and role. This assisted

with the flow and interaction of the interview, which Mason (1996) asserts simultaneously allows the researcher to focus on the issues and topics that are relevant. As discussed above, the researcher undoubtedly influences the process of semi-structured interviews. Mason (1996) argues that it is better to understand the complexities of such bias rather than pretend that it is controlled for. There is a variety of literature offering tips on how further bias can be managed, such as those offered by Robson (2002), which include avoiding long questions, double-barrelled questions, questions involving jargon, leading questions and biased questions. An interview schedule was therefore designed, developed and piloted so that such issues could be considered and eliminated (see Appendix 5). As with the focus groups, all interviews were recorded and transcribed, with permission from participants.

4.4.5 Data collection and analysis

Winter and Munn-Giddings (2001) argue that, in action research, data gathering and analysis is ‘a joint enterprise, undertaken by all participants, in order to give a ‘voice’ to differing perspectives’ (p.19). They go on to assert that data analysis should not be so time-consuming and elaborate that it takes away from the collaborative and action aspect of the research. Instead, data should be considered in ways that ‘reveal or stimulate new possibilities for action’ (p.235). Likewise, Hockley and Froggatt (2006) assert that data analysis in action research is iterative, the extent of which depending largely on the experience of the researcher, and can be both concurrent and retrospective. Given that action research was my chosen approach, there were many options to collect, analyse and present the data from this study. Indeed, a number of theses could have been written as a result of this study.

Data collection was facilitated and led by me in phase one and two of the study. Phase one involved information gathering as part of the literature review, visits to other hospices and Hospice focus groups. This preparation and scoping phase was primarily an iterative process that informed how I engaged with the research sites and participants in phase two of the research. The focus groups transcripts, however, were analysed alongside data from phase two. Data from phase two included the transcripts from the interviews and focus groups together with a detailed, personal

reflective log which I used throughout the research to reflect on the process. I analysed this data retrospectively, under four broad themes identified from the interview and focus group schedules (Appendix 4 and 5). These included: ambiguities; challenges; opportunities and practice ideas. My analysis was then fed back to stakeholders in each setting, in phase three of the research, along with a list of suggested ideas for practice development. This approach to analysis was used due to the time constraints in getting data collated from interviews and focus groups ready for phase three of the research. It was also used to provide an overview of the data, so that participants could use their own skills and experience to explore and analyse emerging issues. Moran-Ellis and colleagues (2006) argue that this approach to data collection and analysis allows the data from each phase of the research to be integrated throughout the research process, enabling information gleaned from the different stages to inform the continuing research process. I had intended that, once participants had identified what practice they would like to develop, data collection would then be joint process, led by participants.

Whitehead and McNiff (2006) argue that learning in action research is frequently presented through critical reflection rather than simply describing or putting data into categories. Literature describing how to present such findings frequently offers a list of questions to aid critical reflection (see for example, Winter and Munn-Giddings 2001; Kemmis and McTaggart 1982). This involves providing a detailed description of how the research idea evolved, the circumstances in which action was taken, problems encountered and how they were solved, the consequences of any actions, and the effects and changes on people that were involved. I initially attempted to structure my findings in this way, however, I found the process of doing so overwhelming and confusing. It was easy enough to give a descriptive narrative of what had happened and how decisions had been made, but much more difficult to clearly indicate how knowledge had been created both personally and in collaboration with participants. Consequently, I felt it necessary to search for alternative frameworks to shape this process that were cognisant of the participatory nature of action research and an extended epistemology.

Chiu (2006) argues that critical reflection in action research is underdeveloped and often presents

‘a nuts-and-bolts account of experiences – describing who does what to who without a clear indication as to how these experiences have been defined, recognised, organised and selected for presentation.’ (p.187)

She develops a framework for reflective practice that attempts to develop this area and take into account the relationship between reflection, knowledge and experience. It is a multi-perspective reflective framework, based on personal (‘I’), shared (‘we’) and community (‘they’) perspectives, and grounded in the four forms of knowing relevant to an extended epistemology. The model draws attention to the three levels of inquiry in action research discussed by Reason and Torbert (2001) which include first person (individual inquiry into own practices), second person (collaborative inquiry) and third person (involving and engaging wider networks of inquiry). I thus found the framework useful in unpicking the complexity of knowledge creation in relation to different accounts of both the research experience and knowledge production. Nevertheless, I felt it failed to highlight the importance of description in ensuring that accounts are authentic and comprehensive. Likewise, although the model was useful in discussing complete action research processes, it did not appear to focus on transparency concerning choices and judgements made within each phase of the research. I therefore considered this model alongside more generic models of critical reflection familiar to me through my social work practice in the Hospice. These included those proposed by Borton (1970), Gibbs (1998), Johns (1998) and Kim (1999), which offer various structures and processes to assist practitioners in generating knowledge from experience. I found Kim’s (1999) model of critical reflective inquiry particularly helpful. It is situated within critical inquiry and action science and employs three distinct phases to aid practitioners in generating and developing practice knowledge. These include a descriptive, reflective and an emancipatory/critical phase, the latter of which focuses on changing personal practice. The phases are reminiscent of the action research cycle and the model clearly highlights the importance of making choices and judgements explicit. Nevertheless, I believe that it potentially over-simplifies critical reflection in

participatory action research by focusing on self-reflection, i.e. how personal and social experiences impact the thoughts, feelings and practice of individual practitioners. Combined with Chiu’s framework, however, I would argue that the dialectic relationship between self-reflection and collaborative inquiry is brought to the fore. I have presented this model in Figure 2.

	Descriptive Phase	Reflective Phase	
		Self-reflective inquiry ('I')	Collaborative Inquiry ('we' and 'they')
Process	Comprehensive description of events	Reflective analysis of both the situation and my approach against espoused theories (ethical, scientific and aesthetic)	Reflective analysis on how a community of inquiry is facilitated and how this community engaged in emancipatory and change processes Reflective analysis on the extent to which the research methodology shapes experiential, representational, propositional and practice knowledge
	Descriptive narratives	Knowledge about personal practice and process Critique of practice and processes within research setting Learning and change in practice	Knowledge about research methodology Critique of practice and processes within research setting Learning and change in practice

Figure 2: Framework for critical reflection (adapted from Kim, 1999, and Chui, 2006)

The descriptive phase of this framework assists in giving focus to the task of re-describing inquiry, which Reason (2003) argues is essential in ensuring that what is presented is authentic and thorough. The reflective phase has been expanded from Kim’s (1999) original model to focus on both self-reflective and collaborative inquiry. Self-reflection refers to my reflection on the research experience and underpins all research practice to ensure transparency. Nevertheless, I have argued earlier that a key assessment criterion in action research is the extent to which the

research process empowers, facilitates and enables both change and knowledge generation in the research setting. This has significant implications for collaborative working, and distinguishing collaborative inquiry as a distinctive aspect of the reflective phase gives attention to how a community of inquiry was promoted, focusing on how knowledge is co-created according to an extended epistemology.

The collaborative inquiry category could have been divided into second person (we) and third person (they) participatory reflection. I would argue, however, that in relation to this thesis, using a broader definition enables a wider discussion by focusing on creating a community of inquiry with other individuals in the context of their own organisations. Both the self-reflective and community inquiry categories are inclusive of Kim's (1999) third phase of critical inquiry (critical/emancipatory phase), as this is an essential feature of action research which should be kept central to any process. The following two chapters present the findings at each school using the above framework to retrospectively provide an in-depth account and analysis of the action research process. This will be discussed in relation to phase one of the action research process (negotiating access/recruitment), phase two (exploration phase), and the initial part of phase three. To some extent, separating these phases is artificial due to the iterative nature of the cycles. Nevertheless, creating boundaries allows focus to be placed on the choices and decisions made at each stage, highlighting the progression of learning and development in myself, individual participants and the organisations across which I was working. Chapter seven brings the findings from the different research sites together into one explanatory framework by discussing the practice developments taken forward and reviewing the action research approach taken.

4.5 Ethical considerations

Ethical considerations were central to this study in part because of the sensitive nature of the research area and also because children were involved. Research with children has received much discussion across the literature, particularly with regard to ethical practice. This attention has been argued as potentially obstructing research with children (Balen et al. 2006; Skelton 2008). It contrasts recent moves in policy

and legislation, such as the United Nations Convention on the Rights of the Child, that recognise the competence of children and their right to participate on issues which affect them (Skelton 2008).

There are a variety of materials available that offer good practice guidelines for ethical research with children (see for example Alderson and Morrow 2004; Cree et al. 2002; Tisdall et al. 2009). Ethical research practice urges that

‘researchers are more reflective about their practices, research participants are better prepared for their involvement, and relationships between researcher and participants in their studies are mutually empowering rather than confused, risky, harmful, exploitive or coercive.’ (Crow et al. 2006, p.94)

It was important that ethical issues were not an afterthought, but integrated into all aspects of design. This included managing sensitive research, consent, confidentiality and anonymity, reporting abuse or neglect, and negotiating research incentives. All of these issues had to be negotiated and agreed with the head teachers at both schools prior to formal ethical procedures being undertaken. The discussion below outlines the issues considered and how these were addressed.

4.5.1 Managing sensitive research

Given that the research was focused on issues connected to death, dying and bereavement I was aware that some participants could potentially experience some discomfort or distress by participating in the study. This could have been influenced perhaps by a prior experience of bereavement and/or a complete lack of familiarity with such concepts. As it is difficult to predict these responses, a number of steps were taken to both make people aware of such responses and glean information about anyone who may find the research area challenging. This included making sure all participants were fully informed as to the nature of the research and were able to self-select, at any stage of the process, with regard to participating or not. Each participant was given an information sheet (see Appendix 2), which had previously been piloted to ensure that it was clear, concise and age-appropriate. The sheet was read out to potential participants and then given to them to take away and read before committing to signing up. Participants were then required to contact me either via

email or telephone or by returning a tear-off slip on the bottom of the information sheet. Anyone who was interested in taking part but had questions and/or reservations was invited to select 'maybe' on this slip, so that I could meet with them to discuss any concerns or questions they had. For adults, this was done on a one-to-one basis. Children were given the option of meeting in a group or individually. These steps appeared to be effective. A number of adults and children requested to meet with me individually so that they could discuss the research more fully. Some children were happy to meet in a group, after which the majority of them decided to participate and others not. Feedback from potential participants identified that they felt able to make a decision about participation based on their preparation for the research. This included recognising how a recent bereavement might affect them, and both opting out because "it was too soon" (adult participant) and opting in because "I've got lots to talk about" (child participant). Teaching staff and parents/carers were made aware of children who were interested in participating as part of the consent process and were invited to contact me if they had any concerns.

Participants were made aware before and after the interview and/or focus group that if they felt uncomfortable, distressed and/or upset as a result of their participation existing supports within the school would be used as well as the Hospice bereavement service. During the interviews and focus groups several participants did become upset, yet did not feel support was necessary. Each of these situations was managed differently owing to who was involved and the context within which they became upset. For example, in an adult focus group where everyone knew each other, the group were able to self-manage this situation, offering support to the person who was upset through normalising feelings and empathising. Conversely, in a focus group with children I provided more input, stopping the group and offering to speak with the child privately. In one situation a girl's grandmother was currently dying. I was aware of this situation, having previously discussed her participation with both her mother and the girl, who both felt she should participate as she would have a lot to offer. When she became upset in the group, the girl and I spoke privately about her continuing to participate. She explained that she really did not want to leave the group as she was enjoying it, but asked if I could let everyone

know about her situation and make sure that they were comfortable with her being upset. We agreed a hand gesture to indicate if she wanted to stop and leave. We also agreed that I would inform the head teacher in case she wanted someone to speak with during the remainder of the school day. The rest of the group appeared accepting and supportive of this situation, which promoted a discussion around feelings connected to loss and what others had experienced. They all also asked if they could come back to the group next week as they had found it an enjoyable experience.

Given my experience of working with people experiencing bereavement, I have frequently had to manage situations where people have become upset. I expected that these responses would happen at some point during the research and felt confident in creating a supportive space where people felt able to speak freely and safely. Several authors argue that action research offers a means not only of generating knowledge, but also an opportunity for personal growth (Noffke and Somekh 2009; Whitehead and McNiff 2006). Noffke (2009) claims that for professionals action research is a way ‘to understand themselves and their work better’ (in Noffke and Somekh 2009, p.10), exploring closer connections between personal beliefs and practice. For children, learning research skills can provide ‘not only a means to deal with current issues, but also develops a sense of agency in dealing with life issues over the long haul’ (ibid 2009, p.17). Despite the sensitive nature of this research, it was possible that an action research methodology would enable both adults and children to engage with the research area and experience an element of personal growth. This could involve assisting participants to become more confident in, and comfortable with, managing and discussing issues related to death and dying, which Kellehear and O’Connor (2008) argue strengthens ‘a community’s inherent capacity to support [each other]’ (p.115).

4.5.2 Consent

Cournoyer and Klien (2000) assert that gaining informed consent ensures that participants are fully aware of what is involved in the research prior to taking part, that participation is voluntary, and that they can withdraw at any time without

penalty. This includes ensuring that participants are aware of any risks and benefits associated with taking part. Written consent was required from all participants involved in this research to confirm that they had understood all of the information explained, verbally and on the information sheet (see Appendix 3). For children, I had initially proposed that I would also contact parents/carers to gain written consent. This was based on both head teachers' preference and discussion with my supervisors, who felt that this would be needed to gain formal ethical approval from the University. Lazar and Tonrey-Purta (1991) highlight the difficulties in obtaining clearance to talk to children about death from both ethical boards and schools. Yet, a number of authors identify contradictions between ethical procedures for gaining consent from parents/carers and the moving trend within literature, service development and legislation concerning the rights of children to be 'active beings' across all aspects of their life (Balen et al. 2006; Skelton 2008). I was initially unsure about gaining consent from parent/carers for children to participate due to adults often excluding children from such conversations, as discussed in the literature review. I felt that by taking this approach some children may not be given an opportunity to talk about something that they themselves might choose to. I raised these concerns with the head teachers who initially decided that, despite being able to give consent in loco of parents for school-related activities, owing to the sensitive nature of the research and the potential personal experiences that families may have of the Hospice, it was preferable to get consent from parents. I felt it was important to keep within the schools' procedures and, if any practice development were to happen, it was also integral to inform and include parents/carers. I thus designed my initial procedure for gaining consent on this basis. This approach, however, was later adapted at both schools owing to each head teacher developing their thoughts on this issue. This is discussed in more detail in chapters five and six.

Cree and colleagues (2002) argue that consent should be kept a 'live issue' where research takes place over a prolonged time period. This requires that participants are reminded that they can opt out of the research at any time. Gaining consent from children raises difficulties owing to power imbalances that can exist between adults and children. This is specifically so in a school setting, where children are a captive

audience and adults are viewed in a position of authority. Children therefore might feel that they have to participate owing to perceived negative consequences of doing otherwise. Likewise, issues of informed consent are also important in relation to active interviewing whereby, owing to their dynamic and interactional nature, the direction and outcome of the interview cannot always be predicted. I thus attempted to make it very clear at all stages of the research that children and adults could stop or opt out at any time during the research. This was reiterated in all written documentation, including the information leaflets and consent forms. In relation to the children specifically, this also included making it very clear that, although I was interested in what they had to say, neither I nor the school would be upset or disappointed in anyway if they decided not to take part. Moreover, I highlighted that they were not obliged to take part and if they chose not to then this would not affect any other aspect of their school life. Although it is difficult to determine to what extent children took this on board, it appeared to be effective, as two children did choose to opt out during phase three of the research. One child said they were opting out because they felt that they had contributed all they could. The other child said that they did not want to miss what was happening in class.

4.5.3 Confidentiality and anonymity

In any research confidentiality is paramount. The research did not require the collection of any personal information. In the interviews, anonymity was ensured through the process of transcription and data reporting. It was difficult, however, to ensure both anonymity and confidentiality within the focus groups as, once the group had finished, I had little control over what the participants shared. Participants were therefore reminded at the beginning of each focus group that any personal matters shared within the group should remain in the group and not be discussed with peers. This included developing a code of conduct for the groups with children to emphasise the importance of confidentiality. Only the researcher and the research supervisors had access to the recordings and transcripts from the focus groups and interviews. These are stored in a locked office and will be destroyed five years after the VIVA. The participants were given a report that details the thematic analysis

from phase two and the evaluation of phase three of the research, discussed in chapters five and six of this thesis.

In the subsequent findings chapters, names have been omitted to ensure anonymity. Given that I have used the name of the Hospice in this thesis, it is likely that anonymity cannot be assured for Hospice staff within the management team. This has been discussed with relevant participants, who asked that I use their job title.

4.5.4 Protecting participants from abuse and neglect

When conducting any qualitative research it is possible that disclosures around abuse or neglect may become evident. These issues become even more pressing where children are involved in research. Although this was not a purpose of the research, the process of action research is to establish a trusting and supportive relationship. It was therefore possible that disclosures may be made in this environment. This issue was discussed verbally at the beginning of the research with the children and adults and reiterated in the consent forms and information leaflets. Such conversations are extremely common in the social work field and as such I am practised in this. In the event that a disclosure was made, child protection procedures would have been followed in line with school policy. This would have involved informing the head teacher at the school or the Senior Social Worker at the Hospice, who are the designated child and adult protection officers. No disclosures were made.

4.5.5 Research incentives

There has been some debate in the literature about providing incentives to research participants, particularly with reference to children (for example, Cree et al. 2002; Fraser et al. 2003). In the nature of action research, the research team should share the goals of the project and actively 'buy in' to the process, which is intended to be completed during school/work time. Monetary incentives were not provided; however, I sought to make the research process interesting and fun, using a variety of methods to engage children and adults as well as bringing snacks and refreshments.

4.5.6 Formal ethical procedures

As this research was conducted under the auspices of the university and across both Hospice and education settings, I had to complete ethical procedures across three sites. This included the university, the Hospice and the local authority (LA) in which the primary schools were based. Haggerty (2004) asserts that ethical procedures are currently growing and intensifying. Despite their focus on good practice, there exist contrasting debates around such governance. Crow and colleagues (2006) argue that the positive view of research ethics is that it results in better quality data through reflective practice, whereby there is ‘no conflict between researching ethically and researching effectively’ (p.85). Conversely, Haggerty (2004) asserts that research ethics can lead to poorer quality data through overregulation, encouraging unproblematic and predictable research methodologies. Ethical procedures are thus, in some instances, perceived as a bureaucratic process; simply a barrier to cross rather than a useful tool for developing good practice. I felt that the ethical procedures I undertook ensured that I thought very clearly about what I was planning on doing in the research and how I ensured that participants were kept safe. I would argue, however, that they were somewhat unsuited to action research as the whole research process was not exactly known and I could not fully predict how it would go.

It was a requirement from both the LA and Hospice that I received ethical approval from the University prior to completing their procedures. Given the participatory nature of action research, I felt that it was important to discuss ethical concerns with the participating schools prior to applying for ethical approval. As there was some delay in recruiting a second school, I met with the head teacher at the first recruited school (RCPS), where we discussed and agreed ethical procedures. The relevant ethical form was then completed and submitted to the University of Edinburgh School of Social and Political Science Research Ethics Committee (see Appendix 6). Owing to staff sickness at the University, it took three months until ethical approval was granted. I then sent a copy of the approval form, along with a cover letter explaining the research, to the Policy Department at the LA (see Appendix 7). At the Hospice, it was a requirement that, once ethical approval had been granted from the

University, I gave a presentation to the multi-disciplinary team to enable an opportunity for them to review the research design (see Appendix 8). Although I would argue that these procedures enabled me to fully consider the ethical issues within this research design, the whole process took three and a half months, thus delaying my entry into the schools and impacting on the time I had available to complete the research.

4.6 Summary

In this chapter, I stated that the purpose of this research is to develop practice between a Hospice and two primary schools that engages children in conversation, education and support around death, dying and bereavement. I asserted that an action research methodology is most suited to this aim, because it focuses on participation and practice development. I described how the action researcher is embedded in the research process. This research design has therefore been affected by my professional and personal value base in relation to including children in education and support around death, dying and bereavement, research with children, and my commitment to practice. Owing to the emancipatory and practice focus of this research, I argued for the use of an extended epistemology, using critical inquiry as a theoretical framework. I explained the action research framework intended to be initiated at each research site based on the spiral of steps originally developed by Kurt Lewin (1952). This includes five phases: preparation and scoping; exploration; planning and developing model(s) for practice; piloting developed practice; and evaluating practice. I made a case for using focus groups and interviews in phases one and two of the research to enable a full exploration of the research area within the structures and demands of the school setting. I argued that the remaining phases of the research would be decided and led by participants. I finished by discussing the ethical concerns relevant to this research and how these will be addressed.

Chapter 5: Investigating and developing practice with the Roman Catholic primary school (RCPS)

This chapter discusses the action research experience at this school (RCPS). Using the framework for critical reflection discussed in chapter four (section 4.4.5), I describe how the research was negotiated and facilitated. This begins with the descriptive phase, which provides an account of the work undertaken. I then go on to the reflective phase, which reflects on both the situation and approach, discussing how collaborative inquiry was facilitated to generate knowledge relevant to the research area and engage in a process of change. I have sought to ensure that research decisions were made transparent at each stage of the process, drawing attention to collaborative working and emancipatory practice. Work with RCPS is continuing to be developed. This chapter discusses phases one, two and three of the research, all of which took place during one school year. Figure 3 shows a timeline of the key events that took place during this time. Appendix 16 shows the developments that have continued to take place after this time.

5.1 Phase one: negotiating access and recruiting participants

5.1.1 Descriptive phase

I initially contacted the school's head teacher (HT1) via telephone. Although he returned my calls we kept missing each other, and I subsequently sent an email outlining the purpose of the research and attaching a copy of the information leaflet. HT1 replied to this email the next day, stating that "the school would be pleased to be part of this proposed research" (email correspondence, 11th October 2012), and a meeting was subsequently arranged. At the meeting the research was discussed in more depth. This involved focusing on the background to the research and my links with the Hospice, recruitment strategies, ethical issues, possible research progression and practical issues such as timescales and space. The following areas were consequently negotiated and agreed:

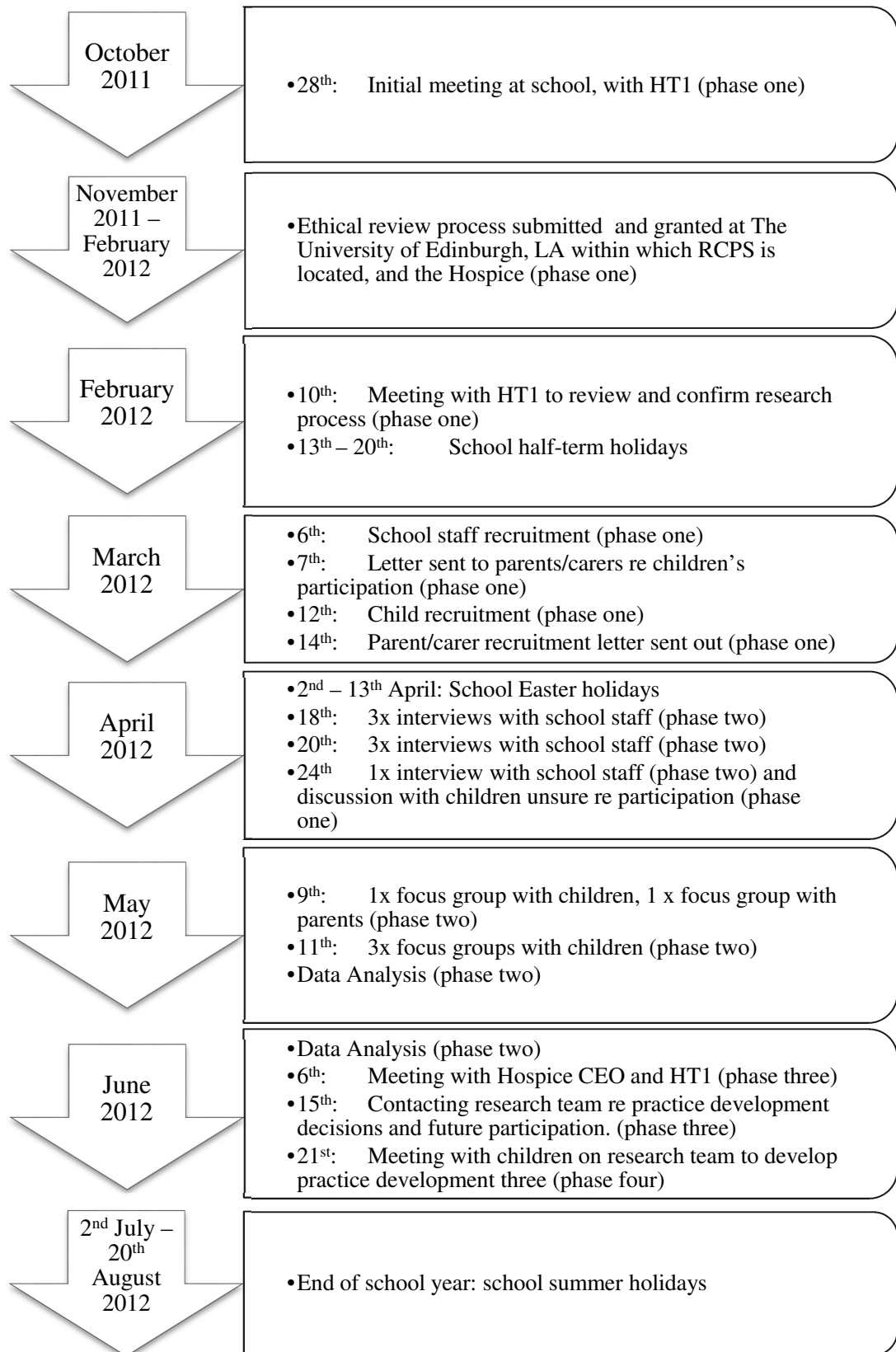


Figure 3: Timeline of events at RCPS

Staff recruitment: HT1 agreed to any staff member being involved in phase two of the research if they wished. I would attend a staff meeting to inform staff of the research and invite them to participate. HT1 would support staff participation by providing a relief staff member to cover staff duties whilst the interviews were taking place. With regard to the later phases of the research, staff participating in phase two would be asked during their interviews if they wished to continue being involved. If they agreed, their participation would then be negotiated between HT1, the staff member and me depending on how the research progresses.

Parent/carer recruitment: A letter would be sent home, from both HT1 and me, to parents/carers of all P6 and P7 pupils. Based on usual school procedures for recruiting parents/carers, this would include information about the research, my contact details should they wish more information and/or have any questions, and a tear-off slip that could be sent back to the school if they wished to participate.

Child recruitment: HT1 advised that the school would not normally ask permission from parents/carers, but would keep them informed via letters home. Due to the sensitive nature of the research area HT1 felt he may need to reconsider this process, particularly if any future practice developments were to take place and be successful. He therefore agreed to discuss this issue with the staff team to ascertain their thoughts before making any decisions about how best to proceed.

Ethical issues: This included reviewing and agreeing issues of confidentiality, research incentives, child protection procedures and managing sensitive research. These were decided as discussed in section 4.5 of this thesis. If, through the process of the research, it became known that a child required bereavement support, HT1 was keen that, in the first instance, they attend a school group which deals with loss and change before referring them on to the Hospice for support.

Timescales and space: At each phase of the research I would meet with HT1 to discuss the next stage. How the school continued to be involved in the research would be reevaluated during this time. The school would provide a room for the interviews and focus groups to be held. This included providing the deputy head's

office for the interviews and the staff room or music room for focus groups. All of these rooms provided private space and were also close enough to HT1's office and the main reception in the event that additional support was needed.

A week after this meeting, I contacted HT1 to see if a decision had been made regarding recruiting children. He confirmed that he had spoken with the staff team and felt that consent needed to be obtained from parents/carers before inviting children to participate. He attached a draft letter to be sent home, asking for parental consent, and suggested I also hold an information meeting for anyone who may have questions or concerns about their child participating. This letter was drafted via email and, once finalised (see Appendix 9), my application for ethical approval was submitted to the university, LA and Hospice.

The ethical approval process took three and a half months. Once approval was granted, I contacted HT1 to inform him of this decision and arranged a meeting to both review the research plan and establish a timetable for phase one of the research. At the meeting, HT1 said he had reconsidered the issue of gaining parental consent for children and now believed that parents/carers should opt their child out of the research. I thus resubmitted an amendment to the relevant ethics committees. Once this was approved, the agreed recruitment process was initiated and the following steps were undertaken:

1. I attended a staff meeting to discuss the research and invite people to participate. Twenty staff members were present. HT1 introduced me to the staff and I spent ten minutes explaining the project in more detail, using the information sheet (see Appendix 2.1) as a guide. Each staff member was given a copy of the information sheet with a slip attached, inviting them to note whether or not they would like to participate. I asked that the slip was put into an attached envelope and left at the school reception for me to collect at the end of the week. As a result of this information-sharing event, seven staff members, one of whom was male, agreed to be part of phase two of the research.

2. HT1 sent a letter to the parents/carers of all P6 and P7 pupils, informing them of the research and why the school was taking part. The letter invited parents/carers to opt their child out of the process, if they wished, by filling in and returning a tear-off slip at the bottom of the letter (Appendix 10). Parents/carers were also given a copy of the children's information leaflet (Appendix 2.2) and were invited to contact me if they had any questions or concerns. Thirteen children, out of a total cohort of 130, were withdrawn from the research.
3. I spoke to all P6 and P7 children who had not been withdrawn from the research. This was done in class groups with the class teacher present. I introduced myself, explained what I would be doing and what would be involved if they decided to participate. I emphasised that participation should be through personal choice and, if they chose not to participate, this would not have any influence on the rest of their school experience. The children were invited to ask questions and were each given a copy of the information leaflet. I then invited all the children to complete and return a slip by ticking one of the following three statements:
 - a. Yes, I do want to be part of the project
 - b. No, I do not want to be part of the project
 - c. Not sure, please can I talk more about it with Sally

This could be completed at some point during the day and left in a bag, placed at the back of the classroom. Ninety-nine children returned slips, 69 agreed to take part, 19 declined, ten were unsure and one ticked a, b and c. I subsequently met with this child and all children unsure about participating. This was done in three small groups, where I reviewed the research and provided an opportunity for the children to ask questions either as part of the group or one-to-one. Questions included: "Will we be seeing a lot of you?" "Do you know this person [at the Hospice] called?" and "I think my parents talk to me okay about death so is there any point in me coming?" Out of the

11 children who were unsure, three children decided not to take part. This resulted in 77 children wishing to participate in the research. I initially planned to hold two focus groups of between four to six children. Due to the large numbers of children interested in participating, I decided to increase this to four focus groups. This involved randomly selecting children by separating the reply slips into class groups and choosing every fourth child. HT1 supported this method, as he felt that focus groups involving children from the same class would be less disruptive to the school timetable and easier to schedule. This method resulted in 21 children, ten boys and 11 girls, being chosen to take part in the research, split over four classes. Three of the children were Polish, but spoke fluent English, and the remaining children were British. The list of children selected was shown to the class teachers to see if there were any concerns about participation. No concerns were raised.

4. HT1 sent home a letter to all parents/carers with children in P6 and P7 classes, highlighting the children's interest in taking part and inviting them to also participate (Appendix 11). One-hundred and twelve letters were sent home to parents/carers and 10 parent/carer responses were received, all of which were women. I was unable to contact two of the people who responded. One of the parents/carers who did respond said that they had misunderstood the letter and had responded to let me know that they were happy for their child to participate. This parent did not want to take part, as they had experienced a recent bereavement and felt it was too soon to engage in related discussion. One parent said that they were happy to participate, but owing to work commitments would prefer to be on a reserve list. This resulted in six mothers available and willing to participate. One of these mothers also had a child participating in the research.

The recruitment process thus resulted in the RCPS research team consisting of: seven school staff (one support staff member, four teaching staff and two members of the management team); 21 children; and six mothers.

5.1.2 Reflective phase

The above description shows that my initial engagement with RCPS was primarily through contact with HT1, who was a gatekeeper in terms of future access to working with the school. Collaborative inquiry thus involved us working together to negotiate a shared research purpose that would set the premise for future work. Gaining access and issues of recruitment and consent were particularly significant in how collaborative inquiry was developed within RCPS. I will review these two areas separately, going on to critique how these experiences set the premise for the future phases of the research.

5.1.2.1 Gaining access

When first attempting to gain access to RCPS, I would have preferred to introduce the research to HT1 in person rather than via email. I felt this would have enabled a more personal approach, whereby HT1 could become familiar with me and the research, as well as provide an opportunity for questions. Nevertheless, the email received a positive response and it is possible that this means of contact enabled HT1 time to reflect on how the research might be relevant to and important for the school, which a phone call may not have allowed. Providing time and space for reflecting on the significance of the research to the school community was undoubtedly important to HT1 in deciding whether or not the school should participate. This is highlighted in HT1's email response:

“I've read your email and attached information and would agree that approaches to children about death can be variable both in frequency and quality of discourse.” (HT1, email correspondence, 12th October 2013)

Likewise, after our initial meeting, I highlight in my reflective log:

“We discussed background to the research, including my role within the hospice. HT1 felt that this was an important issue. The school has Seasons for Growth groups [a loss and change education programme] for children who are struggling in class but he is aware that this is a reactive response and is not sure how, as a whole, the school deals with such issues. He discussed how a child at the end of a Seasons for Growth group returns to class where they spend the best part of the day, but does not know what

the teacher says or how they support the child.” (reflective log, 28th October 2011)

It is unknown to what extent HT1 had considered the research area prior to my involvement, yet the initial research information and our subsequent conversation seemed to identify, or potentially initiate, his curiosity in this area of practice. Such curiosity is argued by Reason (1994) as an essential starting point for initiating action research. This process of gaining access to RCPS thus served to stimulate interest in and critical reflection on current practice, identifying the progression of learning taking place through the contact between HT1 and me. This relates to both experiential and presentational knowledge, that is, how knowledge, through direct encounters with others, is generated, ordered and expressed (Heron and Reason 1997).

Whilst negotiating access to RCPS, HT1 discussed a number of factors which appeared to provide an incentive to participate. My connection with, and practice in, the Hospice appeared to provide legitimacy to the research. HT1 noted his awareness of the positive reputation of the Hospice in the community and enquired about my role and experience. This seemed to give him confidence in the knowledge and expertise that could be shared by establishing a relationship and working together to develop practice. During our initial contact, HT1 referred to some of the debates in the literature around the significance of talking to children about death, dying and bereavement as an “important aspect of their emotional and social development” (HT1, email correspondence, 11th October 2012). After our initial meeting I comment in my reflective log:

“HT1 thinks this is a very useful and important area to research and he is keen to see what the findings highlight.” (reflective log, 28th October 2012)

HT1’s view that the research area was as an integral part of children’s development thus appeared to serve as a motivation for him to agree to the school taking part, strengthened by the practical focus of action research. Likewise, faith also appeared to be an incentive to participate. In our second meeting, after ethics approval had been achieved, I noted in my reflective log that HT1 thought the research findings

“may be important for the faith community in general about talking to children, and that being a faith school will impact how they talk about these matters.” (reflective log entry, 10th February 2012)

Faith was also discussed as being an important vehicle for the gathering support from the wider school community for the research taking place. In relation to gaining consent from parents/carers for their child to participate, HT1 comments

“being a faith school will help with this – give a ‘way in.’”
(reflective log entry, 28th October 2011)

Neither of these issues was expanded on and HT1 did not enquire about my own faith, or the position of the Hospice, yet his comments identify the significance of the research area within the context of a Roman Catholic school. They resonate with literature, which emphasises how faith might provide a helpful framework from which to approach and discuss death, dying and bereavement with children (Puolimatka and Solasaari 2006). His comments also highlight how the process of gaining access to RCPS was influenced by the existing experiential, propositional and practical knowledge on the importance of faith in relation to how death and bereavement are managed with children, and a desire and/or curiosity in exploring and expanding this knowledge further.

5.1.2.2 Recruitment and consent

Collaborative inquiry was particularly relevant in negotiating and deciding recruitment and consent strategies. This process enabled practice knowledge related to researching in RCPS to be developed and piloted. This was particularly the case for research with children. Recruitment and consent is often discussed as a significant issue in research involving children (Cree et al. 2002; Tisdall et al. 2009; Skelton 2008). Prior to engaging the school, I would have preferred that the school gave consent in loco of parents to ensure every child an equal opportunity to hear about the research. Given the complexity of this issue, however, I had decided to take my lead from the school, yet simultaneously be clear about my own apprehensions concerning parents/carers as possible barriers to children’s participation. This was due to my theoretical knowledge on research with children,

but also my professional training and personal beliefs which, I felt, placed a duty on me to promote the rights of the children to participate in issues which concern them (United Nations 1990). Moreover, by raising these concerns I was keeping within the emancipatory purpose of social research. At the first meeting, no decision was made about the best way to proceed with this issue. I was comfortable with this temporary uncertainty as I believed it signified that HT1 had listened to my concerns and needed time to consider the issue with other staff. I also felt that it was indicative of a collaborative approach to working that I hoped would be reflected in the progression of the research. One week after our initial meeting, HT1 said that he had decided that we should ask all parent/carers to give permission for their child to hear about the research. I was concerned about this approach, as noted in my reflective log:

“I can see how this approach keeps parents fully involved in the process, but it also makes them gatekeepers – do children actually have an option to participate or will their parents decide for them?” (reflective log entry, 3rd November 2011)

Nonetheless, having already discussed my concerns around this issue with HT1, I felt that it was important to respect his decision and follow the decided process. I sought ethical approval based on this; however, during the ethical review process (a total period of three and a half months) HT1 continued to develop his thoughts on parental consent and eventually decided to go with an ‘opt out’ approach. This clearly highlighted the process of collaborative inquiry taking place in terms of developing practical knowledge around research with children. Through the process of discussion, firstly with me and then HT1 with some staff, changing to an ‘opt-out’ approach served to readdress power imbalances between adult and child that the original approach had reinforced. The original approach of gaining written consent from all parents/carers required adults to make choices about what a child could or could not do and excluded the child from any decision-making process. Although the ‘opt-out’ approach still meant that children were not given full decision-making power, it invited parents/carers to make an active choice around how much autonomy they wanted to give their child, rather than the school deciding this. This decision was potentially more inclusive to the rights of the child. It may have resulted in the

majority of children being given complete independence to decide about their participation, as only 10% of children were withdrawn. This highlights how practical knowledge was generated through HT1 and me sharing experiential knowledge (experiences of what is usually done and/or has been done) and propositional knowledge (theoretical knowledge on children's rights) on research with children.

Interestingly, I would argue that the recruitment strategy for adults did not receive the same attention as was given to children's recruitment and would have benefitted from further consideration, both organisationally and conceptually. For example, I discuss above how, when recruiting children, I attempted to discuss and address power imbalances to ensure that the research was inclusive and accessible, yet I did not fully explore these issues concerning adult recruitment. When HT1 suggested that I attend a staff meeting, I did not clarify who would be at the meeting, presuming it would be all school staff. At the meeting, it became apparent that only teaching staff were present. I received a good response rate from this group and assumed that speaking to teaching staff would be most helpful, given that they have the most daily contact with children. After my interviews with school staff, I considered that, although teachers see their class every day, this contact is often in large groups and very structured. Consequently, children may choose other staff, such as Support for Learning Assistants (SLAs), reception staff and kitchen staff, to speak with about death and bereavement, as this contact is less formal. It may have been helpful, therefore, to ensure that these staff members were also given an opportunity to participate. One teacher did suggest I speak to a SLA responsible for running the school's loss and change education programme. I did this and she agreed to take part, also agreeing to "spread the word" amongst other SLAs. I had no evidence if this was done and did not reconsider my recruitment strategy. Not specifically engaging HT1 in specific discussion around which school staff should be involved and why, meant that collaborative inquiry was, to some extent, limited to initial assumptions. Such assumptions were based on my own, and possibly HT1's, propositional knowledge that teachers were key staff in talking about death, dying

and bereavement with children, an area which would have benefitted from collaborative critique.

Similar to the above discussion, I was also disappointed by the lack of parents/carers I was able to recruit. This may have been due to a number of factors including availability, interest, or that many parents/carers did not know about the research as the letter did not make its way home with the child. In an attempt to anticipate some of these issues, the letter sent home emphasised: the importance of the research to the school and pupils; that the time of the focus groups would be flexible according to parent/carer availability; and suggesting parents/carers contact me with any comments, concerns or questions. Only parents who wanted to participate contacted me, most of whom had questions around practicalities, such as childcare availability. It is possible that the letter did not provide an incentive to participate and, on reflection, I wondered if it should have focused more on what parents/carers could gain from participation rather than the school and pupils. This situation highlights the significance of the researcher in collaborative inquiry. I discuss this in more depth in chapter seven, yet, in both of the above situations I would argue that my professional and academic focus on work with children meant that I neglected to fully consider adult recruitment.

5.1.3 Reviewing the experience

Phase one of the research primarily involved HT1 and me exploring and addressing procedural and pragmatic concerns. I would argue that this was an important phase of the research as it served to establish how the research would progress as well as begin creating a space for collaborative inquiry. Collaborative inquiry appeared to be enhanced and developed by a number of factors. These included: my approach to introducing the research within the school, my connection with the Hospice, HT1's interest in the research area, the relevance of the research to a faith community, and the practical focus of action research. Being explicit about the purpose of the research in my initial contact provided HT1 with an opportunity to reflect on how these issues were relevant to the school as well as consider opportunities for advancement. This was particularly around how death is managed in the school, in relation to a perceived responsibility to support and enhance the developmental needs

of children, as well the school's Roman Catholic foundation. This confirmed my thoughts about ensuring that a faith and a non-denominational school were included in this study to explore whether faith impacted on how these issues were discussed and how faith inhibited or supported practice development. Similarly, being clear about the participatory focus of action research and that any developments had to be led by the needs of both the school and Hospice potentially established a more equal platform from which to begin discussions on how to move forward. For example, the initial two meetings between HT1 and me each lasted over an hour, during which HT1 and I listened to and challenged each other's ideas about how the research should be conducted, such as HT1 initially choosing to gain parental permission for children to participate despite my concerns. I thus felt that my initial engagement with HT1, and the school, quickly became a space in which ideas and opinions in relation to the research could be shared and navigated, rather than directed by a research agenda created in response to my own research needs.

Overall, I was happy with how this phase of the research progressed. From our communication I felt that HT1 held a similar value base to mine regarding speaking to and educating children, around death, dying and bereavement, which I hoped identified a commitment to taking the research forward. The recruitment process meant that a bigger research team was established than I had anticipated, particularly with child participants. The fact that 90% of children were allowed to participate in the research and 77.8% of children chose to participate was significant. This response rate suggests that there is perhaps more openness around this area than I had considered on the basis of my practice experience. In the Hospice, the children I work with are referred due to perceived bereavement difficulties, which ultimately may impact on how others engage with them around bereavement issues and how I consequently perceived a taboo. I thus wondered if my work with bereaved children provided me with limited and biased experiences. Likewise, when I spoke to the 11 children who were unsure about participation, their questions were based on developing a clearer understanding of the research and what would be involved if they participated. Once they were given more information only three children declined to participate. Two said this was because they weren't very good at coming

up with ideas and so were not interested in participating. The other did not give a reason. These responses indicate that the children not only felt able to say “no” to the research, but also that the majority of children were not deterred by the subject matter. Nonetheless, I felt that the response rate was a positive sign and suggested interest in the research that would hopefully support the further phases.

5.2 Phase two: exploration phase

5.2.1 Descriptive phase

Phase two involved interviews and focus groups with school staff, children and parents. Seven interviews were held with staff, six of whom were women, over a period of two days. Five were teaching staff, two were management staff and one SLA. Four focus groups were held with children aged between nine and 11 years, involving 21 children in total. One focus group was held with four mothers of children in P6 and P7 classes. All interviews and focus groups lasted approximately 45 minutes, in line with the school timetable. During this time participants were also invited to take part in later phases of the research. They were informed that it was not yet clear what future phases would involve, but that they could choose to withdraw from participating at any time. All participants indicated they would like ongoing involvement in the research.

Data from the interviews and focus groups was combined with data from the focus groups with Hospice staff. I have described in section 4.4.5, how this data was thematically analysed in preparation for phase three. Data included recordings from the interviews and focus groups, my reflective log, worksheets completed by the children as part of the focus groups, and a letter from one interviewee. This letter was from a teacher who wanted to capture and include her post-interview thoughts.

5.2.2 Reflective phase

The above description identifies that there were several aspects to developing collaborative inquiry and generating knowledge that require attention. These include: interviews with staff, focus groups with children, focus groups with parents and data analysis. This section therefore reflects on the methods used with the different participant groups, exploring how practical issues impacted on these

experiences, and how knowledge was co-created in each context. The analysis of data generated in this phase of the research was significant in both informing future phases of the research and promoting collaborative inquiry. I described the approach to data analysis in section 4.4.5. As the same approach was used in both schools, I reflect on this method in section 7.3.1. It is worth highlighting here, however, that in this phase of the research data analysis was primarily led by me.

5.2.2.1 Interviews with school staff

I described HT1's preference for employing a relief member of staff to cover the commitments of school staff whilst being interviewed. This decision ensured that participants had allocated, undisrupted time during working hours to speak with me, which I felt confirmed the importance of the staff member in both their school role and as a research participant. In order to facilitate this, HT1 preferred that all interviews were completed in one day or over two half days. I opted for two half days, as I felt that this would allow time to reflect on the process and my interview skills, adapting my approach accordingly. I was also aware, through practice experience, that listening can be tiring, as it requires the interviewer to actively listen. Interestingly, a first-year PhD course on conducting research interviews I attended recommended that researchers ideally schedule one interview per day. This was based on arguments such as those proposed by Corbin and Morse (2003), which suggest that interviewing can be an emotionally exhausting process, particularly when they involve sensitive topics. Although I could have argued for this approach, it would have been difficult to facilitate and potentially more disruptive to the school environment. This situation highlights the complexity of real-world research and good interview practice, emphasising a gap between propositional (conceptual) knowledge and practical knowledge concerned with research in schools. It strengthens Kemmis and Wilkinson's (1998) argument that action research must be responsive to the research environment in order to support effective collaborative inquiry.

Prior to the interview dates, a schedule of who I would be seeing and when was to be coordinated by HT1 according to the different priorities in the school timetable. When I arrived to interview, no schedule had been prepared and a plan was quickly

put together and communicated to staff participants. Although HT1 apologised for this situation, it highlighted the priority of the research within the busyness of the school. This made me appreciate the time already allocated to the research, which, I felt, indicated HT1's commitment to the research. Nevertheless, this situation meant that participants had little warning of when they were being interviewed, which potentially prevented some from giving their full attention to the interview, as they were still processing what they had left behind and how this was being managed. Likewise, it may have made some staff feel unprepared for the interview. For example, one participant said she would have preferred to be interviewed the next day. I enquired if this was because she felt unprepared, offering to both explain the research and reschedule. She refused this offer and commented that she felt informed about the research but would have preferred a later interview so that she could speak with other participants to assist her in preparing for her own interview. This possibly indicated a desire to use the interview as a learning opportunity by reflecting on her practice experience in relation to others. Conversely, it may also have been due to the staff member wanting to say the right thing, portraying their own practice, and that of the organisations, positively. Speaking to other participants may have resulted in allowing time for a pre-rehearsed narrative to be formulated that was potentially an inauthentic picture of their own experience. This situation highlights a possible barrier to developing collaborative inquiry in research, whereby participants may feel obligated to present certain understandings of the research area rather than feel free to inquire, a task which necessarily involves exploration and critique. It identifies the importance of effective preparation alongside effective interviewing skills to ensure that participants feel prepared and comfortable in the interview, but also share honest accounts as opposed to what they think the interviewer wants to hear.

5.2.2.1.1 Knowledge generation

The interviews with school staff were designed in two parts. The first part invited participants to talk about their experiences relating to the research area. The second half encouraged critical reflection on these experiences to explore possible practice developments that would advance this area of work. Sharing experiences seemed to

be relatively comfortable for participants. This involved participants telling stories about specific situations with children who were bereaved. For example, one participant attended the interview with a list of all the children she had worked with who had experienced a significant bereavement and described what she had done in each situation, the child's reaction and how she felt she had performed. Stories are illustrative of representational knowledge. They involve participants making sense of their experiential knowledge by sharing and presenting different aspects of their personal and professional experiences. Active interviewing, discussed in section 4.4.4.4, enabled me to encourage participants to experiment with and reframe these experiences (Holstein and Gubrium 1995). This involved questions such as:

“Would anything have made the easier for you?”

“What made it difficult talking to them?”

“When you look back at these two situations, was there anything that was particularly helpful?”

For example, one participant commented that she had chosen to participate, because she was aware that her experience in this area involves actively avoiding talking with children about issues related to death, dying and bereavement. She commented:

“I think it is probably healthy to be able to do it [talk about death], but as I say I have tended to skirt around it.” (SS4)

This identifies the participant exploring and critiquing her experiential and practice knowledge by using propositional knowledge (“it’s *probably* healthy to be able to do it”). This suggests that she believed that her practice was not ideal and that there was potential for development. By choosing to be involved in the research, she was thus already beginning to engage in developing her experiential and practice knowledge. Sharing these experiences with me meant that I was able to support this process by asking questions, such as those mentioned above, which prompted her to critically reflect on her own practice. Similarly, another staff member mentioned the sensitivity required when talking about death and bereavement, but did not explore this further. I asked:

“In terms of the sensitivity that you talked about, what do you think that would mean?”

She related this to the different cultures and religions within the school that were in contrast with the Roman Catholic foundation of the school. Such discussion not only promoted greater clarity around what might constitute sensitive issues, but also contributed to how practice development ideas were created. She later stated:

“I think information to parents would probably be the thing there. You know, ‘we are going to be doing such and such, this is what we are going to tell the children’ and then if they have got any objections or anything like that I think it would be up to them,”
(SS6)

This process identifies how collaborative inquiry supported knowledge generation, whereby participants were involved in exploring the problems around engaging children in death, dying and bereavement issues and then invited, by me, to be a co-researcher in defining how to best solve such problems. The interviews thus provided an opportunity for co-creating knowledge, whereby participants and I worked together to reflect on what was or was not being done, exploring, critiquing and developing experiential, propositional and practice knowledge.

The interviews highlighted that providing education on death, dying and bereavement in school was not an area many staff had previously considered. None of the participants spoke to or educated children directly about death, dying or bereavement. Instead, some staff said that they occasionally conversed with children about these issues in relation to All Souls’ Day (celebrated by Roman Catholics to remember those who have died) through individual support, after a child had experienced bereavement, or opportunistically, such as if death featured in the news or in response to a specific question. Yet, through the process of active interviewing participants appeared to arrive at a point where they realised that their approach to death, dying and bereavement did not correspond with how they approached all other aspects of the child’s learning and their social and emotional development. In my reflective log I referred to this as:

“A ‘light bulb’ moment when the teacher would go – “why don’t we teach it? We should.”” (reflective log, 18th April 2012)

An example of this is when one participant related death, dying and bereavement to teaching other aspects of the curriculum:

“It’s a bit like learning how to tell directions, but what we do, we will actually take you to [says name of town] and leave you there and you make your way back to school. That’s not the way to teach. The way to teach should be in a non-threatening atmosphere where you are not having to deal with the issue, you deal with it before the issue happens [...]. The same way as you teach directions, the day you do get lost you are better prepared to go “oh right, I know that’s west I know that’s east and I found my way back”, but we don’t tend to do that [for death].” (SS7)

Being challenged to consider their experiences thus encouraged participants to reassess their approach. These “light bulb” moments gave me permission to invite participants to focus on generating practice knowledge to improve this area of work. This appeared to be a relatively simple process for most participants due to their familiarity with the curriculum. For example, one teacher commented that:

“One of the outcomes for health and wellbeing is that children are aware of loss, so it is actually covered in the curriculum. It is something we are meant to be doing” (SS2)

This knowledge was helpful in both justifying teaching in this area and developing specific ideas in terms of how education about Hospice care, death, dying and bereavement could combine with other areas of teaching.

5.2.2.2 Focus groups with children

Organising a time to hold focus groups for children was relatively simple owing to all children being in the same class. HT1 had suggested and supported this idea in the recruitment stage of the research and it appeared to be effective. HT1 was aware of the dates that I could come into the school and informed the appropriate class teacher who, in turn, informed participants. This was communicated to each participant on the morning that I was due to arrive. I felt this was appropriate given the busyness of the school timetable and the priority of the research within the children’s school life. At the start of the focus group, each child was given an opportunity to withdraw from the research. None did and many participants commented that they were pleased to miss whatever lesson was being carried out. I

subsequently wondered if this may have been a motivation for the children to participate as opposed to an interest in the research. I had originally planned to spend a significant amount of time at the beginning of the focus group exploring the children's experiences of group work. This was in order to create a safe and comfortable space for collaborative inquiry by developing a set of group guidelines, based on their experiences of groups, and enabling the children to become familiar with me and talking in front of others about something potentially less threatening than the research area. In the first focus group, this process took longer than anticipated as the children were keen to share multiple experiences. Consequently, less time was available at the end of the group, which resulted in me rushing through the final questions. In later focus groups, I sped up this process by taking a more directive approach. This involved me presenting a basic set of group guidelines, discussing their importance, and inviting the children to add anything else they felt significant. This technique did not appear to impact on how the latter groups worked together. On reflection, it is possible that my original approach was unnecessary as, although the children were unfamiliar with me, due to being in the same class they were familiar with working collaboratively with each other.

As part of my recruitment strategy, teaching staff had been asked to identify any children with recent bereavement experiences that may impact on their participation. None of the children agreeing to participate were highlighted as such and I was thus surprised that 75% of the children discussed bereavement experiences. These experiences involved the death of grandparents, aunts, uncles, cousins, siblings and pets. The time since the person had died varied and obtaining this information from the teaching staff may not have been needed and/or appropriate. Nevertheless, in one group, two participants had current experiences. This included the death of grandmother four days previously and a grandmother who was seriously ill. Both children disclosed this information at the beginning of the focus group, yet appeared determined to continue participating. Despite respecting their decision to participate I remained anxious about how this may affect both them and the group. It seemed, however, that their disclosures enhanced collaborative inquiry by firmly establishing an open space where positive and negative experiences could be shared and

support/recognition obtained from other group members. For example, one of the children (C6) became upset during the group. I stopped the focus group to speak to her privately, which involved discussing her continuing participation. She was clear about continuing taking part, as she felt she had lots to say and that her experience would help her in this. She also said that she was comfortable crying in front of the group, but was concerned that they may worry and wanted me to explain to them what was happening and what they should do if she cried again. I did this, which then led to a group discussion about how different people cope with different feelings and how we can support each other. It appeared that her openness and honesty, which included sharing emotions and worries, prompted similar responses in, and support from, other participants:

C10: “It’s good to let it out.”

C6: “Yeh, but what if no one else is?”

C10: “I’ll join in.”

C6: “Oh. Thanks.”

C10: “All I need to think of is [says pet’s name].”

(focus group 2)

The class teacher of C6 said that she had known that the child’s grandmother was ill, but had not known the seriousness. She had not known about the boy’s grandmother. The immediacy of these events in the two children’s lives, coupled with the frequency of other children sharing bereavement experiences, made me question the extent to which families include the school in bereavement issues and/or children feel able to talk about bereavement with school staff. Nonetheless, creating a space where children felt able to talk openly about their experiences appeared to enhance collaborative inquiry.

5.2.2.2.1 Knowledge generation

Focus groups can be argued as an essential method for co-creating knowledge, as they specifically seek to bring a group of people together to explore a given area.

This purpose was recognised by a child participant who commented that her reason for participating was based on an opportunity to learn with and from others:

“I thought it would be interesting to go along and we all have different opinions and learn other people’s opinions. [...] A lot of us haven’t even discussed it, but this will be like our way to prepare us for it, because it does happen to everyone.” (C18, focus group 4)

Likewise, after taking part in the focus group another child noted:

“I thought it [the focus group] was a good experience learning about what everyone else thinks in the group and all that.” (C10, focus group 2)

These comments identify how the focus group situation enabled an opportunity for both collaborative inquiry and co-creating knowledge that the interviews did not. Similar to the interviews, the focus groups were also designed in two halves. The first half encouraged participants to share and reflect on their experiences related to the research area and the second half aimed at critiquing these experiences to think about if and how practice could be improved. Discussing experiences of how death, dying and bereavement are approached in school appeared challenging for some groups due to a lack of exposure. Two groups commented that their teachers never discussed death, with one child remembering a situation where their teacher actively avoided talking about death:

“[The book] said I remember the way my dad used to cuddle me, my dad, it’s the end, he’s gone, or something, and it’s kind of sad. Mrs X didn’t let us read that story, because it was a sadder story. A sadder story than the others.” (C20, focus group 4)

In the remaining groups, one group said that death wasn’t really talked about, except for “when it’s only just happened a couple of days ago and they’re really upset for it” (C18, focus group 4), and the other said that their teacher had talked about death in relation to a book in which a number of people had died. This corresponds with some school staff noting that they sometimes avoided talking about death and only did so in reaction to a bereavement or opportunistically. The latter focus group, when asked to write down why they thought it might be good to talk about death,

unknown to each other each child wrote “because it’s part of life”. When sharing their answers the children found this amusing, and acknowledged that these were the exact words their teacher had used when discussing the book. This exercise enabled the children to present their experiential knowledge, what they had learnt and experienced in the classroom, through words. It also highlights how talking about death with children can equip them with a vocabulary with which to discuss and develop their own knowledge and understanding.

Identifying gaps in experience appeared to assist participants in generating propositional knowledge. For example, in the groups where the children said that death was not talked about in school I asked if they thought that it should be. Some group members responded by proposing theoretical concepts about why it might be important to include children in such education and conversation:

“I think we should start talking about it to children when they are quite young so they get used to it.” (C7, focus group 2)

“We haven’t really learnt about anything about, like similar to this before, so that’s why it might be good [for children to know about it].” (C2, focus group 1)

“If they did let us know in advance that way we have time to think it all through, so that when it happens it’s not quite as big a shock and it’s not as upsetting and scary.” (C18, focus group 4)

These suggestions were not something the children had experienced, but theories about why developing practice in this area would be beneficial. Given the lack of exposure to direct conversation and education on death, dying and bereavement in the school, I found that I encouraged the group members to think about other areas of school life where death might be discussed. For example,

“What about in books, does it ever come up?”

“Do you talk about death at other times?”

These questions appeared to prompt children to share and reflect on personal bereavement experiences as well as on how they encountered death in the media, such as on the news or in video games. Discussing personal stories was particularly

effective in promoting collaborative inquiry as they encouraged other participants to think about, reflect on and share similar stories. For example:

C4: “I had an uncle that died last year, a few years ago, and it was kind of the same things as C3 cos we had Christmas with him and we took loads of photos. I just kept a book with all the photos in it and then we just look through that sometimes.”

C1: “When I was like, a couple of years back, my Great Granny died. I used to have a Gran then and a Great Gran on both sides of the family but, erm, when she passed away we kept, we put all of the photos in frames and all that and we’ve a really nice photo of her and her husband so, I quite like it.”

(focus group 1)

In this way experiential knowledge was brought together and compared. Using photos to help remember someone who had died was found, in the above example, to be a common practice that helped the children cope with bereavement. Such stories also served to highlight the commonality of bereavement. Likewise, sharing experiences also allowed worries or concerns to be expressed. This in turn seemed helpful in promoting collaborative inquiry and generating knowledge. For example:

Me: “Do you talk about death in other ...

C12: “Like when there’s stuff in the news [...], but it’s not really mentioned much.”

C14: “We watch programmes and when the news is on the people die we kind of talk about it and there is always the night when I go to bed and I think that they are going to jump out at me.”

(focus group 3)

In this example C12 shares his experience, which is affirmed by C14 who then relates the experience to feeling scared. This comment prompted a discussion about what kind of death made them feel scared and what helped them cope. Discussing these experiences thus supported the group to clarify what aspects of death they found scary and how they might manage this, thus developing their experiential and practical knowledge. Similarly, one group also discussed worrying that death might happen to them. I asked:

Me: “Is that something you worry about a lot?”

C1 “Sometimes”

C5: “Sometimes.”

C2: “Because everybody dies [pause], so that doesn’t really, that doesn’t really matter to me, it’s just like...”

C3: “It’s just, if it happens when you’re like in your 30s, or, I don’t mind if I am going to die in my 80s or 90s.”

C2/4: “Yeh”

(focus group 1)

This example shows the children sharing experiences and validating each other’s concerns, but also developing a clearer understanding of what their worries are in relation to death. By talking about these concerns, the children discovered that they primarily worried about premature or unexpected death. This identifies how experiential knowledge in relation to worry about death and dying was initially expressed, defined and then developed. Moreover, it also appeared that the children appreciated the time to talk about these things. When asked, at the end of the focus group, to reflect on how they felt after participating, comments included:

“I thought it would be quite boring, but it’s quite interesting and we should have more sessions like this.” (C10, focus group 2)

“Just really, really enjoyed taking part in it today and talking about death and dying.” (C17, focus group 3)

“I am happy that I was in this group, because I know more things [...] and I think we should write a project soon.” (C11, focus group 4)

This question was included in an attempt to assess how the children had experienced the focus group, prior to returning to their classes. Although it is possible that the children may not have reported negative experiences, the comments suggest the majority of children found the experience interesting and enjoyable, providing them with an opportunity to discuss issues that they had not discussed previously. This is reflected in literature on focus groups and action research that suggest that both offer

opportunities for personal growth (Noffke and Somekh 2009). It identifies how knowledge was generated at both personal and group levels.

Generating practical knowledge on how death, dying and bereavement could be addressed in school was primarily theoretical, as the children clearly stated that they lacked direct experience of this. Existing practice knowledge of how other subjects are managed in the school was thus combined with experiential and propositional knowledge on death, dying and bereavement to develop possible practice solutions. Examples included using their existing “health jotters” to write a personal story about someone who had died, holding “a special assembly”, “making a power point”, “a worry box” and having death and dying as a discrete subject, “like maths or something”. These were all activities currently carried out in school that the children felt could be adapted to talking about and educating people on death, bereavement and hospice care. The experience of participating in the focus group also helped to generate ideas:

“See at school, they should bring groups like this out, but increase the numbers a little bit and then you can have turns speaking about death, so you’re prepared for the worse and you’ll understand more about death so you’ll know. Just like if you have a wee bit of education that won’t fix it, but sometimes it doesn’t matter.” (C10, focus group 4)

This identifies how practical knowledge was developed through both the experience of being in the group and propositional knowledge on why education is helpful. This process of generating ideas further evidenced collaborative inquiry. For example:

C8: “I think maybe the teacher should do like sessions like this more often so that children get used to it like.”

C10: “Like once a month.”

C8: “Yeh, like once a month.”

C10: “Or every year.”

C8: “Or a few times over the term.”

C10: “Like, for P6 and P7, cos the young ones, they might be, they can’t handle it as well.”

C6: “If you could have something every months, just try and remember who died and stuff, just...”

C8: “Like a memorial?”

C6: “Yeh,”

(focus group 2)

This identifies how the focus group situation enabled group members to expand on each other’s ideas to reach a level of agreement around how practice could be developed. It highlights practice knowledge being co-created through a process of negotiation.

5.2.2.3 Focus groups with parents

I discussed in chapter four the importance of involving parents/carers in the research. Out of the six parents agreeing to participate, only four attended the focus group. One parent cancelled due to last minute commitments. The other did not attend and was then unable to be contacted. I raised some of the challenges recruiting parent/carers in section 5.1.2.2. Although the focus group was held after school and childcare was available, arranged by HT1, those attending the group highlighted difficulties in attending anything in the school due to work and family commitments. All participants were women and it was clear that they had the majority of childcare responsibilities in the family. Given the small number of parents participating and the gender bias, I wondered if going ahead was somewhat tokenistic, yet I was interested to hear and involve their thoughts and opinions. All four participants said that they felt that death, dying and bereavement was an important part of life that children should be aware of. They felt that the school had a role in related education, and that parents should be informed of any practice developments in this area. I had presumed that the research would attract parents who were strongly for or against discussing death, dying and bereavement with children and was surprised that all the participants supported practice in this area. This was interesting given that, in the interviews with school staff, parents had been identified as barriers to developing this area of work. Nevertheless, I was conscious that the parents participating were potentially a biased sample. For example, they all noted that, in situations where

there had been a family bereavement, they would inform the school. In the children's focus groups it was apparent that not all parents did this, suggesting that participating parents were perhaps already comfortable with these issues and aware of the supportive role the school has in their children lives.

During the group introductions it was apparent that one parent was participating specifically to gain support:

“So I thought that Sally or anybody else might be able to help how we can cope with [says daughter's name].” (P4)

Prior to the group, I had spoken with this parent who had made it clear that her daughter might need help. We discussed the situation at length and made a referral to the Hospice bereavement service for both the parent and daughter. I had also made it clear that the purpose and aim of the focus group was different to bereavement support and was therefore surprised that she had arrived seeking further help. During the group this parent would often tell lengthy stories about her daughter's experience. At times this was relevant to what was being discussed, but it often served to focus the group on her needs, with the other parents offering advice and reassurance. Given that action research should be led by the participants, I could have allowed these conversations to continue for the duration of the group. They clearly served to develop practice knowledge by broadening parents' skills and knowledge base in supporting bereaved children, whilst providing evidence of collaborative inquiry. Nonetheless, such conversations were not directly related to the overall purpose of the group, to explore practice between the Hospice and school, and I found myself attempting to use direct questions to steer the group back to the focus of discussion. This was difficult to manage, especially as I was often looked to for clarification on what was being advised. These situations strongly drew my attention to my role as researcher versus practitioner, as I found myself walking a fine line between being supportive and helpful and keeping the focus group engaged with the research. This challenge is discussed in more depth in chapter seven, where I reflect on the action research process across both research sites.

5.2.2.3.1 Knowledge generation

The above section highlights how knowledge generation was relevant on both a personal and group level through developing practical strategies (practice knowledge) to support children through bereavement. Similar to the interviews, sharing personal stories (experiential knowledge) was significant in shaping and promoting knowledge generation. For example, one parent discussed how her mother was currently unwell:

- P2: “And we’ve actually talked about her dying, which sounds a bit morbid, just because now I’m sort of just preparing them, but I don’t know how they will cope. In the past [...] our family always go to funerals.”
- P1: “We’ve never really had a funeral for me to make that decision, but see I think my natural reaction would be for my daughter not to go, but I don’t know why. I don’t know why. “
- P3: “I gave my two the choice of what they wanted to do, because it was their Gran. The older one decided he wanted to go.”

This highlights how sharing experiences prompted other participants to share, and critically reflect on, their own experiences. By bringing their stories together, the parents were able to critique their own experiential knowledge of engaging with these issues and consider alternative practices. In this way experiences were brought together, explored, compared, reviewed and adapted where appropriate, which in turn contributed to how practice knowledge was generated.

Developing practice ideas around how the school could work with the Hospice to incorporate education and support on death, dying and bereavement involved the parents combing existing practice knowledge of what currently happens in the school with experiential and propositional knowledge based on death, dying and bereavement. Unlike the school staff and pupils, the parents noted that they were not completely familiar with what was already being taught in the school curriculum and that this was a barrier in terms of the extent to which they felt they could develop practice knowledge. Three suggestions were offered by parents about how this area

of work could be developed in the school. These were related to religious education, science and sex education. One parent in particular felt that being at Catholic school was helpful:

“It’s quite good for us in that, being Catholic, I mean you’ve got an afterlife and it’s good to explain to them in that way. This is what we believe in, it’s not the end of the world sort of thing, and it’s easier for them to cope with. That sort of support as well, because if you go to church every Sunday, so that’s sort of probably built in, part of that’s in the school life as well.” (P3)

Science was thought helpful as it could include education on lifespans, which would mean that education about death was more factual than emotional. The implementation of the sex education programme in the school curriculum was discussed by all four participants as an example of how education that can be deemed sensitive can be carefully weaved into the programme.

“Sex education starts at P1 and people go ‘pardon?’ and you go ‘noooo’. It’s obviously not that in-depth, but it’s obviously a bit, from how they introduce it in P1 and it changes every year until eventually they get to P6 and they deal with it, because they are hopefully emotionally ready at that age, so again, if there was something similar...” (P1)

It was also discussed in relation to involving parents when there might be barriers to implementing what could be deemed a controversial programme of work. For example,

“I think as long as you explain it, let parents see what you are going to be doing and that they are happy with it. It’s the same for that education for love [sex education programme]. Everybody was totally freaked about it when they first heard about it, until they found out about how it was going to be done.” (P3)

After this comment another parent noted:

“I think there is a slight difference with sex education I suppose, there are parents that are always worried that it’s teaching their kids something and there is always that fear. Whereas I think death and dying is a normal part of life, and you would worry that

your child might get upset, but you're not worried that it's teaching them something they shouldn't be familiar with." (P2)

This comment identifies the process of co-creating knowledge, through participants building on each other's contribution to the group to explore and develop their own, and that of the other group members', knowledge claims. It involved one person sharing experiential knowledge with another participant, then combining with propositional knowledge, around death as a more "normal part of life", to develop and support practice knowledge. This suggests that educating children on death, dying and bereavement may be less challenging for most parents to understand and support than sex education.

5.2.3 Reviewing the experience

This phase of the research identified how the interviews and focus groups provided participants with space to share and develop their knowledge relevant to the research area. Overall I felt happy with how these were carried out and supported within the school. Having a relief staff member to allow staff to participate in the research was particularly helpful, as it meant that the staff had allocated time where they were not interrupted and their class was being cared for. I was aware that the school had paid for this staff member out of its budget, which I felt confirmed the importance that HT1 placed on the research within the school. The interviews were helpful in encouraging critical reflection on current school practice as they involved the participant and I working together to explore current practice and think about how this might be improved. I have discussed how active interviewing became both relevant and helpful in the interview situation. For me, this was a new technique and concept that I was both excited and nervous about using. Reason (1994) notes that, when attempting to create situations for collaborative inquiry, participants 'may need facilitative help to develop a capacity for critical self-reflection' (p.55). I felt that active interviewing matched this task extremely well, as it allowed me to be clear in the reasons why I was undertaking the research whilst also encouraging staff to reflect on and challenge their practice. The focus groups enabled a different kind of collaborative inquiry, which involved less engagement between the participant and me, and more engagement between participants. Although this may have been a

preferable situation for school staff, it was challenging to organise within the school setting. Nevertheless, the data achieved from this phase of the research provided ample material to be negotiated in the next phase of the research, and it was clear that participants supported continuing involvement with the research in the school.

5.3 Phase three: planning and developing a model(s) for possible intervention

5.3.1 Descriptive phase

HT1 and the Hospice Chief Executive Officer (CEO) decided who should be involved in this phase of the research from their respective organisations. Both felt that only they should attend because of their position within, and knowledge of, the organisation. They agreed that other participants should be involved during later phases. The findings from phase two were emailed to both HT1 and the CEO one week prior to meeting (Appendix 12). This included a list of themes generated via data analysis as well as a list of suggestions, provided by participants, for future practice. Through a process of discussion and negotiation, three actions were chosen to be taken forward. These were:

1. Integrate education on serious illness, death and bereavement into the curriculum across all ages.
2. Develop and pilot bereavement training for school staff.
3. Develop materials to be used alongside the Hospice ‘Go Yellow Day’ fundraising initiative that inform children about the role of hospices in the community and how money raised is spent.

Given that this meeting was held in June 2012 and the school was due to break for the summer holidays, it was decided that the actions would primarily be developed in the new academic year (starting end of August 2012). Table 1 shows the plan developed to ensure how each action could be advanced.

<u>Action</u>	<u>Plan</u>	<u>Timescale</u>	<u>Person Responsible</u>
1. Integrate education on serious illness, death and bereavement into the curriculum across all ages	Finish current audit of health and wellbeing curriculum. Notice gaps where death education may meet curriculum learning outcomes	By August 2012 (first month of academic year 2012/13)	HT1
	Establish working group with remit of developing curriculum ideas Sally to be included as part of the working group	August 2012	HT1
	Curriculum designed and developed across all ages in the school	September 2012 to June 2013 (school year 2012/13)	Working Group
	Update and inform all school staff	October 2013	Working Group
	Share scheme of work with parents/carers	To be confirmed	Working Group
	Train school staff involved in pilot	To be confirmed	Working Group
	Pilot and evaluate curriculum	January – August 2014	Working Group/Staff team
2. Develop bereavement training for school staff	Meet with the Department of Education, Practice Development and Research (DEPDR) at the Hospice to identify a staff member to take forward training	Summer 2012	CEO and Sally
	Design training in collaboration with research team at RCPS	September 2012	Hospice Department of Education, Practice Development and Research (DEPDR) staff member, Sally and research team at RCPS
	Pilot and evaluate training	February 2013	Hospice DEPDR staff member and Sally
	Write up evaluation findings and share with Hospice management team to discuss ways forward	Summer 2013	Hospice DEPDR, management team and Sally
3. Develop materials to use alongside 'Go Yellow Day' that inform children about the role of the hospice in the community and how money raised is spent	Meet with children on research team to explore ways to take forward	June to August 2012	Sally and research team from phase 2
	Design materials and present to Hospice CEO	September 2012	Research team
	Meet with Hospice fundraising team about incorporating suggested ideas into 'Go Yellow Day' programme	October 2012	Hospice CEO and Sally
	Pilot and evaluate ideas	2013	Hospice fundraising team

Table 1: Action plan for practice innovations

The plans for taking forward the practice innovations were developed and negotiated with HT1 and the CEO after the meeting. All participants from phase two of the research were notified about the decided actions and the plans. They were also asked if and how they would like to be involved. This was done by email to adults and in person with the children. All participants involved in phase two of the research were happy to be involved in any way they could, with the exception of one staff member and two children. The staff member was moving to a new school in the new academic year and would therefore not be available. The two children said that they no longer wanted to be involved, but did not give any reasons for this. At the time of writing the actions were ongoing, and it was intended that they would be reviewed and evaluated within existing procedures at each organisation. Appendix 16 includes an overview describing what took place at each site after this phase of the research.

5.3.2 Reflective phase

Phase three of the research prioritised developing practical knowledge through collaborative inquiry. This involved HT1 and the Hospice CEO discussing data gathered from participants in phase two, alongside their own experiences and knowledge base, to decide how best to develop future practice. I was initially disappointed that HT1 and the CEO had decided that no other staff members could participate in this phase of the research. They both held similar reasons for this decision. These were based on protecting staff, who they felt already had high workloads, as well as recognising their management position in being able to assess the scope of any planned activities and establish what is achievable within the wider organisational agenda. These reasons are undoubtedly significant and without support from management it would have been unlikely that any practice would have been fully embraced and initiated. Nevertheless, I felt strongly that involving other participants in this phase would have ensured that the findings and practice developments were fully debated from the different perspectives of pupil, Hospice staff member, RCPS staff member and parent. Prior to and during the meeting, I therefore found myself making explicit the focus of collaborative inquiry. Prior to the meeting, this was done several times in phase two with all participants, individually with HT1 and the CEO, and then immediately at the beginning of the

meeting. During the meeting it involved me using facilitation skills to both encourage discussion and reflection as well as ensure that contributions from the CEO's and HT1s' was given equal significance alongside data from phase two. This is evident in transcripts from this meeting, where I used a number of statements to highlight different perspectives. Examples include:

“The parents as well talked about ...”

“One thing that came up for the children ...”

“One of the children spoke about ...”

“It definitely came across from the teachers that ...”

This seemed effective, as reflected by HT1's comment about the findings generated by the children:

“It was quite insightful in a sense of the difficulties they felt.”
(HT1)

There are, however, undoubtedly strengths and weaknesses to this approach. The validity of the contributions I made were in part due to how much I remembered from the data as well as the quality of the data analysis, which, as discussed in section 5.2.2.4, had some limitations.

Logistically, having Hospice Staff, RCPS staff, parents and children present in the focus group would have been complicated and potentially challenging to facilitate. Nonetheless, it may have prompted a broader debate of the research findings from phase two, and would also have ensured a wider understanding across both the school and Hospice communities of why particular practice developments were chosen. For example, in relation to practice development three (develop fundraising), had a member of the fundraising team participated in phase three they would have had an opportunity to hear directly from the RCPS staff and pupils the importance of and opportunities within fundraising to raise awareness, and break down associated stigma, of hospice care. Equally, they could have contributed to, and debated, these ideas. In the meeting the CEO said that she would ensure any changes made to fundraising initiatives would be put into practice, and I had every

confidence that this would be done. Yet, I felt that having a member of the fundraising team involved in this decision-making process might have encouraged a sense of ownership around the practice, resulting in informed, consistent and effective delivery, where raising awareness of hospice care was seen as part of the fundraising role rather than an additional task. This example identifies the challenge of good action research practice and working within organisations that may not have the available resources to spare staff members for full cooperative inquiry.

Both participants also maintained the collaborative focus of the research at several points during the meeting. This involved direct calls for specific information to assist service delivery. For example, the CEO requested:

“Some good solid advice on what do you pitch [to children about hospice care] at what age group.” (CEO)

and HT1 asked to use expertise of Hospice staff to find out:

“How do we raise those issues [death and bereavement] in an appropriate way?” (HT1)

Both comments identify the participants focusing directly on how they could utilise each other’s knowledge to advance practice in their own settings. These examples also highlight the difference between collaboration and consultation. In the *Public Participation Spectrum* (a spectrum designed to help define the public’s role in community engagement programmes), consultation is viewed as a significant tool in developing practice, but is typically a one-way process involving listening to concerns, feedback and aspirations with practice changed independently of those consulted (IAP2 2007). In the case of the above examples, opportunities for consultation could have been facilitated by providing time for a short question and answer exchange that would have shaped practice delivery within each organisation independent from the other. Conversely, collaboration requires listening to concerns, feedback and aspirations, but formulating practice solutions together (ibid). This is an integral aspect of action research. It was evident in this phase of the research by participants asking for direct feedback and also working together to reflect and critique practice in the hope of arriving at mutually agreeable practice solutions.

HT1 and the CEO prompted, facilitated and participated in critical reflection by sharing contrasting views and opinions as well as acknowledging areas of cohesion and agreement.

This phase of the research again drew my awareness to the different roles I undertook in the research process. At one stage during the meeting HT1 asked me:

“You know this started from your project and all [...], what’s your take on it Sally, in the sense of, from your perspective, that you think would be fruitful?” (HT1)

By this stage of the research I had undoubtedly developed views on how I thought the research could progress, but had not expected to be asked so directly. On the contrary, I had actively sought to place any decision-making in the hands of the participants. Despite this, I was still asked to actively incorporate my own understanding on what I thought should be taken forward. This felt both encouraging and uncomfortable: encouraging, because I felt that it reflected HT1’s confidence in my understanding of the situation and data; uncomfortable, because, in the context of a research environment, I was more familiar with maintaining an outsider position. This situation identified my role as a participant, which Winter and Munn-Giddings (2001) note requires the researcher making available their own perspectives about the research to be questioned. I was simultaneously balancing this role with that of research facilitator. This involved ensuring participants had equal opportunities to share their ideas, a mutually agreeable outcome was reached and that the meeting stuck to agreed timescales. This was done whilst also being cognisant that the research was within the context of a PhD study, which had particular boundaries around time and process.

5.3.2.1 Knowledge generation

In this phase of the research, creating a space for collaborative inquiry emphasised the symbiotic relationship between generating experiential, representational, propositional and practice knowledge that is relevant to an extended epistemology. For example, during the meeting HT1 drew attention to how the school had taken part in ‘Go Yellow Day’, an annual fundraising initiative aimed at schools that is run

by the Hospice. He highlighted how children raise money “because the teacher said so, and they trust them [the teachers] implicitly” and due to this do not question why they are taking part. Yet he added how great it would be if, alongside the actual fundraising, “children are going ‘I know what that’s for, I know why we are doing it’”. This caused the CEO to reflect on an additional fundraising initiative done with schools, which she noted had been

“picked up as an entrepreneurial thing of ‘let’s try to get P7’s to come up with ideas’ and you know [pause], but the message, we’re not really sending the message out about the hospice and I think we need to.” (CEO)

This highlights how collaboration initiated a new awareness around current practice, thus developing experiential and practical knowledge. According to Reason (1994), experiential knowing ‘is birthed at the moment that curiosity is aroused or incongruity noticed’ (p.44). Although the concept of using fundraising to better educate people on the role of the Hospice was generated in phase two of the research (Appendix 12), the process of collaborative discussion gave this finding more validity. Through direct contact with HT1, the CEO was presented with an opportunity to hear about experiences of current practice first hand, whilst also having time to apply these experiences to other practices within the Hospice. Similarly, HT1 specifically addressed how his experiential knowledge had developed through participation:

“Now I’ve met with you [...] it seems to me that from an education point of view, which I have to say I’ve never thought that much before beyond dealing with that moment of crisis for wee Jimmy because his mum or dad died, or Johnny or little Suzy because mum is in hospital seriously ill, we are, I think you used the word, reactive, and that’s fine, but it’s not good enough.” (HT1)

His comment identifies how engaging with the research prompted curiosity, reflection and critique of his practice, thus developing experiential knowledge. Both examples identify that participants were prompted to recognise aspects of their current practice which were previously unnoticed and, through collaboration, were consequently able to develop and expand their experiential knowledge. The process

of vocalising areas of learning relates to presentational knowledge, whereby the CEO and HT1 actively communicated and presented their learning on and in action. Collaboration thus assisted to develop experiential and presentational knowledge, which in turn informed practice knowledge.

The above discussion identifies that areas of conflict were particularly significant in offering a platform for both personal and organisational critical reflection and knowledge generation. An example of this was towards the beginning of the meeting. After looking over the list of practice examples suggested in phase two (Appendix 12), the CEO stated willingness from the Hospice team to work with the school in developing any new practice idea agreed providing it did not compromise patient safety and wellbeing. HT1 responded that the practice examples involving the Hospice providing a direct service to schools may create an “unserviceable demand” due to the high number of schools in the catchment area. The CEO challenged this concern, stating that “there are lots of ways around that for us”. She gave examples of how requests to work with schools could be managed by staff and the “army of volunteers”, and the associated benefits this would bring to the Hospice team. HT1 stated his ignorance about the “modern Hospice of the 21st Century”, yet offered alternative ways in which children could learn about the Hospice rather than through direct contact. This served to reiterate his concerns whilst also give possible solutions. This example highlights how, through the process of discussion, both HT1 and CEO challenged one another’s thoughts and ideas to prompt critical reflection on personal and organisational knowledge and experience. Personal reflection involved HT1’s recognition of gaps in his knowledge. Organisational reflection involved both participants reflecting on how their individual organisations currently practice and how this may or may not be relevant to developing practice together. The situation thus appeared to effectively enable an opportunity for collaborative inquiry by creating a space for participants to critically engage with each other, the data, their organisation and their experiences.

Although both participants were in management positions their training, professional backgrounds and work experience was very different. Enabling an opportunity to work collaboratively meant that they could also work inter-disciplinarily. This

provided a number of opportunities to share propositional knowledge relevant to their specific expertise, professions and experiences. For example, HT1 discussed what he viewed as a parallel between sex education and death education. When developing the school's sex education programme, he shared with the CEO how developmental theories were significant in deciding how they proceeded:

“When they get to 10, 11, 12 years of age they are becoming aware of themselves as an individual and how those relationships go on and certainly about boy/girl [...] and so it's appropriate. And I think likewise with this.” (HT1)

The CEO recognised this as an area she did not know about and later asked for advice on working with different age groups, such as “What are words you use to a seven year-old, a nine year-old?” This example highlights the significance of sharing specialised knowledge and experience across disciplines as an integral aspect of collaborative inquiry. This willingness to share and learn about their own and each other's organisation, professional knowledge and experience allowed them to generate practice knowledge from a wider perspective. A further example of this was in relation to practice developments one (curriculum development) and two (bereavement training). During the focus group, the CEO shared her knowledge about Hospice care by informing HT1:

“The vast majority of people who come to the Hospice will actually tell us they wish they had come sooner [...]. They resist it because it's where you go to die and it must be sad and it must be gloomy and it must be awfully depressing [...]. Part of the way we could break the adults down if you like is if the children, you know, get involved with the Hospice and if they are all right with it then it seems a bit strange that the adults aren't.” (CEO)

After listening to this information, HT1 acknowledged his ignorance about hospice care by commenting,

“You know, I am even listening to you and I have to hold my hand up and I'm going 'hey?'” (HT1)

He thus began to develop a shared understanding with the CEO that breaking down stigma associated with hospice care was something that needed to be tackled. Despite this, due to the high amount of schools in the area, HT1 was sceptical:

“I do think that there is a danger that either you as an organisation or onsite, your own campus, could potentially get swamped with people coming to visit you and/or you get swamped with requests for you to come and visit us [all schools in the area].” (HT1)

This sharing of expertise, experience, gaps in knowledge and concerns initiated a discussion contrary to how the CEO originally saw practice developing. This involved recognising that attempting to have direct contact with children would be resource-heavy, whereas working with staff would be less resource-dependent and potentially more effective in terms of broadening the impact on of their work. The collaborative process thus influenced developing practice, which may not have previously been considered. In relation to practice development one (curriculum development), this involved the Hospice staff providing leadership in end-of-life care and bereavement, informing and empowering school staff to

“understand what we’re about so they can think how they weave it into the curriculum rather than us [...], and it keeps you in control and it gives you that sense of, you know, the timing thing.” (CEO)

In relation to practice development two (bereavement education), it involved Hospice staff sharing their bereavement expertise with school staff so that, where appropriate, children could be supported in school rather than referred to external support from the Hospice. Both practice developments involve transferring responsibility around education and support on end-of-life care and bereavement issues from the Hospice to the school. They identify how HT1 and the CEO engaged in emancipatory and change process through sharing and negotiating their experiences, opinions and expertise.

5.3.3 Reviewing the experience

When I embarked on this phase of the research, I assumed that one practice development would be chosen, which would be piloted and evaluated within the context of a PhD. I was thus surprised that three ideas were chosen and strongly advocated for, and I comment to participants:

“I’m just smiling because I’m thinking, how does this fit into the PhD research?”

They responded with laughter and I identified that I would explore this with my supervisors. Yet, at this time, I was mindful that what was being planned would go beyond the year that is typically allocated for data collection in a PhD, and I was thus wary of how I should proceed. In my reflective log I noted,

“The ideas that they both wanted to prioritise felt good, but a bit overwhelming.” (reflective log, 6th June 2012)

Reason (1994) highlights that effective participation involves ‘the loss of the myth of certainty, the loss of control, the tempering of the rational mind’ (p. 56). My sense of feeling overwhelmed was related to this loss of control, particularly in relation to how feasible the projects would be within the limits of a PhD. This was more pressing given that after three years I had to return to the Hospice and resume my previous job full-time. Furthermore, the decided practice developments were much broader than my original research questions and design, particularly in relation to practice development two, which involved developing a school-wide curriculum that was beyond my focus on nine to 12 year-olds. I discussed this situation with both supervisors, who also felt that this was a big task to do within a PhD. They called for a more strategic approach that addressed one action at a time. In my reflective log I highlighted that this felt:

“better, more manageable certainly, but also more focused. There is a huge difference, however, between my practice head and academic head. My academic head is more focused and structured. My practice head has wider demands and different time scales.” (reflective log, 8th June 2012)

Broadening the research out with the parameters of my original research question was possibly due to my inexperience as an action researcher. Nevertheless, this situation is potentially concerned with ‘tempering of the rational mind’ that Reason (1994, p.56) notes as a requirement in action research. Collaborative inquiry requires that the different needs and priorities of both organisations are taken into account and in this situation it was apparent that a multi-faceted approach was called for. Although I felt overwhelmed by this, I also felt convinced that the decisions made

were the most appropriate way forward. Action research asserts that the research process should be led by the participants and thus working with the demands and concerns of both organisations, not the PhD timeline, was crucial.

5.4 Summary

This chapter described and reflected on the action research process at RCPS. I discussed how access to the school was arranged and how participants were recruited and their consent to participate achieved. I specifically identified HT1's role as key in both negotiating and addressing these issues, which appeared to be motivated by his interest in the research and my relationship with the Hospice. I highlighted the challenge of recruiting adult participants and suggested that this was partly influenced by my focus on the inclusion of children, which took away from that of adult participation. At each phase of the research I considered how knowledge was co-created and how collaborative inquiry was promoted. I discussed how the research area prompted different reactions in the participant, how this was managed and how it influenced both the interview and focus group situations. I discussed the process of deciding practice developments which, despite being influenced by managerialism, evidenced collaborative inquiry. Throughout this chapter, I described how the research process, and therefore the knowledge generated, was influenced by me: as a researcher, participant and practitioner. This relates to the different selves I brought to the research process, discussed by Rienharz (1997) and outlined in section 4.2.3.1.

Chapter 6: Investigating and developing practice with the non-denominational primary school (NDPS)

This chapter discusses the action research experience at this school (NDPS). In parallel with the previous chapter, I use the framework for critical reflection discussed in section 4.4.5 to explore how the research was negotiated and facilitated. This begins with a descriptive account of the work undertaken and goes on to reflect on the situation and approach, discussing how knowledge was generated and how participants engaged in a process of change. I sought to be transparent about research decisions at each stage of the process, highlighting collaborative working. Work with NDPS continues to be developed. This chapter discusses phases one, two and three of the research that took place between November 2011 and November 2012.

Figure 4 shows a timeline of the key events that took place during this time. Appendix 16 shows the developments that have continued to take place after this time.

6.1 Phase one: negotiating access and recruiting participants

6.1.1 Descriptive account

I telephoned the head teacher (HT2) at NDPS a number of times, leaving several messages. I did not receive any response and so I also sent an email outlining the purpose of the research, noting that ethical approval had been achieved and including a copy of the information leaflet (Appendix 2.1). I did not receive any response to this email and so continued to call until I eventually spoke to HT2. She apologised for the difficulties in contacting her and said that she had read the email and would be happy for the school to participate. A meeting was subsequently arranged where we discussed the background to the research, possible research progression and timescales.

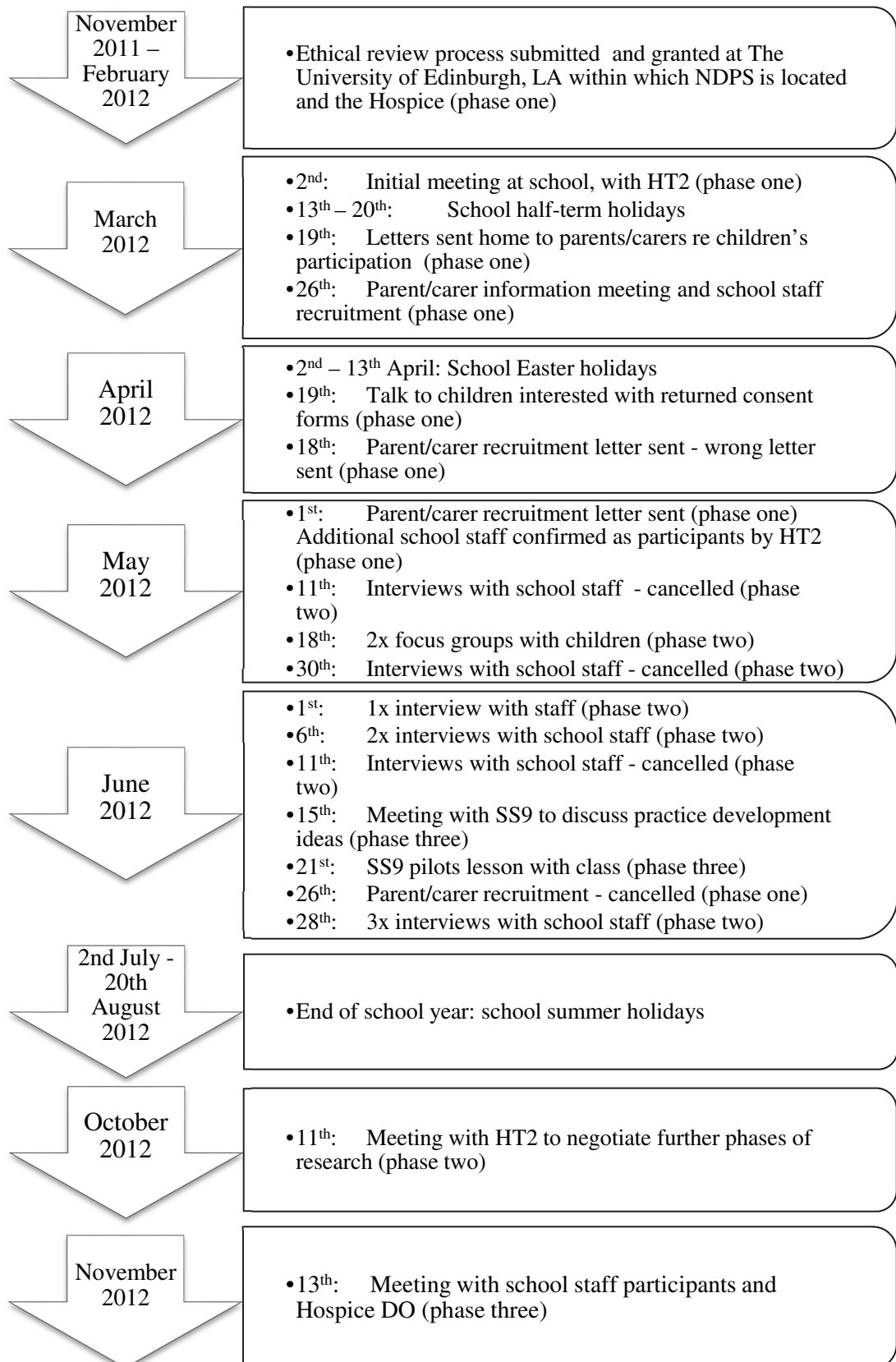


Figure 4: Timeline of events at NDPS

At this stage of the research I was already working with RCPS. HT2 was aware of this and, although RCPS remained anonymous, she wanted to know how recruitment and ethical issues had been managed. Although some of the processes regarding these issues had not yet been implemented, she decided to mimic the same procedures. The following decisions were subsequently made:

Staff recruitment: HT2 agreed that any staff member could be involved in the research if they wished. A date was established on which HT2 would invite all staff to hear about the research. Any staff member wishing to participate in phase two of the research would be given time within their working hours to be interviewed. This would be arranged internally by HT2 once the interview dates had been set. During the interviews, staff participants would be asked if they wished to be involved in later phases. If they agreed, their participation would then be negotiated between HT2, the staff member and me depending on how the research progressed.

Parent/carer recruitment: A letter would be sent home, from both HT2 and me, to the parents/carers of all P6 and P7 pupils informing them about the research and inviting them to participate. If agreed by HT1, this letter would be adapted by me from the letter used at RCPS and emailed to HT2 for any changes. In the event that this process did not recruit enough parents/carers, HT2 would approach the Support for Learning Parent Group, who meet regularly and who HT2 felt would be amenable to taking part in the research. Although the children from this group of parents/carers were of all school ages, HT2 noted that the school were keen to ensure a holistic approach to any work they do.

Child recruitment: A letter would be sent home to the parents/carers of all P6 and P7 pupils, coupled with a copy of the information sheet for children (Appendix 2.2). It would inform parents/carers that the research was taking place and invite them to withdraw their child from the process if they wished. It was also agreed that I would hold an information meeting at the school for any parents/carers with

questions related to the research. Details of this information meeting were to be included in the letter. Dates were confirmed for sending the letter home, the information meeting, when requests to withdraw children from the research needed to be returned by and when I would attend the school to speak to the children. If HT1 agreed, I was to adapt the letter sent at RCPS and email it to HT2 to make any changes. HT2 felt that once I had spoken to the children I should also speak to the parent/carer of any child wishing to participate, informing them of their child's decision and requesting written consent to say that they agreed to their child's taking part.

Ethical issues: These were decided as discussed in section 4.5. If, through the process of the research, it became known that a child required bereavement support, HT2 was happy for the Hospice to provide support.

Timescales and space: At each phase of the research I would meet with HT2 to discuss the next stage. How the school continued to be involved in the research would be re-evaluated during this time. The school would provide the library for the interviews and focus groups to take place. This room provided private space and was close to HT2's office and the staff room should additional support be needed. In the unlikely situation that this room was being used HT2 would provide alternative accommodation.

After the meeting I contacted HT1, who agreed that that the letter we had created could be adapted elsewhere. I sent an email to HT2 immediately, confirming the decisions made at our meeting, the dates established and a copy of the revised letters used at RCPS (Appendix 13 and 14). No response was received to this email or the follow-up calls. Despite this, I attended the school as agreed and the following actions were subsequently implemented:

1. I attended the arranged meeting to recruit staff. Seven staff were present, all of whom were teachers. I was introduced by HT2 and spent approximately ten minutes explaining the research. Two staff opted to take part immediately. The remaining staff took home copies of the information

leaflet. This included a reply slip that they could fill in and leave at the school's reception to indicate whether or not they would like to participate. Due to low staff attendance at the meeting, HT2 agreed to speak with the other staff about the research as well as give out copies of the information leaflet and reply slip. Owing to the Easter holidays and other school commitments HT2 was unable to speak to staff and confirm if any people were interested until one month later. As a result of these processes six staff agreed to participate; all were teachers and female.

2. I attended NDPS to host a parent/carer information meeting as advertised on the letters sent home. No parent/carers attended.
3. I attended NDPS to speak with the children who had not been withdrawn from the research. Twelve children out of 114 had been withdrawn from the research. Eleven replies had also been received from parents/carers saying that their child would like to participate. As this meant that these 11 children already had full consent to participate, HT2 felt that I should work with this group of children instead of recruiting children by speaking to the class groups as previously planned. I therefore spoke to the 11 children whose parents noted they were interested in participating in the research in one large group. I introduced myself, explained what I would be doing and what would be involved if they decided to participate. I emphasised that participation should be through personal choice and, if they chose not to participate, this would not have any influence on the rest of their school experience. The children were invited to ask questions and were each given another copy of the information leaflet. I then invited all of the children to complete and return a slip by ticking one of the following three statements:
 - a. Yes, I still want to be part of the project.
 - b. No, I do not want to be part of the project
 - c. Not sure, please can I talk more about it with Sally

I also asked the children to write “just me” on the slip if they wanted to participate, but preferred taking part in an interview rather than a focus group. All of the children agreed to participate, one of which opted to have an interview. The list of children was shown to HT2 and the class teachers to see if there were any concerns about participation. No concerns were raised.

4. HT2 sent the wrong letter home to all parent/carers of the children in P6 and P7 classes. The correct letter was sent two weeks later. No responses were received. HT2 contacted the Support for Learning Parent Group and informed me that they were happy for me to attend their next meeting. I did this, but was unable to discuss the research as the staff facilitating the group said they were unaware of my visit and, owing to their plans for the evening, felt that it was inappropriate timing. Due to the time the above process took, there were only a few weeks until the school broke up for the summer holidays. It was therefore decided not to pursue parent/carer recruitment any further.

During this phase of the research I was also involved in facilitating a bereavement group at the Hospice. One of the children attending this group was a P6 pupil at NDPS. I was approached by his mother, who wanted to know when I would be talking to his class group about the research. I explained that the original plan had changed and that I was only able to speak with children whose parents/carers had given written consent. She noted that her child was keen to participate and wanted to provide written consent of her preference that he also be included. I met with the child individually to discuss the research, outlining the differences between the research and the bereavement group (including my role), emphasising confidentiality and discussing participation given his recent bereavement. The child noted that he wished to participate. This was then discussed with HT2, who supported his participation.

The recruitment process at NDPS thus resulted in the research team consisting of: six school staff (five teachers and one member of the management team) and 12 children.

6.1.2 Reflective Phase

Similar to my experience at RCPS, my initial engagement with NDPS was primarily through contact with HT2. This contact established the beginning of working collaboratively with the school community to develop a shared research purpose. Gaining access and issues of recruitment and consent were significant in how collaborative inquiry was developed. I will review these areas separately, critiquing how these experiences set the basis for phase two of the research.

6.1.2.1 Gaining access

As already discussed, it took a long time to make contact with HT2 and, when we finally spoke, I was surprised how quickly HT2 agreed, with very little discussion, to the school participating in the research. My experience with RCPS alerted me to the importance of providing thorough written information to head teachers, coupled with direct contact, to allow them to consider the research at a time convenient to their demanding schedules. It is possible that the email I had sent to HT2 had provided ample information, about me and the research, to feel comfortable in moving forward. Nevertheless, I still felt wary about moving forward based on such a short conversation, as I knew little about HT2's motivation for taking part and equally she had not had any opportunity to assess me as a suitable researcher in the school.

At the initial meeting HT2 had very few questions about the research, despite remaining willing for the school to participate. This meeting was, therefore, relatively short and focused on research practicalities. Although I was pleased with this outcome, I remained surprised with how quickly I was allowed access to the school. I noted in my reflective log,

“Somewhat surprisingly, HT2 wanted to know very little information about the research/process and was happy to follow

what that the other school is doing.” (reflective log, 2nd March 2012)

Gaining access seemed largely based on HT2’s knowledge of the Hospice as, in the meeting, she spent time discussing a pupil who was currently receiving support from the Hospice children’s bereavement service. This situation appeared to be particularly difficult for the school and HT2 seemed grateful of the support. This conversation highlighted HT2’s awareness of and experience in supporting children who are bereaved and its significance for the school not only in relation to this young person, but also in previous roles. It also appeared to express trust in the Hospice, suggesting that HT2 might feel confident in establishing a relationship with me. In hindsight, I should have explored these experiences in more depth, yet, at this stage in my journey as an action researcher, I felt that such exploration was more appropriate for phase two.

Reason (1994) notes that, in action research, the lead researcher needs to ‘appeal to the experience of co-researchers’ (p.44) so that they will also engage with the research. I was working with the child that HT2 had discussed. I had not known the child was a pupil at NDPS, as it is not usual practice within the Hospice to have such information unless the school has made the referral and/or it has been negotiated and agreed with both the child and their parent/carer that the school be contacted and involved. I was therefore unsure how much information HT2 had about the bereavement and felt a conflict between my roles as practitioner versus researcher. Had I had permission from the child and his mother to talk to HT2, I may have approached this conversation differently. For example, rather than merely listening to HT2’s understanding of what happened, I could have shared my own knowledge of the situation, exploring how participating in the research could develop the schools response to such experiences. This in turn may have enhanced HT2’s motivation to participate. I thus felt that, in the process of gaining access to NDPS, I should have created opportunities to fully explore the significance of the research for the school community.

6.1.2.2 Recruitment and Consent

The practicalities of recruitment and consent changed considerably during this phase of the research. I discussed how HT2 wanted to primarily address these issues in parallel with how they were managed at RCPS. This situation was representative of consultation as opposed to collaborative inquiry, as it involved HT2 requesting and using practice knowledge developed within RCPS rather than participating in a process of negotiating and building such knowledge together. This being said, collaborative inquiry was evident to some extent within the process of considering consent for children. Although HT2 was fundamentally happy to follow RCPS in terms of asking parents/carers to opt their child out of the research, she also felt that, after speaking to the children, I should gain written consent from the parent/carer of any child wishing to participate. Her reasons for this were based on keeping parents included and informed as well as providing an opportunity for them to discuss any issues they may have concerning their child's participation. Although I felt that this decision potentially served to protect the school rather than the rights of the children, it also promoted a culture of openness that kept parents/carers fully informed and included in the school life of their child. This culture of openness was also enhanced by her suggestion to hold a parent/carer information meeting about the research. I felt that both of these suggestions allowed an opportunity to engage parents/carers in conversation on the background to, and significance of, the research, the rights of children and the benefits of participation. I thus agreed with HT2 that these were things we should try and was keen to see how they would work.

HT2's decision to change the children's recruitment process was surprising to me, given that she had been so keen to follow the procedures in RCPS. When I arrived to talk with the children she noted that she had received a "handful of calls" from parents who wanted to withdraw their children. This was mainly due to recent bereavements. She also said that, when the letters inviting parents/carers to withdraw their child were sent home, she had spoken to each class to let them know that, if they wished, they could complete the reply slip on the information leaflet at home, with their parents. This was contrary to what was written in the letter

accompanying the information leaflet, which stated that all children would be spoken to about participation in research on an agreed date, unless they were opted out (see Appendix 2.2). Due to this she had received 11 slips from children wishing to participate, all of which also had their parents'/carers' consent. Rather than speak to all of the children, she thus felt that I should only speak to those with returned slips. I was uncomfortable with this decision, as highlighted in my reflective log:

“I am not sure if this is entirely fair or great practice. Some children and parents may have read the letter and were following the procedure written down, also showing their support [for the research].” (reflective log, 19th April, 2012)

This highlights my concern that the change in process would exclude some children from participating who perhaps wanted to, but were following written instructions. I raised this with HT2, who felt that, because the 11 children had full consent and this number was close to my intended number of children to recruit, we should just stick with this group. This suggests that HT2 had concerns about the sensitive nature of the research and wanted to be certain that parents/carers of participating children were supportive. My concerns, however, were confirmed by the parent attending the Hospice bereavement group, who asked when I would be coming in to talk to her son's class. Had I not been working with this family, the child would not have participated in the research due to following the recruitment process described in the letter. Therefore, although I only recruited 11 children, there were possibly many more that were interested in participating, but were not actually given the opportunity. It is also possible that the sample of recruited children had specific experiences of the research area. Given that they were able to discuss the research with their parents/carers, it is possible that death, dying and bereavement was spoken more openly about in their families as opposed to others.

Similar to the recruitment process for children, recruiting school staff and parents/carers did not proceed as originally negotiated. In relation to school staff, HT2 and I agreed on a date at the initial meeting for me to meet with all staff and discuss the research. This date was set three weeks prior to the actual date to give

HT2 time to inform staff. When I attended the meeting, however, I was told by those present that they had only been informed five minutes previously. The meeting was at the end of the school day and they noted that most staff could not attend due to prior commitments. Some of those attending listened whilst putting on their coats and packing their bags. Consequently, I felt that I had to hurry my discussion so that I did not impinge on their time. Due to this situation I asked both HT2 and those attending to speak with other staff about the research. This process relied on them communicating a clear picture of the purpose of research and what would be involved. Due to a variety of factors I did not ascertain if any other staff members were interested in participating for several weeks. This meant that I was unable to move forward with phase two of the research, as I was unclear if there was enough interest amongst school staff for the research to proceed.

In attempting to recruit parent/carers, HT2 informed me that initially the wrong letter had been sent home and that the correct letter was sent two weeks later. No responses were received. I found this surprising, given that the parent attending the Hospice bereavement group had already noted her interest in participating. Nevertheless, I was enthused by the link to the Support for Learning Parent Group. HT2 informed me that they were happy to hear about the research and possibly participate. When I attended their meeting, however, I was sent away by the facilitators as they said they did not know about my visit and, owing to their plans for the evening, felt it was inappropriate timing. I consequently took the decision not to include parents/carers in the research. This was partly due to time, as it would not have been possible to proceed with further recruitment strategies and speak with parents/carers prior to the school breaking up for the summer holidays. It was also due to the research experience at RCPS, where feedback from parents/carers had said they wanted to be updated about any practice developments rather than involved in their design.

The experience of recruiting research participants at NDPS indicates the priority of the research within the demands of school life. It also highlights the importance of communication in relation to collaborative inquiry. For example, it appeared that how I understood a recruitment processes had been negotiated and decided upon

was sometimes in conflict with how HT2 understood and facilitated these processes. This was perhaps influenced by the fact that little time was spent fully negotiating these issues, relying on strategies developed elsewhere. These situations required a flexible approach to working within the school. Flexibility has been argued as a key feature of action research (Zuber-Skerritt 2011). It was integral to ensuring that I developed a positive relationship with the school whereby the action research could take place. Nevertheless, I would argue that, at times, it served to highlight power imbalances. For example, although I was able to challenge last minute changes to recruiting children, I ultimately had to go along with how HT2 felt things should progress within the school. This emphasised my position as an outside researcher within the school in contrast to the authority of HT2 in any decision-making process.

6.1.3 Reviewing the experience

This phase of the research focused on negotiating access to the school and addressing procedural and pragmatic issues. This was done with HT2, who was the gatekeeper in terms of how and when I was allowed access to the school community. This was undoubtedly an important phase of the research, as it assisted in establishing a relationship with the school as well as determining the research team for future phases of the research. Similar to my experience in RCPS, collaborative inquiry appeared to be encouraged and promoted by my connection to the Hospice and HT2's familiarity with the Hospice children's bereavement service. Being explicit about the collaborative focus of action research appeared to appeal to both HT2 and potential participants. For example, at the initial meeting HT2 already started to suggest ideas about what developed practice might look like. Likewise, at the meeting with school staff members several questions focused on what phases three and four might involve. This enabled me to further emphasise the collaborative nature of the action research process, which in turn prompted staff to immediately suggest ideas for what might be achieved. This dialogue suggested interest in, and support for, the research. Nonetheless, the process of establishing a space for collaborative inquiry was not as straightforward as I had hoped. Negotiated plans concerning recruitment and consent were often changed at the last

minute due to demands within the school that took HT2's time and focus away from efficiently organising and facilitating the recruitment process. This in turn inhibited the process of collaborative inquiry and emancipatory practice by excluding parents/carers and some children and staff from the opportunity to hear about, and choose to participate in, the research.

Despite the recruitment and consent process not going ahead as originally planned, HT2 did continue to try and make alternative plans to ensure the research could progress within the school (such as speaking to staff directly and attempting to arrange alternative strategies to meet with parents/carers). This suggested a commitment to the research, yet I was nervous about going forward as it was clear that HT2 had a busy role within the school and I was unsure how this might impact on any developed practice. Moreover, although I was able to recruit the intended number of staff and children participants, I was disappointed by the lack of opportunities to explore the research with the wider school community. I only spoke directly to 11 children about the research, as opposed to the 78 I was intent on speaking to, and I did not speak with any parents/carers. This meant that there were limited occasions for the school population to get to know me or engage with the research. This lack of openness was perhaps also reflected in HT2's change in plans for recruiting children. Full consent is not needed for other research in the school or to talk to children about subjects such as sex education. This situation suggested that, despite HT2's experience in childhood bereavement, she still had some anxieties in talking to children about these issues. In hindsight, I should have perhaps discussed these concerns with HT2 at the end of phase one, as it was possible that such anxieties may impact on how any practice developments were embraced by the school. I felt, however, that despite the limitations to the recruitment process, the response rate was a positive sign, suggesting interest in the research that would hopefully support further phases.

6.2 Phase two: exploration phase

6.2.1 Descriptive phase

Phase two involved six interviews with school staff, one interview with a child and two focus groups with children. The interviews with school staff lasted 20 to 45 minutes, determined by competing school timetable demands. The interview with the child lasted ten minutes. This child was aged 11 and had additional support for learning needs. The two focus groups involved 11 children, seven of whom were boys and four girls. One group involved six children aged 10 to 11 from across two P7 classes. The other group involved five children aged nine to 10 from across two P6 classes. Each focus group was held in the library and lasted approximately 45 minutes, to correspond with the duration of one class in the school timetable. During the interviews and focus groups participants were also invited to take part in later phases of the research. Participants were informed that it was not yet clear what future phases would involve, but that they could choose to withdraw from participating at any time. All participants indicated they would like ongoing involvement in the research.

Data from the interviews and focus groups were combined with data from the focus groups with Hospice staff. This data was thematically analysed in preparation for phase three, as described in section 4.4.5. Data included recordings from the interviews and focus groups, my reflective log and worksheets completed by the children.

6.2.2 Reflective phase

The interviews with staff, the interview and focus groups with children, and data analysis are all significant in how the research progressed and how collaborative inquiry evolved. In relation to analysing data from this phase of the research, the same process was used at NDPS as was used at RCPS. This is described and reflected on in section 4.4.5 and section 7.3.1. In this section I reflect on the methods used with the different participant groups, exploring how practical issues impacted on these experiences and how knowledge was co-created in each context. I will then review how this phase of the research informed future collaboration.

6.2.2.1 Interviews with schools staff

In phase one of the research, HT2 had agreed to find cover within the school to allow time for participating staff to be interviewed. Two dates had subsequently been arranged so that cover could be arranged and allow participating staff time to prepare. On both of these dates, however, and on an additional date set thereafter, the interviews had to be cancelled due to staff sickness, which impacted on HT2's ability to provide cover. I agreed alternative dates with HT2, yet, when these dates came around it continued to prove difficult to enable participants free time to be interviewed. Only one of the staff members interviewed was provided with someone to cover their duties during the interview. The remaining staff participants were invited by HT2 to make time within their daily schedule to participate in an interview. As a result, two staff decided to be interviewed during their free period, set aside for lesson planning and marking, one was interviewed in their office but was 'on call' and two were interviewed outside their classroom whilst their class completed activities. These two staff members could only allocate 25 minutes to the interview.

The desire of participating staff to remain part of the research despite not being given time within their schedule suggested that they were interested in, and committed to, the research. Nevertheless, none of the interviews felt satisfactory. They were filled with interruptions and some of the participants were clearly frustrated about having to give up their free time after being told they would be given protected time. The staff member who was provided with cover also experienced interruptions during their interview. This included having to change locations halfway through due to confusion around which rooms were free. All of the participants were extremely apologetic about these situations, but they equally appeared distracted and/or discouraged. I would argue that the circumstances of the interviews undoubtedly impacted on the collaborative focus of this phase of the research. Participants did not have ample or protected time to focus and reflect on the issues being discussed. For example, one staff member was interrupted six times during their 31 minute interview by children from her class. Although the staff member was able to deal with the interruptions quickly, it nevertheless took

focus away from the issues being discussed. This arguably led to a less in-depth interview experience. For example, on two occasions I had to redirect the staff member back to what we had been talking about and on one of these occasions she responded, “I don’t know where I was going with that”, resulting in us moving on to the next question. Furthermore, my behavior also changed, as I did not want to impinge on the staff members’ time more than necessary. Consequently, I felt that in some of the interviews I did not allow space for reflection that I may otherwise have. It is possible that I should have been more assertive with HT2 by requesting that I only speak with participants when they had protected time. Nevertheless, I felt, at this stage in the action research, I was a relative stranger in the school and, if the research was to progress, I needed to work within the constraints of the school setting to ensure that it was collaborative and directed by the school, not me. This situation reflects discussions about the challenges associated with facilitating research as an ‘outsider’, where the culture is unknown (Corbin Dwyer and Buckle 2009). It also highlights issues of power in collaboration.

As a result of not being able to find cover to release staff for interviews, it took nine and a half weeks from the initial staff recruitment drive until the first interview. It then took a further four weeks until all staff members were interviewed. By this point the school holidays were due to start and the research had to be put on hold for another eight weeks. This undoubtedly impacted on how collaborative inquiry was developed. For example, one staff member (SS9) was aware that, in her class, she had two recently bereaved children and one whose sister was living with an incurable illness. She thus felt that any practice development would be extremely pertinent to this class group. As she would not be teaching the same class the following school year, she did not want to wait to discuss how practice could be developed with the rest of the research team. She therefore decided to develop her practice innovation independently and requested that I share resources with her that would assist her in planning a lesson around how to cope with grief. I had hoped to be involved in this planning; however, she was so enthusiastic about the lesson that she taught it the next day and reported back to me that it had been “so good” and she will “do it every year”. This situation, however, highlights a barrier to

developing collaborative inquiry in the context of this research design. The teacher was undoubtedly committed to the research issues, yet did not want to engage collaboratively with the rest of the school community as intended in the research design, as she knew she needed to meet the needs of her class group within a specific timeframe. Brydon-Miller and colleagues (2003) argue that participants in action research can become so involved in what they are doing that they lose the awareness that they are part of an inquiry group: there may be a practical crisis, they may become enthralled, they may simply forget. They assert that it is this deep experiential engagement, which informs any practical skills or new understandings which grow out of the inquiry. It appeared that this was the case with SS9; although her enthusiasm had distanced her from the group inquiry, it enhanced her skills and confidence in teaching about death, dying and bereavement. The situation highlights the autonomy that teachers have in their own classroom, being able to implement changes to their own practice and their children's learning experience independently, according to motivation, interest and skill.

6.2.2.1.1 Knowledge generation

The interviews were designed in two parts. The first part encouraged participants to reflect on their experiences related to the research area. This involved participants sharing their experiential knowledge about what they did or did not do related to children, death, dying and bereavement. The second part of the interviews encouraged critical reflection on these experiences in order to generate propositional and practice knowledge which would advance this area of work. The teachers appeared comfortable sharing their experiential knowledge as they were discussing their experiences, of which they were the expert, through telling stories that related to the research issues. This primarily related to re-telling situations when a bereaved child had been in their class. Two of the six participants said that they had never worked with a child who had experienced a "close" bereavement, but that they had worked with children when a grandparent had died. The remaining teachers had all worked with a child who had experienced the death of a parent. Active interviewing allowed me to encourage participants to critically reflect on these experiences, using comments such as:

“What was it about that situation that you found challenging?”

“Was there anything that you found particularly helpful in the situation?”

“Do you think that your approach is different to most teachers’?”

Kim (1999) argues that critical reflection is the starting point for developing knowledge and practice. In some of the interviews participants needed very little prompting to critically reflect on their experiences. For example, one teacher explained how, if a child had time off for a funeral, she would tell the rest of the class so that they knew what had happened,

“but other than that just leave it up the other children to sort of bring it to the fore for discussion. Being a coward [laughs]. Just not knowing how to handle it probably, appropriately, or in a way that’s best for the child.” (SS12)

This shows the staff member sharing their experiences and then immediately going on to critically reflect on how she managed this experience and the gaps in her knowledge which influenced her behaviours. This suggests that providing time for teaching staff members to consider the research area encouraged immediate critical reflection within the context of their experiences. My role in the above example was merely to ask an opening question and then allow space for participants to embark on their own journey of reflection.

The above example also demonstrates how critical reflection on managing bereavement in the classroom prompted greater clarity on the fears and worries around talking about death with children. Such anxieties were connected with how participants perceived a taboo around death and dying as they posed barriers to communication. This was related to staff being:

“Caught between a rock and a hard place, because do you respond as you feel you want to and you think is correct, but will that conflict with what the parent is saying.” (SS11)

“Frightened you’ll do the wrong thing or you’ll make the situation worse or you’ll unduly upset somebody.” (SS12)

“Tread[ing] carefully because different children react in different ways.” (SS13)

Sharing these concerns evidences participants generating propositional knowledge on how they understand the culture of talking to children about death, dying and bereavement in school. This in turn contributed to how practice development ideas were created. For example, SS12 later commented,

“Because you get taught how to do this, that and the next thing but you don’t get any guidance on how to deal with bereavement in school”

Similar statements were made in three other interviews, with staff noting that they had to rely on their own experiences and/or intuition. In these situations the participants were critically reflecting on their skills around managing bereavement and, consequently, noticing gaps in training.

When prompted to think about where death, dying and bereavement are discussed out with the individual experiences of children, none of the participants shared stories about discussing death more generically. One teacher remembered a religious education lesson which discussed how death is managed in all the world religions, but she could not remember teaching this or to which age group. Nonetheless, all of the participants were clear that they felt the curriculum held capacity to discuss death, dying and bereavement as part of the Health and Wellbeing programme within the Curriculum for Excellence. This awareness was prompted by participants applying knowledge about teaching other subjects to the research area. For example,

“Just treat it like internet safety, where it is showing them [the children] that there are steps they can take to keep them safe, so that if it does happen there are things that can help.” (SS9)

This identifies the staff member using experiential knowledge of other subjects in the school curriculum to develop practice knowledge relating to teaching death, dying and bereavement. Likewise, sharing knowledge about how other subjects are taught encouraged staff to consider what age groups might benefit from education on death, dying and bereavement.

“We are supposed to start sex education in nursery so why not start that kind of, introducing it in, because I am sure they will have had pets or animals, or people, neighbours, whoever, you know, what’s wrong with starting it off early at an appropriate level.” (SS12)

This shows the staff member developing propositional knowledge. As a result of providing sex education from nursery to primary seven groups, SS12 could see how education on death, dying and bereavement could be relevant across all ages of the school.

The second part of the interview was specifically designed to enhance collaborative inquiry by inviting participants to define and help solve the research problem. For two participants, however, collaborative inquiry appeared to be established not by how I designed or facilitated the interview, but by the opportunity to talk directly with me. For example, during the interviews, I was specifically asked by both participants for information on the role and remit of the Hospice as they knew little about the Hospice in the community. The information I gave then enabled the participants to consider how they, as a teacher and organisation, could share skills and expertise. Likewise, one of the participants asked for advice and resources on how to work with a child in her class. This initially felt uncomfortable: in my experience of conducting research interviews I only asked questions, reflected on answers and so on. Nevertheless, providing information, education and sharing my own experiences is clearly within the remit of participatory research. At the end of the interview this teacher commented:

“It’s been great because it’s made me think, because there isn’t anything in black and white, say like there is in maths or something, saying that this is what you must do and because of what’s happened [...] it’s not just about having them talk, but helping them with strategies and that’s where the Hospice could really help.” (SS9)

This clearly highlights the active nature of the interview experience. The participant is expressing how her experiential knowledge of teaching other subjects does not compare to teaching about death, dying and bereavement. This leads her

on to generate practical knowledge on what could be done in her class through sharing knowledge and expertise with a Hospice staff member.

6.2.2.2 Focus groups and an interview with children

During phase one of the research, a time had been arranged for me to meet with the child participants. Due to some of the difficulties encountered facilitating interviews with staff, I was nervous that this may not go ahead as planned. I therefore decided to call HT2 the day before, and the morning of, the focus groups and interview to remind her that I was coming. On arriving at the school, it was clear that HT2 was expecting the research to go ahead as planned. Both the staff and children commented that they had been expecting me, and the library had been reserved as a space to use. I was pleased with this, as it meant that the children had been given time to think about the research and their participation prior to my arrival.

Prior to facilitating the research with the children, parents/carers and school staff had been asked to identify any child agreeing to participate with a recent bereavement experience that may affect their participation. With the exception of the boy previously discussed, whom I had worked with as part of the Hospice children's bereavement group, no children were identified. Yet, similar to the children taking part at RCPS, all of the child participants at NDPS had experienced a bereavement, the majority of which in the past two years. These bereavements involved the death of a father, sister, grandparents, an uncle, an aunt, a neighbour and pets. The deaths were due to a number of causes, including heart attacks, serious illness, drug overdoses and suicide. Those children with deceased grandparents, aunts, uncles, neighbours and pets discussed their experiences in relation to their impact on their home lives. Those children with a deceased father and sister, however, discussed the impact of their experiences on both home and school life. I was thus surprised that these children had not been identified to me. This suggests that school staff were either not aware of the impact of the bereavement on the children's school experiences or that they were aware but confident that participating in the research would not negatively impact on them. It is also possible that school staff felt that I would be able to manage any situation

and, although I felt I was able to do this, it would have been helpful to have some insight into the children's school experiences so that I could be fully prepared.

The focus groups were facilitated using the same format employed with the children at RCPS (see Appendix 4.1). I began by describing the purpose of the research and giving each child an opportunity to ask questions as well as withdraw from the research. I then reviewed/established group guidelines in partnership with the children in an attempt to make a safe place for collaborative inquiry, going on to discuss the research questions. Both groups consisted of children in the same year group. This meant that they knew each other and had experience of working in groups together. I was concerned that this would inhibit some group members from speaking due to a fear of how this would portray them in front of their peers. It was not possible to tell if this was the case; however, it did seem that the groups' familiarity with each other and the school environment was a positive factor that encouraged openness and sensitivity towards each other. For example, when negotiating the group guidelines one child said:

“If I'm feeling like I am going to cry I'm just going to go around the corner [to a bean bag area behind a book shelf in the library].” (C32, focus group one)

The child's knowledge of the school environment meant that they were able to identify a safe place to go if needed. This prompted another child to say “same”, whereas others discussed how they would manage their emotions differently:

“I probably wouldn't go [cry] here, cos when my dad told me my sister died I only had a tear in my eye.” (C30, focus group one)

This identifies the group immediately becoming a space where the children openly discussed difficult emotions, such as sadness, as a normal part of life as well as how they manage these emotions. It shows the children relating to each other's experiences, but offering their own stories as a contradictory narrative. Had the group been strangers in a new environment such honesty at such an early point in the focus group may not have been achievable. These comments, however, also suggest that there was an expectation that participating in the research would be

upsetting. This was confirmed by one child commenting at the end of the group that:

“I thought it was going to be a bit uncomfortable, but I was fine.” (C25, focus group two)

At the beginning of the focus groups, all of the children were given an opportunity to withdraw from the research and were informed that they could leave the focus group at any time. None of them did, nor did anyone get upset. The fact that the children still wished to participate despite their initial expectations suggests they were either comfortable with being sad and/or upset in a group setting or that they had specific experiences or issues they wanted to discuss.

The format of the focus groups was used as a basis from which to carry out the interview with C33 (see Appendix 5.2). I found, however, that I had to use more questions to promote and develop discussion about the research area. This may have been, in part, due to the personality of C33, who I was informed struggled to interact with peers and had never participated in an interview. Nevertheless, it was apparent in the focus groups that peer interaction generated a space for collaborative inquiry; as one person finished telling their story about someone who had died this would then immediately lead to another group member telling their story, despite the experiences being very different. In the interview there was not an opportunity for this kind of interaction. Bloor and colleagues (2001) highlight a benefit of focus groups in enabling participants to explore new concepts as opposed to the preconceived ideas of the researcher. Although I actively encouraged the interview to be directed by the experiences of the participant, it was apparent that by using more questions my role was more pronounced in generating knowledge. Conversely, in the focus groups, sharing, listening and responding to others' experiences promoted self-reflection and a more creative exploration of the research.

Winter and Munn-Giddings (2001) argue that action research involves identifying and including people who would like to take part for their own purpose. This was

demonstrated in the interview with C33, who immediately stated that she wanted to take part because,

“It is a nice thing to do because my Granny was in [the Hospice].”

The whole interview involved C33 reflecting on this experience, despite my encouraging a consideration of other experiences and/or situations. Similarly, in a focus group, one child shared the experience of his father dying, beginning the story by saying:

“Well I think everyone knows my dad’s dead, but I don’t know they know how he died [...], because he actually decided to get a knife and stab himself.” (C31, focus group one)

This suggests that the child wanted an opportunity to tell the truth about his father’s death. He continued to talk, in detail, about the night his father killed himself and the following weeks, including what he thought the reasons were behind his death. Sharing his personal story, in detail, appeared to promote collaborative inquiry:

C32: “What did your dad do?”

C31: “That’s how. He got angry and took a knife out. But my mum tried taking the knife away from him, but he just went [makes action] right in his stomach.”

C28: “That must have been scary.”

C32: “How did the police know already?”

C31: “No, she phoned an ambulance. She phoned an ambulance, but the police turned up from the, so I think one of our neighbours might have called.”

This demonstrates the group working with the child to develop a shared understanding of the child’s experience as well as recognising what a difficult experience it had been. This was potentially a cathartic experience for the child, not only because there was an opportunity to let the truth be known, but also because the other group members were empathising with the experience. Theoretical, and my practice knowledge, on childhood bereavement suggests that being able to communicate an honest and confident life story was a possible relief

to this child (Monroe and Kraus 2005; Stokes 2004). Yet, given the level of detail that was being shared I was concerned about the impact of the story on the other group members. Moreover, I was also concerned about protecting C31's right to confidentiality out with the group. There is a great deal of stigma surrounding death by suicide and, by making his story known, such stigma may negatively impact on how the death of C31's father is perceived by others which, in turn, would impact on C31. Once this group had finished I therefore reiterated confidentiality guidelines, made HT2 aware of what had been shared, and offered one-to-one support to any of the group members if needed. No one requested further support and HT2 commented that there had been no issues, either with individual participants or in class, after the group had finished. Nevertheless, I have no evidence if confidentiality was ensured or any knowledge about how the child felt after sharing his story.

My experience of working with the child participants drew my attention to the different aspects of children's lives. This was particularly due to the child discussed above, who was also participating in the Hospice children's bereavement group. In the bereavement group, he had shared only basic information in comparison to the level of detail he shared in the focus group. It is possible that our pre-existing relationship encouraged such openness. It is also possible, however, that participating in a group with peers rather than strangers with similar experiences (as is done in the Hospice bereavement group) was key in establishing a safe place to share detailed stories. In the initial evaluation of the children's bereavement group, meeting others who had also experienced bereavement was identified as important and enjoyable (Paul and Freeland 2012). Nevertheless, the research experience suggests that creating space for children to share their bereavement stories, and develop a coherent story, with peers is significant. This is in line with arguments for health promoting palliative care, which Kellehear (2005) argues should focus on practice which supports and enables people to manage their experiences within the context of their specific personal community.

6.2.2.2.1 Knowledge generation

Similar to the interviews with school staff, the interview and focus groups with children were designed in two parts. The first part encouraged sharing and reflecting on stories relevant to the research area. The second part aimed to promote consideration on if and how practice could be improved. Parallel to the focus groups at RCPS, there appeared to be a lack of exposure to conversations about death, dying and bereavement in school and it was challenging for participants to remember any specific conversations and/or lessons. In the interview and one focus group the participants could not think of any examples where a teacher had discussed death. In the other focus group, the initial response from group members had been:

C25: “No”

C26: “Never”

C22: “Never”

C27: “They never talk to us about it or anything.”

(focus group two)

After allowing time to further reflect on this question one child remembered their teacher talking about her dead cat which, in turn, promoted memories in other group members:

C23: “[says teachers name] talks about death as her cat only died a couple of years ago, and that’s all she ever”

C27: “She said her cat is the closest thing to death.”

C26: “Didn’t she say she’d like her dad to come back up again.”

C24: “Aye”

C27: “Yeh. She talks about her dad being dead.”

C24: “But that’s the only teacher who has ever said anything.”

C27: “Don’t really go over death at all.”

(focus group two)

This clearly demonstrates the participants working together to capture their experience in the classroom by validating and building on each other’s memories. This story then prompted other group members to discuss how their class had read ‘The Boy in the Striped Pyjamas’, which involved talking about Jewish deaths during the war.

Due to a lack of exposure to conversation and education on death, dying and bereavement in the classroom, participants primarily talked about personal experiences of bereavement. For example, in the interview, C33 could not remember any discussion with her teachers about death and so talked about her grandmother’s illness and death. This involved reflecting on the experience and generating theoretical knowledge about why the adults around her behaved the way they did:

“It’s just not to let them [the children] get really upset.”

I discussed how, in the focus groups, one child’s story promoted another child’s story. For example, one participant commented that he had not been told about his Grandfather’s death until five years after the event. This story was immediately followed by a participant saying that he had not been told his Uncle had died until two years later. The act of generating bereavement stories during the focus group meant that the participants were individually creating knowledge about their own lived experiences. This involved sharing and reflecting on what had happened in order to develop a coherent story. In the above example, the child who was not told about his Grandfather later stated:

“They [adults] usually keep it a secret, because they don’t want you to become sad and get all emotional.” (C27, focus group two)

This highlights the child using his experiential knowledge to generate theoretical knowledge to understand his personal experience about why adults do not always talk to children about death. The other participants not only listened to the stories,

but also actively engaged in the storytelling by asking questions that helped clarify what was being said. Such questions appeared to focus on the details of the death, including how the person died, the name of the illness and if the person knew what was happening. The process of storytelling thus evidences participants co-creating knowledge together. The questions allowed the group members to gain a clearer understanding of the story being told, whilst enabling the storyteller an opportunity to define their own knowledge and develop a coherent story of the experience.

In the focus groups, telling stories allowed personal experiences to be brought together and compared. This was most apparent in the group with two children who had experienced the death of someone in their immediate family:

C30: “The worst thing is when somebody dies and you come back to school and they all crowd around you.”

C29: “Exactly.”

C30: “That’s what they done when my sister died, they all crowded around me.”

[...]

C29: “I was off for about 2/3 months, I came back on a Friday [...] I remember [says a pupils name] coming up to me and shouting ‘where you been?’ and then a big big big big big crowd surrounded me. I just, I was just about to hit, kick, punch, get them away.”

(focus group one)

This example shows how the focus group provided an opportunity for the participants to affirm each other’s experiences of bereavement in school. Similar to the interviews with school staff, I encouraged critically reflection on these experiences to promote knowledge generation. For example, in the above situation I encouraged the children to consider how their experiences could have been better. Both said that they would have liked to have been left alone and for the other children to act normally, with nobody,

“whispering about me and pointing at me and staring at me.”
(C30).

This suggests that the children’s class could have been prepared for their return to school by being informed about appropriate behaviours, in line with their wishes. It identifies how practice knowledge is developed through collaborative reflection on experiential knowledge. A further example included one participant explaining that,

C24 “My mum’s best friend’s husband, he’s dying of cancer and he is going to die in a few weeks and they said that they’ve not told the kids yet or that.”

Me: “Right. [pause] And what do you think about that?”

C24: “I think they should tell their children.”

Me: “Why?”

C24: “So they don’t get as upset when...”

C27: “When he does die.”

C24: “They need to know and they then can get ready for it.”

(focus group two)

This demonstrates how I attempted to encourage C24 to critically reflect on their experience and consider alternative practices. By considering the experience, C24 was able to advocate the rights and needs of children in relation to serious illness and bereavement. Both examples highlight the importance of participatory approaches in research focused on change. In the first example, the participants evidently had a challenging experience in school after their bereavement and it is important that these experiences are given a voice when thinking about changing practice. In the second example, the participant considered the needs of children in relation to the research area based on their experience. Likewise, it is important that this knowledge is shared with people, such as teaching staff, who are ultimately in a more powerful position.

The second part of the interview and focus groups was focused on developing practice knowledge. In both focus groups the children worked together to generate ideas that were adapted and designed according to input from the different group members. This appeared to be an exciting process for the group members, who often appeared quite animated as they offered their suggestions:

C30: “A club, a club, a club.”

C32: “Yeh.”

C28: “Yeh.”

C32: “A death club.”

C30: “Yeh, a death club.”

C29: “I don’t think anybody would want to go to that. It doesn’t have a good name.”

C31: “Unless they were into death metal and they would just think it was a music club with death metal.”

C28: “It could be a class.”

C32: “Science.”

C28: “And it could be like about talking death.”

C32: “If anybody wanted to.”

(focus group one)

This example shows every group member contributing their ideas to developing practice. It identifies practice knowledge being co-created as the participants build on each other’s thoughts about what could be done. Discussing running clubs versus using science classes also highlights participants using their experiential knowledge of the school environment to develop feasible practice knowledge. Moreover, by C32 inferring that the class is optional, thus taking into account the possible sensitivity of the topic and the needs of different pupils within the school, propositional knowledge is also developed and incorporated. In the interview, C33 had to rely on her own creativity and knowledge to generate practice ideas. This involved using her experiential knowledge of the Hospice, which she thought was

“a bit scary”, to develop practice ideas that might enhance this experience. The idea entailed creating a video that children would understand “that tells you about that, like death and dying”.

6.2.3 Reviewing the experience

This phase of the research provided opportunities for participants to share and develop their knowledge in relation to the research area that would inform the following phases. The interviews encouraged participants to reflect on, and challenge, current practice as well as consider developmental areas. The focus groups provided opportunities for participants to explore and develop the research area together, working towards a shared understanding about how practice might be developed. Several issues arose, particularly in relation to interviewing school staff, that impacted on how collaborative inquiry was established and developed. This made me question the extent to which HT2 was committed to ensuring that the research developed, collaboratively, within the school. This experience demonstrated to me the significance of working with external agencies where the leadership style and culture is unknown. Yet, this experience also alerted me to how my own practice knowledge evolved in relation to working with external agencies. For example, at the end of this phase of the research I recognised that I actively needed to take responsibility for ensuring that the research took place by continually prompting HT2 to ensure that everything was in place for when I attended the school.

Kemmis and Wilkinson (1998) argue that choosing research methods that are most suited to the environment and/or participants, is an essential factor in a successful action research project. Being flexible was important, as it allowed me to use research methods more suited to different individuals, such as interviewing a child. Yet, I found this experience much more challenging to promote and develop collaborative inquiry, thus confirming my decision to use, primarily, focus groups with children. The information gathered during this phase of the research, however, provided significant material to be reviewed and negotiated during phase three of the research.

6.3 Phase three: planning and developing a model(s) for possible intervention

6.3.1 Descriptive account

HT2 and the Hospice Chief Executive Officer (CEO) decided who, from their respective organisations, should be involved in this phase of the research. HT2 felt that all staff involved in phase two should attend due to their commitment to, and possible involvement in, taking any practice developments forward. She agreed that child participants could be involved during later phases. The Hospice CEO felt that only she should attend due to her position in, and knowledge of, the organisation. She agreed that other participants from the Hospice could be involved during later phases. A group meeting was therefore set up and the findings from phase two emailed to participants one week in advance (see Appendix 15). This included a list of themes generated via data analysis as well as a list of suggestions, provided by participants, for future practice. Due to sickness on the day of the meeting, both the CEO and one school staff member were unable to attend. The Hospice Director of Operations (DO) attended in place of the CEO. Both the CEO and the school staff member requested that they were kept informed about what happened at the meeting and included in later meetings and/or phases of the research. Through a process of discussion and negotiation, three actions were chosen to be taken forward. These included:

1. Develop activities to use alongside the schools current Hospice fundraising initiative that inform the children about the role of the Hospice in the community and how money raised is spent.
2. Develop bereavement training for school staff.
3. Develop a workshop for parents/carers on the role of the Hospice and the bereavement needs of children.

This meeting was held in November 2012. Table 2 shows the plan, which was negotiated at the meeting, to take forward each action. All of the children who participated in the research, and were still attending the school, were notified about

the decided actions and asked for feedback. They were also informed that the teaching staff involved in taking forward action one (develop fundraising activities) may invite them to be involved. All participants were happy to do this if needed. At the time of writing, the actions were ongoing and it was intended that they would be reviewed and evaluated within existing organisational procedures. Appendix 16 includes an overview describing what took place at each site after this phase of the research.

<u>Action</u>	<u>Plan</u>	<u>Timescale</u>	<u>Person Responsible</u>
1. Develop activities to use alongside the Hospice's 'Schoolfriends' fundraising initiative that inform children about the role of the Hospice in the community and how money raised is spent.	School staff to develop activities to do in the school. Ideas include: wall display; memory tree; and assembly. Sally and/or DO to be contacted if more information and/or marketing material is needed about the Hospice.	December 2012/January 2013	NDPS staff research team. Sally and DO as and when needed.
2. Develop bereavement training for school staff.	Show training developed with RCPS to research team at NDPS. Amend as necessary	January 2013	Hospice DEPDR staff member, Sally and research team at NDPS
	Pilot and evaluate training	March 2013	Hospice DEPDR staff member and Sally
	Write up evaluation findings and share with Hospice management team to discuss ways forward	Summer 2013	Hospice DEPDR team, management team and Sally
3. Develop a workshop for parents/carers on the role of the Hospice and the bereavement needs of children.	HT2 to discuss possible parent/carer workshop with parent and get back to Sally about the best way to take this forward.	December 2012	HT2

Table 2: Action plan for practice innovations

6.3.2 Reflective phase

This phase of the research specifically invited school staff members and the Hospice DO to develop practice knowledge through a process of collaboration. This involved reflecting on and critiquing knowledge gained in phase two of the research to consider how practice might change and/or be developed. I felt that HT2's decision to include staff in this phase of the research indicated a collaborative approach to developing practice. It recognised the importance of their views, skills and expertise and allowed opportunities for collaborative inquiry that would not have been possible if only management staff had been involved, for example, by staff advocating for innovations to be taken forward due to their own knowledge of what is possible within their actual experience of school life as opposed to a management overview. Having only the DO and me from the Hospice, however, meant that there was much more representation from the school than from the Hospice. When the meeting was first discussed with the CEO this was not viewed as an issue. In the meeting I felt that this was also the case as DO's confidence and awareness of the research, coupled with my role and familiarity with the school staff, meant that we were able to contribute equally.

Three and a half months passed between phases two and three. This was due to a break for the summer holidays and HT2 working part-time as an acting head teacher at another school. This situation made it difficult to contact HT2 to arrange for the research to continue. I felt that the length of time between phase two and three took focus away from the research. I had hoped that emailing the findings from phase two in advance of the meeting would overcome this. I believed it would allow time for the participants to re-familiarise themselves with their own involvement of the research and that of the other participants. Yet, when the meeting started, it was apparent that a number of participants had not read the findings and I therefore had to dedicate time for these staff members to do so. This situation challenged collaborative inquiry as it meant that some of the participants were individually trying to retrieve, readdress and reflect on their thoughts instead of collectively.

Similar to the experience at RCPS, I would have preferred to include children in this phase of the research. It was clear, as the meeting progressed, that school staff

participants often neglected the voices of the children, becoming focused on their own relationship with the research findings rather than that of the children. For example, at one stage the DO asked:

“Just for my own information, in terms of, what your sort of approach is at the moment if one of the kids loses his parent or grandparent? I’m just interested in that comment where one of the kids is saying that he had come back to school and it was kind of like “tell us what’s happened? What’s it like?” It must be a very difficult.”

The DO was referring to a situation mentioned in the information given to participants from phase two (see Appendix 15). This involved two children discussing their return to school after a significant bereavement where they became surrounded by their classmates, in the school playground, all wanting to know what had happened. One school staff responded, saying:

“I think it’s down to the individual teacher, because fortunately it doesn’t happen that often, so it’s not really an everyday occurrence that you need to focus on.” (SS12)

This prompted a discussion about what each of the individual school staff members did if they had a bereaved child in their class. Although the discussion was helpful in generating experiential knowledge, I felt that it failed to specifically explore the lived experience of the child participants. Having the children present in this phase of the research may have made their experiences more powerful. Similarly, when I directed participants to consider the information presented from the children, they responded based on their own experiences and understandings:

Me: “I put quite a lot of information about the kids stuff. Did you have chance to read it?”

HT2: “It worried me about the video games. Because that’s not real.”

SS8: “It’s also quite violent.”

SS13: “Having two teenage boys, it’s not the same thing.”

SS11: “I don’t think the line is quite so clear when the children are younger.”

This demonstrates participants considering the children's experiences alongside their own experiential and propositional knowledge. Including children would have allowed them to translate their own experiences of death and dying in video games, which may have critiqued or challenged that of the adult participants, thus generating a deeper understanding of the issue. Likewise, including parents/carers in the action research would have also allowed a deeper understanding of the research. Practice development three (a parent/carer workshop) was identified by school staff and, I would argue, was therefore not genuinely participatory-borne; as no parents/carers were involved in the research it is not possible to ascertain if this action was needed and/or wanted.

Interestingly, in five of the six interviews with school staff, participants commented that only some staff members discussed death, dying and bereavement, according to individual comfort levels. All staff identified strong links for teaching about death, dying and bereavement within the Curriculum for Excellence as part of the health and wellbeing curriculum and suggested this as an area for practice development. Yet, in the meeting, the consensus was that school staff routinely taught about these issues and developing practice in this area was not viewed as necessary. It is possible that being in a group allowed a deeper exploration of practice within the school. For example, early on in the meeting HT2 commented that school staff members did talk about death in response to the experiences of the children, in the media and in Religious and Moral Education. This contribution may have encouraged participants to reflect on, and acknowledge, times when they did discuss death, dying and bereavement. Nevertheless, it is also possible that the role and presence of HT2 impacted on what staff felt comfortable to share and challenge. This draws attention to power imbalances in collaborative research and how they may affect the quality of knowledge generation in action research. Kemmis and Wilkinson (1998) argue that action research should involve challenging assumptions and testing out things that are taken for granted. On reflection, I could have challenged HT2's viewpoint by highlighting the interview experiences. Yet, at this stage in the meeting, I was just getting to know the group dynamics and had hoped that the other participants would feel comfortable to share

conflicting experiences. This highlights a challenge to facilitating action research within organisations, where the dynamics, leadership style and culture are not completely known.

6.3.3 Knowledge generation

Heron and Reason (1999) claim that, in collaborative inquiry, expressing experiences (experiential knowledge) through stories (presentational knowledge), understood through theories which make sense to the individual and/or group (propositional knowledge) and expressed through action (practice knowledge) serves to validate knowledge. Creating an opportunity for school staff and a Hospice staff member to come together revealed these concepts of knowledge generation and highlighted the purpose of the meeting in both validating and generating practice knowledge. This was pertinent numerous times during the meeting. For example, several school staff shared their experiences and ideas around working with a boy whose Grandmother had died over the summer holidays:

SS13: “I took it from his lead.”

HT2: “It was the parents that weren’t coping and the child was really manifesting their lack of coping.”

SS12: “But this poor wee sod is maybe just holding together. I don’t want to be the one that’s tipping him over the edge.”

This demonstrates the staff members sharing their experiential knowledge going on to discuss and develop propositional knowledge, i.e. how they understood the situation and their role. The DO responded to this story by sharing his experience of encouraging adults to write wills:

“Legacies are a huge thing for us at the Hospice, people leaving money in wills, and we were trying to find the best time for people to broach the subject [...]. You can write a happy will and you can write sad wills.” (DO)

By sharing this story the DO reflected on how his practice knowledge and experience with adults might be relevant within the context of the school. This

prompted HT2 to consider and validate existing practice knowledge in schools, saying:

“I think you do that in schools. People die in the media and we will come in and talk about it. Pets particularly, and it’s almost like a natural conversation and the children accept that, because it’s not contrived.” (HT2)

This process shows knowledge from different individuals within their respective organisations being brought together, compared and confirmed.

It was apparent during the meeting that the participants were aware of the collaborative purpose of this phase of the research and the focus on developing practice knowledge. At one point in the meeting the DO directly asked:

“If you could have anything to help bring this subject forward, do you have any ideas on that what might be?”

The other participants responded by discussing their experiences with bereaved children and specifically where they needed help.

SS8: “The thing that concerns me is, I’ve had lots of children in my class who have lost grandparents, but I think parent’s is different. I think that’s when I would feel out of my depth and think ‘I need help here’.”

HT2: “I’ve had a number of parents who have died, but every single circumstance has been different and there isn’t a I don’t think there is a model you could put on to fix it.”

This example identifies participants using the meeting as an opportunity to share experiences, with propositional knowledge being presented and developed that focused on generating practical knowledge. It also highlights the variety of personal experiences that are brought to the meeting, emphasising the purpose of the research in co-creating knowledge through collaboration with others.

O’Brien (2001) asserts that the researcher’s role at this phase of the research is to primarily enable a mutually agreeable outcome for all participants that requires creating a space where all experiences and opinions are valued. On hearing the above comments from school staff, I was aware that there had been several

concerns raised, in both this meeting and in phase two, from school staff about talking to children around death, dying and bereavement. Moreover, I was cognisant of how the children's experiences were managed in the school, particularly in relation to returning to school after a bereavement. I was thus keen for participants to give these issues some attention and commented:

Me: "I think there are two things here though, just listening to you, there is that bit about how the child copes and manages that grief and that can be different for every single child, as it is for adults, but there is also that bit about how you respond as a teacher, straight away, or you know short term, medium term, even long term."

My input appeared to confirm worries, as two participants immediately shared their concerns about not wanting "to do anything wrong" (SS13) or "make a horrible situation even worse" (SS12). This in turn led school staff participants to consider how the Hospice may be able to share their expertise in supporting children experiencing bereavement and support them in related conversations. This included exploring the potential role of the Hospice in equipping school staff with the skills and confidence to initiate conversations where religious and spiritual beliefs are different and/or unknown. Both the DO and I recognised the ability and expertise of Hospice staff to address these issues, thus leading to the development of practice development two (bereavement training). This demonstrates collaborative inquiry working to allow experiences, skills and expertise to be acknowledged and change processes initiated to share and address associated strengths and limitations. Furthermore, this situation identified the unique overview that I had of the different voices in the research and my role in both generating knowledge and promoting collaborative inquiry.

The concerns that school staff participants shared about talking to children impacted on how they conceptualised initiating conversations about death, dying and bereavement. It was apparent that school staff worried that they would begin a conversation, but then realise that it was "not the time to do that" (HT2) because someone had experienced bereavement and this may negatively impact on the child. This propositional knowledge was key in developing practice development one. As

the meeting progressed, the school staff thus came to a consensus that the concept of death, dying and bereavement should be introduced to children as a seamless part of school life:

HT2: "It's not something you can drop into conversation."

SS12: "No, you're right."

SS11: "I think, if they ask."

In the second part of the meeting, when I invited participants to consider their discussion, the development of this propositional knowledge was thus integral to how practice development one was developed:

HT2: "We're doing that £10 thing [the Hospice's 'schoolfriends' fundraising project]"

DO: "Oh yeh."

HT2: "And some of the pupils have done it already, by enterprise, have got some money, so we could actually genuinely take something to the Hospice, which would be a start wouldn't it?"

SS12: "That's a good idea. And then the children that go could come back to assembly, you know present it to the whole school, you could invite some parents."

SS13: "I'm thinking like even getting the [school] radio involved."

SS12: "Yeh."

HT2: "We could interview somebody from the Hospice. We could come to the Hospice and do that?"

DO: "Absolutely."

Me: "So using fundraising as an opportunity to ..."

SS12: "It's one way in. It doesn't need to be the only way in I suppose, but maybe for us it is an opportunity."

SS8: "It seems most obvious, logical. It's not contrived."

This discussion demonstrates the focus from participants on incorporating education about the role of Hospice in a way that “has to make sense” (SS13). This meant using existing opportunities within the school rather than developing discrete activities. The conversation went on to discuss and negotiate how both school staff and the Hospice could support such practice. It evidences participants building on each other’s contributions to develop the initial practice idea into something that was acceptable to everyone. This involved school staff recognising opportunities within the school that could be utilised and going on to engage in a process of negotiation with the Hospice DO to work out how such opportunities could be maximised. It is this process of creating a space to develop a consensus and/or shared understanding about what to do which Kemmis (2001) argues is part of the action research task. It shows participants reflecting and building on their personal and organisational experiences through a process of collaboration.

6.3.4 Reviewing the experience

When I undertook this phase of the research I had already completed the same phase at RCPS. I was excited to see how different the developments would be in NDPS, given that school staff participants were also included. I had presumed that this would be more collaborative. I had not considered, however, the potential impact of having HT2 present or how to maintain the voice of the child when there were so many adults. Several authors describe the action researcher as an integral part of the change mechanism (Hockley et al. 2013; Gray 2009). This experience highlighted the significance of this argument, clearly identifying my role in both facilitating change and ensuring the level to which this phase of the research was inclusive. Similar to RCPS, NDPS also decided to take forward three practice ideas. I felt comfortable with this decision, based on my experiences at RCPS, and because practice development one (bereavement training) would operate in parallel with the activities at RCPS. I was unsure about practice development three (develop a parent/carer workshop) as this had been decided in the absence of parents/carers. I was thus keen to see how, and if, it would develop.

6.4 Summary

This chapter described and reflected on the action research process at NDPS. I discussed how access to the school was arranged and how participants were recruited and their consent to participate was achieved. I specifically identified HT2's role as integral to this process, which, due to competing demands meant that, at times, the research seemed to move much slower than hoped and appeared somewhat disorganised. I discussed the challenge of recruiting children and suggested that this was, in part, due to some anxiety about the sensitive nature of the research. I also highlighted the difficulties of recruiting adult participants and suggested that this was somewhat influenced by the wrong materials being sent home and time constraints. I suggested that both of these experiences draw attention to the importance of communication and emphasised the importance of adopting a flexible approach. At each phase of the research I considered how knowledge was co-created and how collaborative inquiry was promoted. I discussed the process of deciding practice developments, which was in essence collaborative but excluded the voices of children and parents/carers. I highlighted my role in challenging this and how, therefore, the knowledge generated was influenced by me in collaboration with participants.

Chapter 7: Discussion

This chapter brings together the two action research processes completed at RCPS and NDPS into one explanatory framework. I begin by summarising the practice innovations chosen at each site, exploring what they suggest for the role of the Hospice in working with primary schools and how they interact with theoretical debates, discussed in chapter two, on the taboo of death, dying and bereavement. I then discuss these activities alongside the principles of health promoting palliative care and Kellehear's 'Big Seven Checklist' for genuine health promoting palliative care activities, discussed in section 3.2.1. As the process of action research was extremely important in determining how the practice developments occurred and how they do, or do not, continue to progress, I go on to review the action research approach, exploring the strengths and limitations.

7.1 Practice innovations

In the previous chapters, I discussed the action research process at two different primary schools. Both research sites identified three practice innovations to take forward. An additional practice idea, discussed in Appendix 16, was also identified by the LA Education Services as a result of the action research process at RCPS. The activities are summarised in Table 3, which, for ease of discussion, have been numbered from one to seven.

Given the scale of this research and the methodology used, the practice innovations do not provide any finite conclusions concerning the role of Hospices working with school communities more broadly. They are site-specific and as a result only identify the role of the Hospice working with that particular school. Yet, when brought together, it is apparent that there are a number of similarities across the different activities. Two of the practice innovations were replicated in each school: (3) and (5) (use fundraising events as an opportunity to inform pupils and staff about the role of the Hospice) and (2) and (6) (provide bereavement training to school staff). This is significant given that the ideas were generated at each school without any knowledge of what was happening at the other school.

	Practice development	Description	Lead responsibility
RCPS	(1) Integrate health and death education throughout the curriculum.	Create and implement an education programme that integrates education on health, illness, death and bereavement into the curriculum across all ages.	School
	(2) Provide bereavement training for school staff.	Design and facilitate a bereavement training programme that provides information on childhood bereavement and the skills to manage related issues, where appropriate, in the school setting. The training is aimed at all school staff, including teachers and support staff.	Hospice Department of Education, Practice Development and Research (DEPDR) and Social Work staff
	(3) Provide information about the Hospice during the Hospice's 'Go Yellow' fundraising event.	Develop materials to use with the Hospice's 'Go Yellow' annual fundraising event. The materials should inform school staff and pupils about the role of the Hospice in the community and how money raised is spent.	Hospice Fundraising Team
NDPS	(4) Carry out activities about the Hospice during the Hospice's 'Schoolfriends' fundraising event.	Develop a series of activities for school children about the role of the Hospice that can be carried out when participating in the Hospice's 'Schoolfriends' fundraising event.	School
	(5) Provide bereavement training for school staff.	Adapt the bereavement training programme designed with RCPS (practice development two) to suit the needs of NDPS. Facilitate with all school staff.	Hospice DEPDR and Social Work staff
	(6) Provide a parent/carer bereavement workshop.	Establish need for a parent/carer workshop on the bereavement needs of children and the role of the Hospice in the community. Develop and facilitate workshop.	School; Hospice DEPDR and Social Work staff
LA Education Services	(7) Develop a bereavement policy	Develop a LA schools bereavement policy. The policy should include specific guidelines on how to respond to bereavement in a school community.	LA Education Services and Policy and Development Team

Table 3: Summary of practice innovations

This indicates that there were commonalities in how the different schools perceived working with the Hospice to be most helpful. Moreover, despite being developed at a denominational and non-denominational school, none of the practice ideas assign themselves to a religious framework. This is interesting given that both the literature and staff participants, at RCPS and NDPS, highlight that religion ‘offers answers to the problem of death and reflect[ing] on the nature of the afterlife’ (Puolimatka and Solasaari 2006, p.203) and thus provides a structure from which to develop conversation and education with children. The practice innovations suggest, however, that the denomination of the school was not significant in determining the activities and should not impact on how the Hospice works with primary schools. This finding is perhaps representative of the Curriculum for Excellence and the Hospice being inclusive of all belief systems.

In chapter three, I discussed the DEMOS report *Dying for Change*, which asked for a ‘Big Society’ response to improve end-of-life care experiences (Leadbeater and Garber 2010, p.16). It identified four kinds of public and social practice innovations to achieve this. These are innovations that improve, combine, reinvent or transform. In relation to the Hospice: ‘improving’ is based on the Hospice developing existing service delivery; ‘combining’ involves the Hospice making better connections with community services; ‘reinventing’ involves the Hospice evolving to do a radically different job; and ‘transforming’ involves creating effective alternatives to hospice care to enable people to create their own solutions to managing death, dying and bereavement. Although this research set out to improve service delivery, with the exception of practice developments (3) and (4) (develop existing fundraising initiatives), all of the activities are concerned with radically transforming practice in school communities to better manage death, dying and bereavement. Practice developments (3) and (4), however, also involve improving current service delivery. This suggests that the relationship with me as Hospice representative and the process of action research assisted in mobilising the school communities to consider and improve their response to death, dying and bereavement.

All of the practice innovations directly respond to advancing practice that supports and/or educates children on death, dying and bereavement. If, as Walter (1991) argues taboo refers to something that is prohibited or forbidden I would argue that this challenges the concept of death as a taboo. The practice innovations identify that, in school communities, death is not prohibited, forbidden or unmentionable but subverted due to a variety of influences. In chapters six and seven I discuss some of these influences. For example, the child participants encouraged education and support around death and bereavement but recognised that adults may feel unable to do so due to fears about causing upset. This was also acknowledged by adult participants. Behaviours which may prompt children to become upset thus appeared to be considered forbidden and this, in turn, inhibited conversations and education on death, dying and bereavement. Such experiences were compounded by a lack of guidance (policy and curriculum) and training on how to teach about and support experiences related to death, dying and bereavement. Although this situation strengthens the death as a taboo argument, by providing evidence of death-denying policies and procedures, the practice innovations actively challenge these practices.

Based on the seven practice innovations (see page 186), I would argue that three key themes can be identified according to the goals and method of each activity. These include: raising awareness of hospice care and end-of-life care issues more broadly; education and training; and providing leadership in death education and bereavement. The themes are summarised in Table 4, which offers a model for practice with school communities. I will discuss the themes separately, exploring what this suggests for the role of the Hospice working with primary school communities and how they are concerned with the contested taboo of death, dying and bereavement.

Role of Hospice	Goal	Method
Awareness Raising	Dispel myths associated with hospice care, end-of-life care and bereavement.	Fundraising campaigns: practice innovations (3) and (4). Education and training opportunities: practice innovations (2), (5) and (6).
Education and training	Increase awareness of childhood bereavement. Develop capacity of school staff and/or parents/carers to manage childhood bereavement within the school setting and at home.	Bereavement training for school staff: practice innovation (2) and (5). Bereavement workshops for parent/carers: practice innovation (6).
Leadership in death education and bereavement	Influence policy makers and/or management teams to establish death, dying and bereavement affirming activities, policies and procedures.	Engage with school communities to raise awareness of end-of-life care issues: practice innovations (2), (3), (4) and (5). Work with school staff to develop a death-affirming curriculum: practice innovation (1). Work with school staff to develop bereavement policies and procedures: practice innovation (7).

Table 4: Role of the Hospice in working with primary schools: a model for practice

7.1.1 Raising awareness

Raising awareness and providing education could be discussed under the same banner, as education undoubtedly involves a level of awareness-raising and vice versa. In the context of the practice innovations suggested, however, raising awareness is limited to informing staff, children and parents/carers about the role of the Hospice and/or end-of-life care issues, whereas education focuses on raising awareness coupled with skill development. Across the different practice

innovations, raising awareness was primarily linked to using fundraising events as an opportunity to educate fundraisers on the role of the Hospice and dispel associated myths (practice innovations (3) and (4)). Fundraising is integral to the Hospice, given that £3.5 million need to be raised per year in order for existing service provision to continue. As a result, fundraising activities permeate a variety of community groups and are constantly evolving to maintain the interest of potential fundraisers. It was apparent during phase two of the research that, if the research participants did not have personal experience of family members using the Hospice, the main reason they knew of the Hospice was via fundraising campaigns. Parent/carers, school staff and child participants could all recall Hospice fundraising campaigns run in the school, yet they were not able to recall discussing the Hospice when participating in these events. For example, one child at NDPS remembered being given a Hospice magnet after participating in the 'Go Yellow' schools fundraising event, but was unsure what the Hospice did. It was also apparent that there was no guidance and/or direction from management staff in the school and/or the Hospice fundraising materials to use fundraising events to talk about the Hospice. This links to Allan and Burrige's (2006) argument that taboos are linked with avoiding certain behaviors or practices through social cohesion. Although school staff may not have been specifically avoiding conversations about hospice care, without explicit direction to do so, the common practice in the schools was to raise money for the hospice without raising awareness. This situation identifies how a status-quo was maintained that diverted focus away from discussions and education on hospice care and the importance of developing practices that challenge this.

At both schools, several staff participants acknowledged that they probably had the "totally wrong perception" (SS2, RCPS) of what the Hospice is and does. This was viewed as a barrier to discussing the role of the Hospice with children. Nevertheless, doing so was identified as a natural extension of participating in fundraising events:

"It seems most obvious. Logical. It's not contrived." (SS11, NDPS)

Through participating in the research, school staff participants at both schools thus began to view fundraising events as missed opportunities to share the work of the Hospice and end-of-life care more broadly. These events were highlighted as allowing staff to incorporate such education seamlessly into the curriculum without needing to create a discrete module of lessons, or a lesson that may seem artificial. This demonstrates that, through fundraising, the Hospice has existing relationships with school communities that could be optimised to ensure that the role, remit and philosophy of hospice care is brought more to the fore. This was also identified as resulting in more effective fundraising:

“It probably means they [the children] are going to be much more engaged and it is possibly more meaningful for them.”
(HT1, RCPS)

Fundraising thus becomes a “vehicle [...] to explain, you know, what the Hospice is about” (CEO, meeting at RCPS). It potentially requires a reorientation of the goal of fundraising within the Hospice that views related activities as having a dual role: raising money and awareness.

Raising awareness of the Hospice was also suggested as being relevant to practice development (6), develop a parent/carer workshop. This initiative was highlighted as having a double purpose, whereby education on childhood bereavement could be provided alongside a discussion about the role of the Hospice. This also became relevant to practice developments (2) and (6), provide bereavement training. The purpose of this training was initially focused on the bereavement needs of children and was not concerned with transferring knowledge about the role of the Hospice other than highlighting the childhood bereavement service. However, in the process of developing the training with RCPS (discussed in Appendix 16), the seminar room at the Hospice was suggested as a space to facilitate the training as opposed to using a room on the school premises. This offer was accepted, prompting some school staff to ask if they could receive a tour of the Hospice. A tour was thus arranged and offered to all the staff, the majority of whom decided to take part. As a result, a tour was also offered after the training with staff at NDPS and similarly the majority of staff took part. This illustrates how providing

education became an opportunity to raise awareness of the role of the Hospice, allowing participants to learn about, and experience, the Hospice first-hand. This was suggested as also being relevant to children, as one teacher commented:

“If I’ve been [to the Hospice] then I tell them [the children]. If you teach me, I teach them.” (SS13, NDPS)

This identifies opportunities within education and training, offered by the Hospice, to simultaneously raise awareness about the role of hospice care.

7.1.2 Education and training

Hospice staff providing education and training to school communities was an integral aspect of practice innovations (2) (5) and (6). Practice innovations (2) and (5), bereavement training, involved Hospice staff educating school staff on childhood bereavement as well as the skills and techniques needed to meet the bereavement needs of children in a school setting. Practice innovation (6) involved Hospice staff working with parents to share information about childhood bereavement as well as dispelling any myths associated with hospice care. This practice development required school staff identifying a need for such education within their parent/carer community and inviting Hospice staff to meet this need. In both contexts, the role of Hospice staff was highlighted as transferring professional knowledge and expertise related to childhood bereavement and hospice care with the aim of equipping school communities to cope with death and loss. Developing training challenges the death as a taboo argument as it emphasises the rights and agency of children to be included in support and education about death, dying and bereavement, recognising that children are shaped by their experiences and environment.

The emphasis on Hospice staff providing education is in keeping with the modern Hospice movement. As mentioned in chapter one, teaching and research have always been an integral part of the modern hospice movement. The Hospice has always had an education team (currently the Department of Education, Practice Development and Research - DEPDR), providing education and training on end-of-life care and bereavement to a variety of professionals. These programmes are

designed by the DEPDR or in response to specific request from community groups. In relation to childhood bereavement, it has offered both a two-day childhood bereavement course aimed at all professionals working with children and tailor-made training sessions at the request of particular groups, including schools and social work departments. The uptake on the two-day course has been low for the last few years and, anecdotally, potential participants have commented that they either do not have the funding or the time to attend. In the process of designing and piloting practice innovations (2) and (6), discussed in Appendix 16, cost was not discussed perhaps due to the nature of the research which was based on a reciprocal process of sharing knowledge and expertise. Time, however, was identified as an area of conflict. This was because Hospice staff felt that at least one day was needed to cover the identified training needs, whereas staff at both schools felt that they could only dedicate two hours. This two-hour window was due to limited opportunities within the school timetable for training, competing training demands and the relevance of the training to their current class/school situation. This highlights the importance of collaboration in designing education programmes to ensure that training programmes meet the needs of both organisations.

In both schools, faith was discussed by staff participants as a barrier and opportunity in relation to providing bereavement support to children. In the interviews with school staff, having a religious foundation and/or knowing about a child's religion was discussed as providing a framework from which to discuss bereavement. For example, one staff member comments:

“Having a faith made a difference as well. So you've kind of got some ... you know, when I am talking to my boys, it's connected with ... you've got ideas of heaven and God and all the rest of it, and I think in some way for us, for me, that's made it easier to explain. Working in a Catholic school you can do that as well.” (SS1, RCPS)

Conversely, discussing bereavement with a child whose religion was unknown was described as more challenging owing to the need to be “politically correct about everything” (SS11, CPS), and not using any references linked to certain faiths which may conflict with what the child has been told at home. This situation was

relevant in RCPS as, although it is a denominational school, staff members were aware that some children and their families were not Roman Catholic and their faith was unknown. This situation links to Elias's argument (1985) that the process of secularisation has supported the death as a taboo thesis by removing guidance on what is, or is not, appropriate behaviour. By not having a known framework from which to discuss death and bereavement staff were immobilised. During the process of developing the bereavement training (discussed in Appendix 16), school staff requested guidance from Hospice staff about how to approach such conversations without challenging a child's personal belief system. This further illustrates the role of Hospice staff in sharing their expertise and experience to enable school communities to open up discussion about death, dying and bereavement that is sensitive to a variety of religious and spiritual frameworks.

7.1.3 Leadership in death education and bereavement

Providing leadership relates to the role of Hospice staff in influencing death and bereavement affirming activities, policies and procedures. This specifically relates to practice innovations (1), integrate health and death education into the curriculum and (7), develop a bereavement policy. School staff members were solely responsible for taking these activities forward. The role of Hospice staff was to provide leadership and guidance on best practice. For example, in practice development (1), discussed in Appendix 16, RCPS established a working group to develop a curriculum of which I was invited to be part. It was clear that, due to the school staff's familiarity with the curriculum and expertise in developing age-appropriate activities, my role was less concerned with developing ideas and more about noticing gaps where activities did not affirm death or when opportunities were missed to develop coping strategies related to loss and change. Once the curriculum was developed, I agreed to be contacted on an as-and-when basis if staff felt they needed support. This highlights school staff viewing me as having expertise in this area and identifies the leadership role that Hospice staff have in promoting and encouraging death-affirming activities. Similarly, practice development (7) was generated as a result of my presence in RCPS, which served to raise the profile of the bereavement needs of children, prompting management

staff to notice a gap in policy. A Hospice volunteer and I were consequently invited to be part of a working group that sought to develop a LA schools bereavement policy. We were specifically asked to provide input as Hospice representatives, using our experiences to share best practices in bereavement support for children. This demonstrates the role of Hospice staff in simultaneously raising awareness of, and providing leadership in, good practice around bereavement support. If, as discussed in the literature review the taboo of death is defined by its setting, this includes actively challenging death-denying policies and practices which may reinforce death as a subject to be avoided.

Providing leadership also became relevant to practice developments (3) and (4), develop fundraising to raise awareness of hospice care. Both schools decided on different approaches to do this. At RCPS, this activity was led by Hospice staff. Child and staff research participants provided initial support by suggesting ideas on how to most appropriately raise awareness of the Hospice in the school. The fundraising team were then responsible for initiating these suggestions alongside their fundraising campaigns. Conversely, at NDPS this activity was led by school staff. Hospice staff completed fundraising as usual and school staff independently developed activities to raise awareness of the Hospice, aware that Hospice staff could provide support, such as information and materials to aid activities, as and when needed. In Appendix 16, I discuss how a leaflet was created by child participants at RCPS, which was then sent out to all school pupils participating in the 'Go Yellow' fundraising event. I also discuss how the research team at NDPS, to my knowledge, never piloted any activities. This seemed to be due to a lack of time from staff to develop such activities, despite prompts from Hospice staff. These experiences suggest that, if fundraising is used to raise awareness of the role of hospice and end-of-life care, the Hospice fundraising team has a key role in providing leadership. This involves encouraging and guiding school communities by identifying fundraising as opportunity to discuss hospice care, explaining why it is important and equipping school staff with the tools (information and activities) to use such opportunities.

7.2 Health promoting palliative care

In chapter three, I discussed the move towards public health approaches to palliative care. I specifically highlighted health promoting palliative care activities as seeking to develop community capacity in end-of-life care and bereavement. Through the process of conducting this research it could be argued that the Hospice is taking a health promoting approach to service delivery by considering its role beyond direct service provision to develop work that is more sensitive to the needs of school communities. Kellehear (2005) argues that this is fundamental to health promoting palliative care, as it involves the Hospice exploring its role in, and working towards, broader social change in relation to issues around end-of-life care and bereavement. An example of this involves how school staff began to change their perception about Hospice care by participating in the research. For example, when I initially entered NDPS, I was continually referred to by one staff member as 'Dr Death'. This staff member believed that that the Hospice was a place where everybody dies. She said that she wanted to avoid me as every time she saw me someone she knew died. This demonstrated to me the stigma that is associated with hospice care and that, by association, I also represented. Through the process of conducting the research, however, this staff member slowly began to interact with me and we became engaged in conversations about the role of the Hospice and what happens to people who go there. This highlights that by using research opportunities to engage with school communities, the Hospice contributes to dispelling negative imagery around hospice care.

This research did not set out specifically to create health promoting palliative care activities. Such practice and its significance in end-of-life care was discussed as a basis from which to explore and critique practice developments arising from the research process. It was also a contributing factor in choosing an action research approach, which I argued paralleled the ideology of health promoting palliative care. Nevertheless, by considering the process, goals and ownership of the practice developments taken forward, I would argue that these innovations are representative of health promoting palliative care activities. I will therefore address how I view the practice developments to be relevant to health promoting palliative

care under the three themes discussed previously. I will then go on to illustrate how these practice developments address Kellehear's (2005) 'Big Seven Checklist' for health promoting palliative care activities, as identified in the literature and demonstrated through the research experience.

7.2.1 Health promoting palliative care and raising awareness

Kellehear (1999) asserts that health promoting palliative care seeks to 'alter community attitudes to a wider range of ideas that have attracted negative imagery' (p.78). It was apparent during the research that some participants did not clearly understand what the Hospice did or held negative views of the service it provided. This identified a variety of negative images and/or ignorance about hospice care, which are potentially unhelpful in conceptualising end-of-life care issues. This concept was strengthened by the CEO who noted that:

“The vast majority of people who come to the hospice will actually tell us they wish they had come sooner. And they resist it, because it's where you go to die and it must be sad and it must be gloomy and it must be awfully depressing.” (meeting with HT1, RCPS)

This suggests that ignorance or confusion about the role of the Hospice can be a barrier to accessing hospice services. Practice developments (3) and (4) identified that Hospice fundraising initiatives were an opportunity to raise awareness of the Hospice and tackle such negative imagery. Providing materials alongside fundraising events was identified as a way in which information could be communicated to school staff, pupils and parents/carers. Holding school assemblies when participating in fundraising activities was also identified as a way in which school staff could further inform children about hospice care. Both of these ideas attempted to develop positive attitudes towards hospice care by providing accurate information. Such actions have been classed as a health promoting palliative care activities by other authors (Salau et al. 2007; Gallagher 2001).

Providing information to community groups is opportunistic work that does not focus on promoting community capacity in end-of-life care, but is significant in drawing attention to issues relating to end-of-life care and bereavement (Sallnow and Paul 2014). Providing written materials to school communities has cost implications for the Hospice and therefore relies on the Hospice management team prioritising funding for this. The extent to which such information is shared with school children and their families, however, relies on school staff having the time and motivation to do so. This is equally relevant to school staff holding assemblies to inform children about the Hospice. School staff participants noted the importance of discussing the role of the Hospice when fundraising, yet a number of barriers were simultaneously identified. These included staff having recent experiences relating to end-of-life care, bereavement and/or the Hospice, as well as personal opinions about whether or not children should be involved in such discussion. Thus, although the Hospice can provide information and support to raise awareness of hospice care, school staff members have control over whether or not this is done, which is a limitation to the success of these activities. I would assert, however, that providing information about the Hospice to school communities is a health promoting palliative care activity. It promotes and encourages openness about hospice care which may, in turn, positively impact on how people discuss and/or consider such care, whether or not this information is accessed and used. Furthermore, it gives school communities a choice around whether or not this information is shared, which they did not have previously. Kellehear (2005) argues that a goal of health promoting palliative care is to draw attention to end-of-life care issues. I would assert that ensuring information about hospice care is available and appropriate to school communities is a step towards this goal.

7.2.2 Health promoting palliative care and education provision

Education is a central feature of health promotion. According to Downie et al (1996) the significance of education in health promotion is in 'seeking to enhance positive health and to prevent or diminish ill health through influencing beliefs,

attitudes and behaviour' (1996, p.49). Education is also identified by Kellehear (1999) as a goal of health promoting palliative care and involves 'providing education and information for health, dying and death' (p.19). Education was a key factor in practice developments (1), (2), (5) and (6). Across these practice examples, education sought to promote openness around death, dying and bereavement whilst also developing personal resources and community supports to cope and adapt when such experiences occur. This relates to Huber and colleagues' (2011) definition of health which is based on 'the ability to adapt and self-manage in the face of social, physical and emotional challenges' (p.11). Conway (2008) argues that this is a key factor in health promoting palliative care, which seeks to develop personal and community capacity to manage and cope with end-of-life care and bereavement.

Practice developments (2), (5) and (6) were focused on the Hospice providing education to school staff and parents/carers that aimed to encourage compassionate behaviours towards bereavement both at home and in school. It can thus be asserted that these practice ideas focus on enhancing the social experience of bereavement for children. Kellehear (1999) argues that the social aspect of end-of-life care and bereavement is a key, and often neglected, aspect of health promoting palliative care. Working with people who have daily contact with children is significant in developing supportive communities. Moreover, adults have been identified as negatively impacting on children's experience of loss by refusing to discuss such issues (Monroe and Kraus 2005; Smith and Hunter 2008). Equipping the adults involved in children lives with the skills to approach such issues may, therefore, positively affect children's experiences. This is highlighted by one teacher, who comments:

"I think that there is definitely a need for something [training] at the school, I think, to help teachers to help pupils." (SS11, NDPS)

This identifies a potential cascade of knowledge and support. Educating school staff, and parents, thus seeks to transfer professional bereavement knowledge and develop confidence to empower school communities to engage and support children

through bereavement. This develops community capacity in bereavement support, broadening the impact of the role of hospice care. It may also potentially ensure that support from external agencies is appropriate and timely. Such practice identifies the role of the Hospice operating alongside Conway's (2008) two models for a health promotion approach to palliative care, which encourages services to focus on direct support (a reform model) and enabling community support (a reorientation model). By offering bereavement training the Hospice can be seen to promote equity in bereavement care through developing support in the community as well as offering individual support to those who meet defined referral criteria.

Petersen and Lupton (1997) criticise health promoting activities for determining the type of society we should live in by defining acceptable and non-acceptable behaviors. They assert that such activities can isolate people who do not sign up to the set of values and behaviour promoted. The action research approach attempted to counteract this power imbalance by encouraging and enabling areas of conflict to be raised and negotiated. This was specifically during phase three of the research, which allowed space to develop a consensus about the most appropriate ways forward according to the values and experiences of those involved. Nevertheless, when piloting the bereavement training, discussed in Appendix 16, it was clear that this was an issue. One staff member commented that she did not want to engage with the materials as this would make her think about things she did not want to. She also did not feel that it was her role to talk about bereavement with children. In the group exercises it was evident that this staff member was alone in her thinking and, although the training sought to include differing views and perspectives it primarily encouraged school staff to address bereavement with children. This potentially served to minimise the staff member's views and concerns. It relates to Downie and colleagues' (1996) argument that health promotion activities are concerned with values and, therefore, any intervention may be perceived as a threat, which can affect the success of any activity. Kellehear (1999) argues that reorientation towards end-of-life care issues is a goal of health promoting palliative care so that people can be prepared to cope with personal changes. It could be argued that by participating in the training the staff member was being encouraged

to participate in such reorientation. Nevertheless, it is questionable to what extent this individual wanted to take part in this process. If health promoting palliative care is responsive to community needs, then individual views also need to be respected.

7.2.3 Health promoting palliative care and providing leadership in death education and bereavement

The practice developments affirm that the expertise and experience of Hospice staff places them in a key position to provide leadership in issues related to end-of-life care and bereavement. Kellehear (1999) argues that providing leadership that seeks to combat ‘death-denying health policies and attitudes in the wider society’ is a key goal of health promoting palliative care (p.27). This is an essential aspect of practice developments (1) and (7). Practice development (1) requires school staff to teach about death as a normal part of life, supporting children to develop skills associated with managing change and loss. This was considered relevant to children throughout their entire curriculum and across all ages. Teachers are described by Thornton and Krajewski (1993) as primary role models for children, responsible for teaching a body of knowledge and life skills that should include developing healthy emotional responses. Providing education on death and how to cope with loss and change seeks to achieve this. James and colleagues (1998) argue that the curriculum is a social process which maps out the whole school experience. One staff participant commented:

“If it’s in the curriculum, the bottom line is we teach it.” (SS13, NDPS)

Including death education in the curriculum therefore attempts to ensure that such teaching takes place. School staff taking ownership over how this teaching is developed ensures that it is sensitive to the needs of the school. The Hospice role was to provide leadership by supporting staff to develop curriculum materials and the skills and confidence to teach. I would argue that this is health promoting palliative care, as the activities of both Hospice and school staff attempt to address death-denying practices by ensuring that death is included in the curriculum as a normal part of life. In relation to practice development (7), develop a bereavement

policy, the role of Hospice staff was firstly in raising awareness of bereavement issues in school communities and then providing leadership around best practice. Developing a bereavement policy to be implemented across the whole LA requires that all schools acknowledge and respond to bereavement in a particular way. This establishes a benchmark from which every school should respond to bereavement and is essentially a death-affirming policy, as it recognises the impact of bereavement in a child's life.

The two practice developments discussed above involve school staff members being completely responsible for taking the activities forward, with Hospice staff providing leadership and guidance on best practice. In the spectrum of community engagement for end-of-life care services (Sallnow and Paul 2014), these activities can be argued as falling under the banner of empowerment. This involves school communities taking full control of the activities, developing their own responses and calling on external agencies when needed. This was made explicit during my maternity leave. After a seven month break, I returned to this PhD to find that both developments had continued to progress without any input from me or the Hospice. Empowering practices are identified by a variety of authors across public health, community engagement and palliative care fields as achieving greater community capacity in the area it addresses (Conway 2007; Kellehear 2005, 1999; Sallnow and Paul 2014). These practices therefore align themselves to Kellehear's (2005) argument that palliative care providers are well positioned to develop community capacity, but should not have the sole responsibility for delivering such activities.

7.2.4 Practice developments and the 'Big Seven Checklist'

In chapter three, I highlight Kellehear's (2005 p.156) 'Big Seven Checklist' which is designed to help understand genuine health promoting palliative care activities. It identifies three key aspects of health promoting palliative care, at least one of which all of the activities must align themselves with. These are: preventing social difficulties; harm-minimising or early intervention. Activities must also positively change an environment; be borne and/or nurtured by the community; be sustainable; and evaluative. Although I would argue that some of these questions

are open to interpretation, the checklist offers a broad platform from which to understand and develop health promoting palliative care. This breadth is necessary, given that experiences of death, dying, and bereavement can feature across a variety of circumstances, communities and environments and, therefore, so can health promoting activities. It is important, therefore, to consider the checklist in relation to the practice developments identified through this research to both explore the extent to which they meet Kellehear's definition of health promoting palliative care and identify areas for development.

Table 5 outlines the seven questions, detailing how I consider each practice development to meet the specified criteria. With the exception of practice development (6), provide parent/carer workshops, all of the practice developments complete the checklist. This suggests that they can be viewed as genuine health promoting palliative care activities. There are a number of gaps under practice development (6), primarily because this activity has never been initiated and it is therefore difficult to anticipate if and how it might progress. Moreover, in chapter six, I argued that it was not genuinely participatory borne. This therefore means that it does not meet the guidelines for health promoting palliative care.

The majority of the developments meet all of the first three questions on the checklist due to their focus on establishing death and bereavement as a normal human experience, seeking to develop individual and community capacity to cope with such experiences. For example, practice development (1), curriculum development, relates to what Rowling (2003) deems as external agencies having a preventative role with school communities. This includes activities designed to educate and support children so that they are better able to cope with loss and change. I have argued, however, that practice developments (3) and (4), use fundraising to raise awareness of hospice care, can only be understood as an early intervention due to their focus on informing as opposed to empowering.

'Big Seven Checklist'	Practice Examples:				
	(1) Curriculum Development	(2) (5) Bereavement training to school staff.	(3)(4) Fundraising to raise awareness	(6) Parent/carer workshops.	(7) Bereavement policy.
<p><i>In what way does/can the project:</i></p> <p>1. Help prevent social difficulties around death, dying and loss? or</p> <p>2. Harm-minimise difficulties we may not be able to prevent around death, dying, loss or care? or</p> <p>3. Be understood as early interventions along the journey of death, dying, loss or care?</p>	<p>- Health and death education is part of the syllabus (1,2,3)</p> <p>- Open culture of talking about death and loss (1)</p> <p>- Children aware of issues related to death and grief before they happen (2,3)</p>	<p>- Develop skills and confidence of school staff to address bereavement (1,2,3)</p> <p>- Develops culture on supporting bereaved children in school (1)</p> <p>Raises awareness of bereavement needs of children (2)</p> <p>- Raises awareness of specialist support to be accessed when needed (2)</p>	<p>- Introduces hospice care to school communities (3)</p> <p>- Uses accessible, child friendly language (3)</p>	<p>- Develop skill and confidence of parents/carers to notice and address bereavement (1,2,3)</p> <p>- Raises awareness of bereavement needs of children (2)</p> <p>- Raises awareness of specialist support to be accessed when needed (2)</p>	<p>- Establishes culture of supporting bereaved children in school (1)</p> <p>- Raises awareness of bereavement needs of children and provides guidance on how to meet these needs (2,3)</p>
4. In what ways do these activities alter/change a setting or environment for the better in terms of our present or future responses to death, dying, loss or care?	Establishes death as a normal part of life. Develops skills to manage loss and change.	Assists in creating a responsive and supportive bereavement culture in school.	Assists in breaking down stigma of hospice care.	Assists in creating a responsive and supportive bereavement culture in school and at home.	Establishes a supportive bereavement culture in all schools in the LA.
5. In what way are the proposed activities participatory borne , partnered and nurtured by community member?	Action research	Action research	Action research	Action research	Action research
6. How sustainable will the activities or programmes be without your future input?	Rolling programme in school	Led by Hospice DEPDR. Ongoing training needs identified by school.	Led by Hospice fundraising team.		Ongoing policy, implemented across all schools.
7. How can we evaluate their success of usefulness so that we can justify their presence, their funding and their ongoing support?	School audit and evaluation procedures.	Led by Hospice DEPDR.	Led by Hospice fundraising team.		School audit and evaluation procedures.

Table 5: The practice developments and Kellehear's' (2005) 'Big Seven Checklist'

In relation to question four (alter an environment for the better), it is not possible to tell how the practice innovations will change the school environment until they are fully evaluated. Nonetheless, by considering the purpose of the activities, it can be assumed that their main intention is to raise awareness of end-of-life care issues or improve how schools respond to loss and bereavement, both of which aim to positively affect school communities. This question, however, highlights a key criticism of health promoting activities. Pomerleau and McKee (2005) assert that such activities assume 'that it is justifiable to constrain the freedom of one individual to benefit the population as a whole' (p.10). Health promotion is therefore not value free and systemically changing an environment, for example by policy and curriculum development, prioritises one value over another. This demonstrates the significance of question five, that all activities are participatory borne, but also suggests that there is value in developing activities that are local and relevant to specific community groups rather than more broadly.

Initially, question five (participatory borne activities) seemed an easy question to fulfil, given that the innovations were a result of action research which focuses on developing practice which is shaped and owned by community members. Yet, although all of the activities were identified by research participants, parents/carers were not involved in choosing practice innovation (6), parent/carer workshop. Instead, this development was identified by school staff during phase three, who argued that it would be a beneficial practice development for their parent/carer community. It could therefore be argued that this activity was not fully borne by community members. This identifies power within communities which can influence how practice is shaped by determining and responding to need without actually involving the people the practice is aimed at.

It can be argued that all of the activities are sustainable, therefore addressing question six, as it is planned that all of the innovations will continue without my ongoing involvement. At the time of writing it is not possible to say if this is the case, as some of the activities are still in the process of being developed. Practice developments (1), curriculum development, and (7), policy development, will be incorporated into existing school frameworks and because of this it is likely that

these two developments will be sustainable. This, however, is not a feature of all activities and as I will not be involved in all of the activities there will be no external facilitator to maintain the momentum of the work. Instead, these activities will rely on motivation, and time available, of the responsible staff. A challenge in initiating activities that seek to empower communities to develop and carry out activities is then the extent to which such activities can be supported and monitored. If focus continues to be placed on developing health promoting palliative care activities, it is important therefore that systems and procedures are in place for acknowledging, reviewing and sharing these activities.

Question seven (evaluate success) was difficult to answer as the practice developments are led by different groups of people (Hospice fundraising and DEPDR staff and school staff), and the level to which these groups prioritise evaluation is unknown. It is likely that practice developments (1), curriculum development, (2) and (5), bereavement training, and (7), policy development, will be evaluated, because they have pre-existing evaluation procedures. Yet, the purpose of these evaluations may not always be linked to the success or usefulness of the innovations. For example, the Hospice DEPDR always evaluates participant experience after any training programme, yet it does not always evaluate if and how the training has been put into action. Lupton (1995) criticises health promoting activities for often being short-term and below the threshold to make sustainable effects. This suggests that, when developing health promoting palliative care activities, focus should be placed on the purpose and method of evaluation from the beginning so that this can be incorporated effectively, including measuring the impact of such activities.

7.3 Reflecting on action research: strengths and limitations

The methodology chapter argued that adopting an action research approach was integral to ensuring that this research focused on both collaborative inquiry and practice development. For me, this was a new way of researching and thus this thesis is the product of two journeys: exploring and developing practice and experimenting

with a new methodology. Literature on action research highlights the importance of being led by the needs of participants and thus I was prepared for this research to evolve in ways I had not considered. I discussed in chapters five and six how, from the initial recruitment phase of this research, the research design was challenged and adapted differently in each school and how this continued throughout the research. Thus, although the same action research process was initiated at each school, it occurred differently according to a number of factors. In the following section, by exploring these factors, I discuss the strengths and limitations of action research in the context of this study. These include: research design and methods; leadership and culture; missing voices; time; external factors and use of self.

7.3.1 Research design and methods

Much of the literature on action research emphasises that the research questions and/or problems should be directed by research participants. The methodology chapter described how I began with an initial set of research questions, which were adapted during the course of the research. Through the course of conducting the interviews and focus groups it became apparent that these questions were not relevant and/or a priority to the research participants. For example, I initially asked how the principles and practice of health promoting palliative care encourage and facilitate a new approach to death, dying and bereavement for children in Scotland. When I raised this with participants they were unfamiliar with health promoting palliative care as a concept and, although I was able to give an explanation of this, their focus was on exploring practice relevant to them and their school rather than a particular theoretical model. Coghlan and Brannick (2001) argue that this is a necessary feature of action research, as what appears to be clear at the outset may change as the project unfolds. It was therefore more fitting that, if this research was to explore the principles of health promoting palliative care, this was done in relation to the decided actions and not the other way round. This experience related to Chiu's (2006) argument that action research is concerned with the creation of knowledge rather than discovery. In this research, the original questions thus provided a framework to develop a research proposal to engage with the schools. The action research approach allowed this pre-determined focus to be deconstructed and

then reconstructed in a way that was acceptable to the participants. This identifies the multi-disciplinary focus of the research, which progressed in a way that was appropriate to the schools and Hospice. A strength of action research is then that the initial problem can change as the research focus emerges. This is confirmed by Carr and Kemmis' (1986), who assert that, because action research has to respond to a variety of conditions, its development must be pragmatic, uncoordinated and opportunistic.

Several authors highlight that there is no single method most suited to action research (Sanders and Wilkins 2010; Levin 2012). In phase two of the research, I argued for the use of interviews, focus groups and thematic analysis, as I felt that these methods would help develop a relationship with the research team, establish a platform for collaborative inquiry and maintain momentum in the research process. Nevertheless, these methods were chosen by me, which is in contrast to participatory research. During the research I repeatedly questioned the choice of analysis for data emerging from phase two. I had initially intended for this process to be negotiated with participants and carried out accordingly, so that what was presented was constructed in collaboration. It became apparent, however, that there was not enough time to facilitate participant analysis of all the data in any meaningful way within the time-frame allowed. This time-frame was set by the limits of my secondment from work, the PhD time-frame, and the impending school summer holidays, after which some of the child participants would go to secondary school and would be no longer able to participate. I thus devised four themes from which to understand the data. I felt this would enable me to synthesise a large amount of data from a range of perspectives, which could then be presented back to participants to stimulate debates about the analysis, create new interpretations and develop practical solutions. Yet, my analysing the data meant that I was presenting my interpretation of the data, which may not truly reflect participant views. Likewise, although I developed a framework from which to write up the research findings that focuses on collaborative inquiry, in writing this thesis I primarily present one account of the research, that is, my own. I would argue that these decisions were due to the constraints of a PhD and my own inexperience with action research. I could have experimented with different

methods, analysis and ways to present this data, which further promoted collaborative inquiry and emphasised the variety of voices included in the action research process. Despite these decisions, however, I would also argue that, by presenting and reflecting on my own account of the research, I have been transparent in describing and critiquing how collaborative inquiry was established and engaged in change processes.

7.3.2 Leadership and culture

In the context of this research, leadership within the schools was primarily provided by the head teachers and the CEO at the Hospice. Although all of these individuals verbally expressed their commitment to the research, differences in their leadership styles impacted on how the research progressed. For example, HT1 took a pragmatic approach to ensure the research took place, such as hiring a supply teacher to make sure school staff were free to participate. HT2, however, was more relaxed in her approach, hoping that other school staff would be free to provide cover for participants. Arguably, both approaches demonstrated a supportive school community, as the head teachers recognised that staff participants needed support to take part in the research. Nevertheless, HT2's relaxed approach was less effective in ensuring that the research moved forward in a timely fashion as it did not consider external factors, such as staff illness. As a result, the interview schedule had to be changed several times, which was frustrating for both the staff and me. This identifies the importance of recognising what Healy (2005, p.12) refers to as constraining and liberatory effects of power in action research, as this study relied on the head teachers exercising their power in order for it progress.

The above examples identify the significance of power from key players in shaping the research process. Coghlan and Brannick (2001) argue that power dynamics are a common feature of action research and that managing such issues is more important than 'rigid adherence' to how the action research cycle might work (p.86). At several points in the research I had to decide if I was going to challenge these power imbalances by addressing the issues with those in leadership roles or work with their decision making. For example, I discussed in chapters five and six the decision not

to include children in phase three of the research. Jones (2003) argues that when children are involved in research, the power relations that exist between child and adult may prevent equal participation. The researcher therefore has a responsibility to ensure that the adults are committed 'to the seeing that children are not separate from the worlds they inhabit' (Jones 2003, p.116). Both head teachers expressed reasons why it was more appropriate for management to be involved in this decision-making and, having already discussed the involvement of children concerning previous issues such as gaining consent, I felt that I had to accept this decision. I thus found myself being the voice of children. The power of those in leadership positions in relation to decision-making therefore determined the extent to which the research was collaborative as well as shaping my role in the process.

Despite the different leadership styles, I would argue that the cultures within the organisations were similar. All staff involved in the research were cognisant of the management role and it was clear that they did not want to make significant changes to their practice without first gaining approval. Brydon-Millar et al. (2003) highlight that, when conducting an action-orientated process, many organisations remain hierarchal and operating democratically and inclusively can be challenging. I have described the challenges of creating participatory structures, for example when no children were allowed to participate during phase three. This also became an issue when developing practice, as it was decided by the CEO that fundraising staff should not be involved in developing ideas (3) and (4) (use fundraising to raise awareness of hospice care), due to a recognition of the pressure they were currently under. Although this is a justified reason, it potentially situates the voice of fundraising staff as a low priority in developing practice that directly impacts on their role. Coghlan and Brannick (2001) assert that 'any action research project which involves separate departments working together must take account of how each department has its own concerns, its own view of the world, its own political interests in the work project and even its own terminology and language' (p. 22). Therefore, excluding fundraising staff may result in developing practice that is not suited to the concerns, skills and culture of that department. This identifies the challenge between

participatory research practices and real life research, where organisations are subject to competing demands.

7.3.3 Missing voices

This research is context-specific. It represents the action research approach at RCPS and NDPS and therefore excludes other primary schools in the Hospice catchment area. The methodology chapter outlined the reasons for this choice of research design. It is worth highlighting, however, that different accounts might have been heard if I had recruited different schools and different participants. For example, it is possible that the head teacher's in the participating schools were more supportive of the research issues than those who refused. Similarly, only a small number of parents were recruited to participate and these parents may have been more open to the research area. The missing voices of those who did not participate may, therefore, have had a completely different contribution to the research. This needs to be recognised by the Hospice when taking forward any practice ideas that may impact on other primary schools. It suggests that further action research cycles are essential to ensure that these practice developments are evaluated and adapted accordingly in partnership with those they impact on. Moreover, the research initially set out to explore the experiences of children in P6 and P7 classes, yet the practice developments are not class-specific. For example, practice development (1) (curriculum development) is aimed at children from nursery to P7 (age five to 12). Although this decision arose from the input of both children and staff at both schools, children from these other classes were not included in the research and therefore their voices are missing. It would have been challenging to include the voices of children across this range in any meaningful way, yet, in taking forward this practice innovation it will be important to do so. Again, this stresses the importance of repeated cycles of action research to continue developing these activities appropriate to the population they serve.

Gaventa (1993) refers to action research as 'guerrilla research', in that it attempts to expose and confront those in powerful positions (p.36). I discussed in the methodology chapter that this was pertinent to this research, which attempts to

challenge children's exclusion from issues related to death, dying and bereavement. Furthermore, action research focuses on democratic forms of decision-making and it was intended that this focus would ensure that any practice developments were responsive to the needs of the school communities rather than my own and/or the Hospice. I therefore sought to include the voices of all those who may be involved in any practice innovations (hospice staff, school staff, parents and children), recognising that certain power imbalances existed and working to confront these. This goal, however, was not easy due to the leadership and culture within the organisations discussed above, which determined the extent to which the research was collaborative. As a result, I felt that the voices of those in management positions were prioritised during key decision-making within the study, with the voices of children, parents and staff underrepresented. I discussed in chapters five and six my attempts to enable meaningful participation and my role in advocating the views of those voices which were not physically allowed to participate in phase three of the research. Had I had more experience in action research, it is possible that I may have been able to offer alternative methods to ensure more meaningful participation from all the participants. For example, Fern (2011) established an 'expert consultant' role, whereby she held consultation meetings for children to inform key stages of the research, such as data analysis, forming questions and so on. Yet, the speed in which decisions sometimes had to be made within the research meant that I did not always have time to fully consider alternative approaches.

Makhoul and colleagues (2013) identify that meaningful participation should not be expected of all the research participants at all the phases of the research. They argue that building trust and respect is more important, so that the research can progress. I would agree with this, as it enabled the research to progress and potentially developed trust by evidencing my awareness of the different issues involved in developing practice. Nevertheless, I would argue that prioritising some voices over others could negatively impact on the success of the practice developments taken forward. For example, the voices of parents/carers were completely excluded at NDPS, yet practice development (6), develop a parent/carer workshop, was identified based on school staff identifying a need for training and education within this

population. Had parents/carers at NDPS been involved, this would have created a more holistic understanding of their experiences and opinions that would, in turn, inform more holistic changes to practice.

7.3.4 Time

In PhD research, it is usual to have one year for data collection, yet, trying to fit a complete action research cycle into this year and within the school timetable was not possible. This challenge was exacerbated by changes in the schools, discussed below, and by being employed by the Hospice, where it was expected that I return to full-time work after three years and with a completed PhD. On reflection, I would assert that fuller consideration needed to be given to this issue prior to embarking on this research. For example, when I started writing this thesis in my third year, the practice developments had only just been chosen. It felt dissatisfying to be in a position where I could only write up to this stage, given I had intended to write up to phase five, pilot and evaluation. Being on maternity leave meant that I was able to extend writing this thesis and enabled more time for the practice developments to evolve. This potentially enabled me to retain my involvement with the research more so than if I had returned to my position in the Hospice and had to balance competing workload demands. Moreover, the length of time taken to initiate phase two meant that some of the children involved in the research were moving to secondary school and would no longer be able to be part of the research. Although I discussed this with them, it felt unsatisfactory to be taking forward their ideas when they were unable to be involved in how they were facilitated. Nevertheless, based on my experiences, the length of time it took to facilitate the research was also positive. It allowed relationships to be forged and collaborative inquiry to be established that assisted in developing practice which is sensitive to the community's need.

7.3.5 External factors

In the findings chapters and Appendix 16, I discuss several events which impacted on the progress of the action research. This included: staff sickness, which delayed both ethical approval and the interviews at NDPS; and the changing roles of members of the research team. The latter was perhaps the most disruptive as it

meant that there were changes in the management at both schools which slowed down the progress of the research. For example, in chapter six I note that the head teacher at NDPS became acting head at another school and this meant that it was difficult to maintain contact with her and to progress the research in the school. Likewise, in Appendix 16, I describe how several members of the research team at RCPS left the school for various reasons, which meant that piloting practice innovation (1), curriculum development, had to be put on hold. These changes could not have been anticipated and thus the research had to adapt as necessary. This further demonstrates the need for flexibility in action research.

7.3.6 Use of self

The methodology chapter described the significance of reflexive practice in action research, highlighting the impact of self on the research process. I specifically discussed the three selves brought to the research area, described by Reinharz (1997), which influences how the researcher orientates themselves to the research and what kind of knowledge is shared and created. These include: the research-based self, the brought self and the situationally created self. As a novice action researcher, negotiating these three roles was, to some extent, a mentally exhausting process. My previous research experience had meant that, although I recognised the different selves I brought to the research, I still attempted to adopt what Denscombe (1999) refers to as a 'passive neutral stance' (p.117). Yet, there were times during this research where this was impossible as participants would position me in a certain role. This included viewing me as an expert practitioner, seeking advice on childhood bereavement or affirmation of their practice, or as a PhD student, asking how they should develop the research to meet the PhD requirements. The brought self and the research-based self thus influenced how the research participants interacted and engaged with me and how I began to situationally create myself within the action research process. This demonstrates Coghlan and Brannick's (2001) argument that the researcher becomes an 'instrument in the generation of data' (p.38); the research is thus created by participants, the researcher and their relationship. Levin (2012), however, claims that action research is often mistrusted due to the researcher's intense involvement in the field. He asserts that the action

research should have an ethical, moral and professional code of conduct. This identifies the importance of the researcher actively recognising their own biases in order to address the conflict between knowledge creation, subjectivity and objectivity.

7.4 Summary

In this chapter, I argued that role of the Hospice in working with the two primary schools can be summarised under three themes according to the goals of the identified practice developments, summarised in Table 4, section 7.1. I proposed that these themes suggest a reorientation of service delivery across both the Hospice and school services. At the Hospice, such reorientation has implications for the role and remit of Hospice staff, in particular those working in fundraising, education and social work. Across the primary schools, reorientation involves establishing life-affirming and death-acknowledging policies and procedures. The latter requires the Hospice optimising current links with communities to raise awareness of hospice care and transfer professional palliative care knowledge to empower school communities to engage children on issues related to death, dying and bereavement.

I suggested that the themes of raising awareness, providing education and leadership are in line with the principles of health promoting palliative care due to their focus on developing community capacity in end-of-life care and bereavement. I argued that the individual practice developments can be viewed as genuine health promoting palliative care activities according to Kellehear's (2005) 'Big Seven Checklist'. In doing so, I identified how power can influence authentic participatory-borne activities and identified the importance of ensuring that focus is given to evaluation at every stage of practice development.

I finished this chapter by exploring the strengths and limitations of the action research approach. I discussed several factors which influenced the action research process including: research design; leadership styles; culture of the school; missing voices; time; external factors; and the use of self. I highlighted the opportunity within action research to deconstruct power dynamics, but that this was complex within a community where there are existing hierarchal structures. I identified the

importance of self in action research and how this was fundamentally linked with how the research progressed.

Chapter 8: Conclusion

This chapter comprises of three parts. Firstly, I directly respond to the research questions, demonstrating the ways in which this study has developed the practice base for work between a Hospice and two primary school communities. Secondly, I consider the implications of this study for policy, teaching, research and practice. I close this chapter by reflecting on my own experiences, including how I have developed as both a researcher and social work practitioner.

8.1 Research Questions

8.1.1 Research question 1: What are the challenges and opportunities for discussing and teaching death, dying and bereavement with children in primary schools in Scotland?

A number of challenges and opportunities were identified at each school in relation to discussing and teaching death, dying and bereavement with children. The main challenge appeared to be a fear around saying the wrong thing to a child and/or class group, which may cause unnecessary harm. This served to immobilise staff, as it was felt that doing nothing was better than causing avoidable upset, referred to by one staff member as “the kind of old ostrich syndrome” (NDPS, SS13). This suggests that the taboo, which is often associated with talking about death, dying and bereavement with children, was not related to the subject matter, but to managing emotion. This was linked to staff feeling ill equipped with the necessary training and skill base to initiate conversation, support and teaching. No training was given to school staff about how to manage bereavement with children and/or talk about death and dying at any point in their professional training.

The majority of children participating in the research had bereavement experiences that varied in both length of time and attachment to the deceased. Most children felt that school staff did not talk to them about these experiences. They were supportive, however, of school staff talking to them about, and educating them on, death, dying and bereavement and had a number of related questions they felt their teachers might be able to answer. Children, school staff and parents identified a variety of

opportunities within the Curriculum for Excellence where teaching about death, dying and bereavement could be included. These were primarily as part of Religious and Moral Education, Health and Wellbeing and Language (literacy) curriculum areas. The opportunities, however, were rarely utilised due to a lack of focus placed within the syllabus on discussing death, dying and bereavement. Such teaching therefore depended on the individual interest and motivation of teaching staff.

Faith was discussed as a barrier and an opportunity in providing bereavement support to children. When the faith of a child was known, this was considered as providing a known and comfortable framework from which school staff could initiate conversation. When faith was unknown, this was seen as preventing staff from engaging in supportive conversations as they did not want to say something that would contradict with the beliefs of the child and their family.

Parents were considered, by schools staff, as a barrier to teaching and discussing death, dying and bereavement with children. This is because school staff felt that some parents/carers may have concerns about their child receiving such education and thus challenge any practice in this area. This concept was not, however, confirmed by the parents participating in the research. They were supportive of any developments in this area, but expressed a desire to be included and updated on any plans. Nevertheless, only a small number of parents participated in the research and it would have been helpful to have a larger representation from this group.

Teaching about death was frequently related to providing sex education. Several school staff discussed that, when the sex education programme was first introduced, a number of parents/carers withdrew their children from the classes. Now that the programme is fully established, however, this is rarely the case. This relates to Gorer's (1955) argument that death has replaced the sex taboo.

8.1.2 Research question 2: Is there a role for primary schools and hospices to work together to develop discussion and education on death, dying and bereavement with children?

The process of the action research resulted in seven practice innovations being identified across both schools that developed discussion, education and/or support around death, dying and bereavement with children. These included:

1. Integrate death and health education throughout the curriculum (RCPS)
2. Provide bereavement training for school staff (RCPS)
3. Provide information about the Hospice during the Hospice's 'Go Yellow' fundraising event (RCPS)
4. Carry out activities about the Hospice during the Hospice's 'Schoolfriends' fundraising event (NDPS)
5. Provide bereavement training for school staff (NDPS)
6. Provide a parent/carer bereavement workshop (NDPS)
7. Develop a LA bereavement policy (Local Authority Policy and Development Team)

These innovations were led by staff at both the schools and Hospice, according to the goals of the activity. Sharing expertise across Hospice and school settings was fundamental to their development. This suggests that there is a role for hospices and primary schools working together to develop education, discussion and support with children on death, dying and bereavement.

The role of the Hospice in working with the primary schools was summarised under three themes according to the identified practice developments. These were: raising awareness, education and training, and providing leadership in death education and bereavement. The themes suggest a reorientation of service delivery across both the Hospice and school settings. At the Hospice, this has implications for the role and

remit of Hospice staff, in particular those working in fundraising, education and social work. For fundraising, it involves reconfiguring fundraising activities so that they simultaneously fundraise and raise awareness of hospice care, dispelling any negative imagery. Although this is potentially already an aspect of the fundraising role, the practice innovations demonstrate that this role needs to be made more explicit. It involves raising awareness of hospice care with school staff and encouraging them to do the same with children through providing appropriate tools and information. For education, it requires engaging with communities to both determine the level and type of training that is needed and to develop appropriate education programmes. Likewise, for social work, reorientation involves engaging with communities to determine the gaps in support and develop appropriate strategies to meet these gaps. This requires working from a health promoting perspective that focuses on empowering communities to support its members. Reorientation of service delivery within the primary schools involves establishing life-affirming and death-acknowledging teaching, policies and procedures. The Hospice was viewed as having a role in this reorientation by raising awareness of hospice care, transferring expert knowledge and skills, and providing leadership to empower school communities to engage children on issues related to death, dying and bereavement.

8.1.3 Research question 3: If so, what actions can be successfully implemented?

At the time of writing, five out of the seven practice developments are still being piloted and evaluated and therefore it is not possible to fully ascertain if they can be successfully implemented. The remaining two practice developments have, so far and to my knowledge, never been piloted. These activities were designed to be initiated and led by staff at NDPS and include: providing a parent/carer workshop; and carrying out Hospice-based activities during the Hospice's 'Schoolfriends' fundraising event. It would appear that, due to competing demands placed on school staff, time was not available to prioritise developing these activities. This was not the case for all of the activities led by school staff. The curriculum development and bereavement policy are led by school staff and are still moving forward. It is intended that both will be piloted in 2015. These activities are designed to fit within

existing school structures, namely the Health and Wellbeing curriculum and the LA policy framework. Although it is not yet possible to determine if they will be successful in terms of their aim, it is likely that they will be effectively incorporated into the school communities because of this. Conversely, the two practice developments not piloted relied on school staff creating both opportunities to include the activities and the tools/materials from which to facilitate them. For example, although the Hospice's 'Schoolfriends' fundraising initiative provides an opportunity to raise awareness about end-of-life care, the practice development idea relied on the school staff agreeing to participate in this campaign and develop activities and/or find the time to discuss hospice care with the children. It has been highlighted in the literature that teaching on death, dying and bereavement is dependent on a number of factors including: curriculum priorities; the skills, comfort and motivation of teaching professionals; the learning environment; and the learning context (Rowling 2003; Crase and Crase 1979; Adams and Deveau 1995; Dubow et al. 1993). This suggests that if activities to engage children in issues concerning death, dying and bereavement are to be successfully implemented they need to be incorporated and prioritised as part of core teaching and school procedures.

In Appendix 16, I describe how the practice developments led by Hospice staff, (bereavement training and develop the Hospice's 'Go Yellow' fundraising event) have been piloted and evaluated, but that further pilots are planned. The initial evaluation of the bereavement training viewed the programme as successful in meeting the needs of school staff. This training is now being rolled out to other schools in the LA, yet it is clear that schools struggle to attend due to a lack of free time in their timetable and competing training demands. This was also a factor in designing the original training programme and suggests that the Hospice must recognise the practical constraints of working within a school timetable and develop training plans appropriately and in advance. Participating in bereavement training also relies on the head teachers within the schools identifying the relevance of the training to their community. This highlights the role of Hospice staff in raising awareness of the needs of children experiencing bereavement and the importance of developing good community support.

In relation to developing fundraising, a draft leaflet was designed and sent to every child participating in the 'Go Yellow' fundraising event. The evaluation of the initial use of the leaflet did not include exploring how it was used in the schools. It was realised, however, that if the same activity was carried out the following year then every child would receive the same leaflet and conversations are currently being held about what to do next. This identifies the importance of evaluation and further action research cycles to continue developing and adapting practice that is suited to the needs of the school and the Hospice.

8.1.4 Research question 4: How do these actions relate to the principles and practice of health promoting palliative care and hospice service provision?

I argued that the practice innovations are in line with the principles of health promoting palliative care due to their focus on developing community awareness and capacity in end-of-life care and bereavement: to do what Kellehear and O'Connor (2008) call 'strengthening a community's inherent capacity to support [each other]' (p.115). Promoting openness and providing education and leadership were essential in this quest. This involved Hospice staff raising awareness of childhood bereavement and developing the skills of school staff to manage related issues, which is then reinforced by appropriate policy-making. School staff members were responsible for promoting openness and developing the skills and capacity of children to cope with issues related to death, dying and bereavement as well as loss and change more broadly. The activities therefore seek to assist people to adapt and cope with the physical, emotional and social experiences relevant to death, dying and bereavement. Several authors argue that this is a key feature of health promoting palliative care (Kellehear 1999, 2005; Abel et al 2011; Conway 2007,2008). Kellehear's (2005) 'Big Seven Checklist' was a useful tool to further explore and develop the relationship of the practice developments to health promoting palliative care. It allowed a consideration of how power influences authentic participatory-borne activities and identified the importance of ensuring that focus is given to evaluation at every stage of practice development to ensure that activities remain relevant to their own community's needs.

None of the practice innovations involve Hospice staff working directly with primary school children. Instead, they focus on Hospice staff working with adults and/or providing information to adults with the intention that these adults would then go on to work with children. This relates to empowering communities to take full control of service delivery in relation to issues relating to end-of-life and bereavement care, which Kellehear (1999) argues is a central feature of health promoting palliative care. It was apparent whilst on maternity leave that this was a particular feature of the practice developments involving curriculum development, policy development and bereavement training. All of these developments progressed with little or no involvement from me.

According to Kellehear (2005), health promoting palliative care should not be defined by the boundaries of the institution. This identifies the difference between community engagement approaches versus direct work. Conway (2007) argues that both are essential for providing good quality end-of-life and bereavement care, yet little attention is given to the role of the community. The practice developments address this. They seek to promote openness about end-of-life care and bereavement, which focuses on death as a normal part of life, and develop the skills, policies and procedures to ensure effective social support, when needed, for staff, children and their families. It would be challenging, if not impossible, for the Hospice to work in any meaningful way with all children at the 160 schools in the Hospice catchment area. Developing the capacity of school staff is therefore essential if the Hospice is to serve these children. This practice challenges critics of hospice care, which claim hospice services neglect social networks by focusing on individual and interpersonal levels of care (Abel et al. 2011; Conway 2007).

8.1.5 Research question 5: What can be learned from the action research process?

The action research process enabled me to draw people together in a discussion that had not taken place. Due to its focus on democratic decision-making, the significance of sharing and transferring knowledge and expertise across Hospice and school communities was identified. The action research was therefore multi-disciplinary, which was a strength of the research process as it enabled practice

developments to be considered that were responsive to the needs of both the Hospice and school communities. Working across different organisations, with different cultures and leadership styles, however, challenged the extent to which democratic spaces were created and power imbalances addressed. This relates to what Coughlan and Brannick (2001) call 'lighting many fires' (p.121) which involves moving across different organisations, departments and individuals in a way that engages them and recognises that they operate in different ways. This demonstrates the adaptability that is required of the action researcher to work with competing demands and conflicting values. Nevertheless, the action research process highlights the significance of community engagement and ownership in developing practice that is responsive to community need.

I argued that action research is well suited to developing health promoting palliative care activities as it involves engaging and encouraging groups or communities to identify their own needs and develop strategies for managing them. In relation to health promoting palliative care, Kellehear and O'Connor (2008) argue that this process is integral to creating 'ownership' of health promoting palliative care programmes. Likewise, Sanders and Wilkins (2010) claim that the two main aims of action research are:

'to produce knowledge and action directly useful to the community and secondly, to raise awareness and empower people through constructive use of their knowledge.' (p.173)

Ideas and plans for change should therefore come from people who will be delivering, or subject to, that action. In this research, the action research process aimed to encourage research participants to explore the research area, individually and collectively, and develop ownership of the ideas that were identified and taken forward. The influence of leadership within the organisations was identified as a threat to democratic decision-making, yet the emphasis on collaborative working as well as reflexive practice enabled these issues to be brought to the fore, facilitating transparent research practices and decision making. As Levin (2012) outlines, 'deep empathic and political involvement must be confronted with critical and detached reasoning' (p.136). This was challenging, given the level to which I was immersed

in the research. Through the process of reflecting on the action research process, however, it is clear that the action researcher's role has an ethical, moral and professional code of conduct that needs to be adhered to. Exploring this role was aided by individual and group reflection with colleagues, members of the research team and my supervisors as well as keeping a research log.

Unlike other research social science methodologies, Brydon-Miller and colleagues (2003) highlight that action research meets the test of action. This is significant to this research. Two practice developments did not progress and this assisted in developing practice knowledge around what does and does not work. This practical knowing is argued by Reason (2001) as the primary purpose of action research; yet, this identifies a challenge of action research in having to invest in ideas that may not turn out as planned. This also raises the issue of time. Action research takes time, requiring commitment from both the action researcher and the organisations involved. Again, this demonstrates the flexibility required in action research, both by the action researcher and the research participants, to respond to, and accommodate, changes that may happen during any extended time period.

8.2 Implications and recommendations

This study contributes to practical, theoretical and methodological knowledge in relation to the field of study. It adds to the limited body of practice knowledge concerning the role of hospices working with schools to engage children in conversation and education on death, dying and bereavement and the emerging theoretical base of health promoting palliative care activities. It also contributes to the methodological knowledge in relation to the role of action research in developing health promoting palliative care activities. In this section I suggest the implications and recommendations this study has for future policy, research, teaching and practice.

8.2.1 Policy

In the UK, policy making on end-of-life care focuses on the importance of continuity of care and choice in how that care is delivered (Scottish Government 2008; Department of Health 2008; Department of Health 2010). This has prompted

campaigns and activities to raise public awareness and promote community involvement in death, dying and bereavement, recognising the importance of public health approaches to end-of-life care. In Scotland, school communities have been identified as a target for such activities (Scottish Government 2010). I would agree with this focus. This study identified that discussing death, dying and bereavement with children is not always done, both at a basic education level and in response to personal experiences of bereavement. Thus, this study makes three recommendations for policy making:

- In relation to education on death, dying and bereavement, the identified practice innovations suggest that focus needs to be placed at policy level, through the Curriculum for Excellence. This means integrating such education as a core part of teaching to ensure that all children receive the same learning opportunities. There is currently no direct learning outcome in the Curriculum for Excellence that directly addresses these issues. Although such teaching can be incorporated as part of other existing learning outcomes that focus on developing emotional awareness, resilience and capacity, an explicit focus would be more helpful in developing this work.
- In relation to bereavement support, the significance of an LA-wide school bereavement policy was identified to ensure that all schools in the area acknowledge and respond to bereavement appropriately. This demonstrates the significance of developing a death and bereavement affirming policy in establishing a uniform response that does not vary from class to class or school to school, but which can be tailored according to specific need.
- In relation to the role and remit of hospice care, the opportunities, skills and expertise of hospice staff in relation to raising awareness, providing education and training, and providing leadership in end-of-life care and bereavement were identified. This suggests that hospices are in a key position to engage with communities to develop community capacity in providing end-of-life care and bereavement support. Such work is not commonly included in

policy development, but needs this level of focus if such practice is to be embraced and developed.

8.2.2 Teaching

This research reveals three main implications for teaching. These relate to teaching school staff about death, dying and bereavement issues, action research and health promoting palliative care:

- The study identified that school staff do not receive any formal training on how to approach and manage death, dying and bereavement in the classroom. This deficit was identified as preventing some individuals from responding to discussions about, education on, and support in, end-of-life care issues and bereavement. The role of the Hospice in providing such education was recognised, specifically in developing the capacity, confidence and skills of school staff to manage bereavement. This was as part of post-qualifying training during school in-service days. This finding, however, identifies a gap in training on undergraduate and postgraduate teaching programmes. Including teaching at such a level would ensure that all school staff members are effectively taught about this area prior to beginning direct work with children.
- Throughout my PhD, training on action research was absent from core research design modules. This study identified that action research can be an effective methodology for practice-based professions and can offer flexibility to address the needs of a broad spectrum of interested parties: participants; funders; PhD supervisors; and academic criteria. This suggests that more attention should be given to action research in the university research design courses to both encourage more action research and to further develop arguments for and against an action research approach.
- It was apparent from the scoping phase of this research that there exists some confusion around the role of hospices in engaging with health promoting palliative care principles. More training on this area is necessary to ensure

that staff members involved in delivering palliative care understand how health promoting palliative care is applicable to their role and organisation, and its significance in developing equity in care.

8.2.3 Research

The findings of this study point towards a number of directions for future research:

- Owing to the focus on developing practice, the research did not fully explore children's experiences of a taboo around death, dying and bereavement. The literature review identified that the voices of children are frequently underrepresented in research relating to this. In this study, the voices of children were arguably also underrepresented due to working within the cultures of the school. Nevertheless, their views and opinions were integral to motivating and empowering adults to change practices that did not respect the rights of children to be included in information and education about an integral aspect of life. This allowed an opportunity for the children to challenge beliefs such as 'children shouldn't be spoken to about death'. This suggests that more research needs to be done that includes and responds to children's views, specifically in relation to developing practice that seeks to support children in these issues and conceptual arguments on the death taboo.
- The practice innovations arising as a result of this research identify the role of the Hospice in developing the capacity of school communities to respond to, and support, experiences of death, dying and bereavement. This suggests that there is a role for hospices in mobilising communities more generally, alongside providing direct support to patients and their families. More research is needed to explore how the Hospice can engage with other community groups to develop capacity in end-of-life care and bereavement, thus integrating related experiences into the community as opposed to something only professionals can deal with. For example, is there a role for the Hospice in developing community capacity in relation to: providing bereavement support for adults; supporting patients and their families at home; supporting carers, and so on? Such research would be in line with arguments

such as those by Stjernsward (2002), which state that socio-economic cultural solutions are equally as important as medical contributions for achieving meaningful end-of-life care coverage.

- This study demonstrated that action research is well suited to developing health promoting palliative care activities. More research needs to be completed and disseminated to develop this argument further through engaging with other community groups, using action research, to explore practice that responds to death, dying and bereavement.
- In chapter three, I identified that despite the move towards public health approaches to palliative care there has been little research that fully explores the development of health promoting palliative care activities. Moreover, there are a range of terms describing similar work and this has been identified as confusing (Paul and Sallnow 2013). Through the process of doing this research a colleague and I developed a spectrum of community engagement for end-of-life care that sought to respond to this confusion (Sallnow and Paul 2014). More research, however, needs to be completed and disseminated to develop conceptual clarity further in relation to developing health promoting palliative care activities, specifically around what this means for the hospice movement.
- Through the process of completing this research, working inter-disciplinarily was extremely beneficial in developing my understanding. Health promoting palliative care, as highlighted by Kellehear (1999), is multi-disciplinary and more research needs to be done that is reflective of this. This includes working with colleagues in public health, medicine, social work, nursing and community development.

8.2.4 Practice

Given that this research was focused on developing practice, this thesis identified several practice implications between a Hospice and schools. The findings, however,

suggest broader implications for both the role of hospices in the community and social work:

- The study demonstrates the significance of hospices in engaging with school communities to develop capacity in end-of-life care alongside direct service provision. This suggests that hospice communities should consider and embrace how social networks can fulfil roles relating to end-of-life care rather than rely purely on services. This concept runs parallel to the hospice movement which Saunders (1978) envisioned as holistic in its approach, recognising that people at the end of life have physical, psychological, spiritual and social needs. Yet, Abel and colleagues (2011) argue that the focus on the social needs of patients and their families has been lost. For hospices, developing community capacity in end-of-life care requires a reorientation of service delivery that focuses on transferring professional knowledge and expertise to mobilise and empower communities to support their own community members. Such practice would seek to further develop choice in end-of-life care and bereavement by providing community support alongside expert service provision.
- In this study, my role as a social worker and researcher was integral to the action research process. This suggests that the social work profession has skills in engaging communities to develop health promoting palliative care activities. Brown and Walter (2013) argue that, although palliative care claims to be holistic, health professionals take the lead role and the role of social work is less clearly defined. They claim that social care professionals are well situated to develop community capacity in end-of-life care due to this flexibility, as well as their culture, value base and ‘expertise in communication, family dynamics, promotion of choice, empowerment and advocacy’ (p.11). This suggests that there is both scope and the relevant skill base within the social work profession to develop community work.

Community work is argued by Ewijk (2011) as being an accepted aspect of social work practice in the 1970s, alongside group work and individual work,

but that this declined during the Thatcher period due to the promotion of individuality. Likewise, Forde and Lynch (2013) claim that review processes which has arisen in the aftermath of tragic events has placed increasing attention on the role of social work in child protection and deflected attention from the social work role at community levels. They go on to assert that for social work to fulfill its commitment to social change it must involve some community development. This highlights that social work practice is in a key position to develop work with communities and that such work needs to be embraced in order to keep the value base of social work and address the need for better community support in end-of-life care. Reith and Payne (2009) argue that loss is both a personal and social problem. As such, experiences of loss must be supported and addressed at individual and social levels.

8.2.5 Reflections on my development during the PhD journey: the never-ending road of new learning

In the introduction I described how this research was the product of my role as a hospice social worker and PhD student. This dual role was central to the PhD journey and one that brought both opportunities and challenges. Coming from the hospice, where I was comfortable and confident in my position, to being a student was somewhat unsettling. Watts (2009) claims that this is not an uncommon experience: many professionals struggle to make the ‘psychological transition from expert to novice’ (p.689). In my social work role, people had come to me for advice and now I had found myself unsure of how to proceed. Meeting with my supervisors, coupled with university courses, became extremely helpful in helping me navigate this journey: to begin deconstructing the knowledge I had built in practice so that I could progress as both a researcher and practitioner.

For social work practitioners, research opportunities are rarely available. Orme and Powell (2007) argue that the culture within social work severely limits its capacity to undertake high quality research and for the research to transcend to practice. They note that this is despite the recognition that ‘high-quality research is needed to both inform professional [social work] practice and to engage with policy development’ (p.989). I thus felt very fortunate to have this experience. Because I was sponsored

by the Hospice, however, the prospect of failing had personal and professional implications. It also meant that there were certain limits around what and how I could research, as the Hospice had emphasised practice development as a condition of my funding. This focus led me to pursue action research, despite my unfamiliarity with this research approach.

Learning to become an action researcher was challenging. Levin (2012) argues that

‘the formation of an action researcher can be seen as a complex process involving both the ability to ‘live’ the field and to critically reflect and analyse experiences (data) from deep engagement and involvement in local transformation.’ (p.141).

The skills listed of an action researcher are vast. Heron and Reason (1999) provide just one of the many catalogues of skills, some of which include being: present and open, bracketing and reframing, radical in practice and congruence, emotionally competent, managing distress and so on. At first these lists were somewhat daunting, yet facilitating and participating in the action research process enabled me to develop a better understanding of what these skills meant in the context of this study.

Winter and Munn-Giddings (2001) argue that action research is a model of work as well as a model of research. Fuller and Petch (1995) recognise that there is a significant link between the skills and practices of research and social work practice. ‘Doing’ research can potentially enhance professional skills (and vice versa), which Cheetham (2000) asserts can enable increased insight into what the real problems are. For me, using action research defined this concept of research as a practice methodology, i.e. a way of engaging with practice to improve service delivery. It enabled me to create an opportunity to explore and understand lived experiences to inform and transform practice. Furthermore, it emphasised Payne’s (2014) claim that the knowledge base for social work is ‘a continuous process of constructing and reconstructing professional knowledge’ (p.134).

Social work is concerned with the interaction between individuals, communities and the state. Yet, in my role in the Hospice I had primarily worked with individuals and groups, focusing more on the personal than the social. Using action research and

exploring the principles of health promoting palliative care helped me to better understand the 'social' in social work. It necessitated an exploration of the social and recognition that the communities I was working with never expected or wanted me, or the Hospice, to provide all the support around end-of-life care and bereavement. Instead, these communities wanted to support their own members, but needed the confidence and tools to do so. This helped me to understand that social work intervention in palliative care should assist people and communities to seamlessly travel the boundary between personal and public, and fully participate in dying and grieving as a natural, individual and social process. Stepney (2005) argues that community work releases the emancipatory potential of social work and calls for critical practice that is innovative, creative and preventative. The PhD process made me aware that as a social work practitioner I have the skills to engage, mobilise and support both individuals and communities in relation to managing death, dying and bereavement experiences.

I am aware that when I return to my role in the Hospice my opportunities for research will be severely limited due to both the demands of service delivery and lack of funding opportunities. Likewise, given that community engagement is not a requirement of my job, my energy for such practice may be diluted. Research conducted by Forde and Lynch (2013) around social workers' engagement with community approaches found that their involvement in such work was sporadic or intermittent due to competing demands. The process of undertaking this PhD and developing my research skills and community engagement skills has been extremely rewarding. I am therefore concerned about how I will continue to progress this learning. This experience is not uncommon and Marsh and Fisher (2008) argue that 'most practitioners leave practice to in order to undertake research, and most researchers have little ongoing practice responsibility' (p.973). It is therefore with some hesitation that I return to my previous practice role. This is not because I do not enjoy practice, far from it, but because I am concerned about how I can share, apply and enhance the knowledge I have developed through the process of this PhD.

8.3 Concluding thoughts

This study demonstrated that hospices are in a key position to develop practice with school communities that builds capacity to discuss, educate and support children in death, dying and bereavement. It recognises that palliative care providers can be involved in community engagement and development practices. If, as Sayer (2010) argues, death and bereavement are hidden, not taboo, this study establishes that the role of the Hospice in working with school communities is concerned with ‘finding death’: through raising awareness of end-of-life care and bereavement; developing staff skills and confidence to engage with these experiences; and providing leadership to develop death and life affirming policies and procedures. Such practice involves a reorientation of service delivery that builds capacity within school communities by transferring professional palliative care knowledge, expertise and control alongside direct service provision.

Appendix 1: Search terms used

Search terms relating to the ‘death taboo’

(death or dy* or bereave* or “end of life” or thanatology) AND (taboo or stigma or hid* or deny or denied or forbidden or barred or reject or refuse or disallow or judg* attitudes or perception or understand*) AND/OR (child* or adol* or youth or teen*)

Search terms relating to public health approaches to palliative care

(“community engagement” or “community empowerment” or “health promot*” or “public health approach*” or “health promoting palliative care” or “community development” or “community participation” or “community empowerment” or “compassionate communit*” or “compassionate cit*” or “death education” or thanatology) AND/OR (“palliative care” or “end of life ” or “terminal care” or hospic*) AND/OR (child* or adol* or youth or teen*)

Appendix 2: Information Sheets

2.1 Adult information sheet

Let's talk about death and dying:

An exploration of how schools and hospices can work together to address the social taboo of death and dying with children.

Information Sheet

The research project

Research has identified that there is a social taboo around talking about death and dying, particularly with regard to children. Health promoting palliative care is an idea that has arisen to help tackle this taboo. It aims to develop conversations about death and dying, believing that if we are more open about it and treat it as a normal part of life we will be much more emotionally and physically able to support ourselves and each other through death and bereavement. This research intends to explore to what extent this social taboo exists in Scotland and how schools and hospices can work together to break down barriers and encourage more openness about death and dying with children.

About the researcher

My name is Sally Paul. I currently work four days per week as a PhD researcher with Edinburgh University, and one day a week as a hospice social worker. I previously worked at the hospice full-time, as a social worker and the children's bereavement coordinator. This involved facilitating one-to-one and group support for children and their parents/carers, as well as bereavement training for professionals in a variety of fields. In this position I was continuously aware of how adults sometimes struggled to discuss death, dying and bereavement with children, often meaning that children were excluded from information about significant aspects of their lives. The idea for this research came as an approach to help tackle this issue. It is supported by the hospice management team who are keen to explore better ways at working with schools to break down the social taboo that surrounds death, dying, bereavement and hospice care.

Project aims

- To meet and talk with school teachers, hospice staff, parents and carers about their experiences of talking about death, dying and bereavement with children.
- To meet and talk with children aged 10 and 11 about their experiences of having conversations about death, dying and bereavement.
- To explore new ideas for hospice and schools working together to talk to children about death, dying and bereavement.
- To try out some of these ideas and evaluate them to see how well they work.

Would you like to be part of this research?

I am hoping to speak with 16 hospice staff about their experiences of talking to children about death and dying as well as explore ideas for how schools and hospices can potentially work together.

Deciding to participate

It is up to you to decide whether or not to take part.

If you agree, you will be asked to sign a consent form. You can decide however to withdraw from the study at anytime, without giving any reason.

What it would mean for you

If you decided to take part in the study you will be invited to attend a focus group. In the group there will be four to six other hospice staff members. The focus group will:

- Take place in the hospice at that is convenient to you.
- Last approximately one hour.
- Be recorded, if you agree.

After the initial focus group you will be asked if you would be interested in participating in additional focus groups. These focus groups will aim to explore ways in which the hospice and school can work together and will be made up of teachers, hospice staff, parents/carers and children. These ideas generated in the focus groups will then be tried out and evaluated with the support and involvement of the focus group members. It is anticipated that this may take several meetings over a period of three months.

The results from the research will be written up in a report. I will send you a short report of the findings next year. The findings from the research may also be used for research publications to share the work that has been done with wider education and hospice community. Direct quotes from the focus groups may be used in these materials. Whilst every effort will be made to anonymise the study's findings, on occasion it may not be possible to guarantee anonymity.

Confidentiality

- All names will be changed in all research documents, tapes and reports.
- All research records, such as recordings, will be kept in a locked filing cabinet and destroyed at the end of the research
- All personal information will be treated as confidential unless children or young people say they are at risk.

Ethics

This research has met both Edinburgh University, XXXX council and Strathcarron Hospice ethical standards for research.

What happens next?

If you are interested in participating please fill in the reply sheet attached to this form and put it in the 'Research Box' in the XXX office. I will then be in touch to discuss the research with you and answer any questions you may have. Alternatively, please feel to contact me either by email on sally.paul@nhs.net or by phone on 01324 826 222.

If you would like to talk to someone else about the study please contact: Professor Vivienne Cree, on 0131 650 3927; or Professor Scott Murray on 0131 650 9498.

If you have any concerns about the study, please contact XXX, Hospice Chief Executive, on 01324 826 222.

Thank you for taking your time to read this information. I look forward to hearing from you.

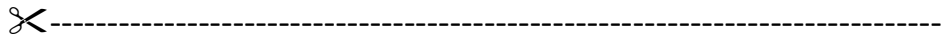
Kind regards

Sally Paul

2.2 Child information leaflet



If you would like to help with this study, please fill in the form below and return it to your teacher as soon as possible. I will be near reception at lunch time today so you can also give the form directly to me and/or ask any questions you have.



I am interested in being involved in the study and would like to talk about it with Sally.



Name:



Class:

My name is **Sally Paul**.



I am doing a research study with Strathcarron Hospice and Edinburgh University.

The research study is about how people talk, or don't talk, to children about death and dying. It is also about coming up with new ideas to see if your school and the Hospice can work together to help children talk about death and dying in a way that is helpful.

The Hospice helps people who have an illness that cannot be cured. Many people believe that everyone who goes to a hospice dies. This is not true - often people go home but sometimes people die.

I would really like to know what you think about how people should talk to children about death and dying, illness and hospices. It would be great if you could take part in this study

Would you like to take part in this research study?



Taking Part



Please read this carefully and let me know if there is anything that doesn't make sense.

First of all I will meet with you and the other children who want to take part. I'll tell you more about the study and you can ask me questions about it.

If you want to be part of the research then we'll get together with a few other children to do some talking and play some games. I will ask you questions such as:

Do you think people talk about death and dying?

Has anyone every spoken to you about death and dying?

Was it a helpful?

Do you think adults should talk to children about death and dying?

How should they do this?

Do you have any ideas for how schools and hospices can work together to encourage such conversations?

At the end of the group meeting I will ask if you would like to meet again - this time with some adults (a teacher, somebody from the hospice and maybe another adult). At this meeting we will come up with new ideas for how your school and the Hospice can work together and then try these ideas out.



What happens next

I am also talking to teachers, hospice staff and parents/carers. When I have spoken to everyone I will write a report about everyone's views. I will have a report for children too. I hope this will help schools and hospices to talk to children better about death and dying.



Before you take part it is important for you to know that:

You can choose whether or not to take part.

Your parent or carer needs to give permission for you to take part. I'll ask them to sign a form to say it is OK for you to take part.

Once you have understood what it means to take part in the research you will be asked to sign a form to say that it is OK.

I will not discuss anything you say with anyone else, unless you tell me that you, or someone else, might be hurt. In this case I will have to tell a teacher.

The meeting will be recorded so that I can listen to what you say without having to take notes. When the study is finished I will delete your recordings so no-one else can listen to them.

If you would prefer not to talk in a group we can meet in school and talk together. If you like, you can ask a relative or friend to be present during this meeting.

If you change your mind at any time about taking part you can tell me you want to stop without having to say why.

To keep what you say private I will not write your name in the report even if I write down some of the things that you say.

no thank you



Appendix 3: Consent forms

3.1 Adult consent form

Let's talk about death and dying:

An exploration of how schools and hospices can work together to address the social taboo of death and dying with children.

Consent form

Please read the following statements and initial them to indicate that you have read and understood them:

I have read the information sheet.

I have had the chance to ask questions and talk about the project.

I understand that it is my choice to participate in the study and that I can withdraw from the project without having to say why at anytime.

I understand that I will be interviewed and/or part of a focus group and that this will be audio recorded, if I agree at the time of the interview/group.

I understand that anything I tell the researcher will be confidential unless I give information that a child/young person has been harmed or is at risk of harm.

In this case the researcher may have to report this; but they will discuss with me the best way to do this.

I understand that no names will be used in the research report but some direct quotes may be included as explained on page two of the information sheet. Information will only be used for this study and destroyed once the research is completed.

I agree to take part in the study.

NAME..... SIGNATURE..... DATE.....

3.2 Child consent form

Who talks to you about death and dying and how can your school do it better?

Consent form [children]

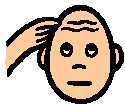
Please read the following statements and tick the box to indicate that you have read and understood them:



I have read the information sheet.



I have had the chance to ask questions and talk about the study.



I understand that it is my choice to help with the study.



If I agree, what I say will be recorded for the study.



I understand that I can stop helping with the project at any time without having to say why.



I understand that anything I say will not be discussed with anyone else, unless I say that I, or someone else, might be hurt.



I am happy to take part in the study.

NAME/SIGNATUREDATE.....

Appendix 4: Focus group guide sheets

4.1 Child focus group guide sheet

Introduction: Thank for coming
Introduce myself
Remind the child about the project
- Do you remember?
Explain why and how they were chosen
- Do you still want to take part?
Discuss what will happen today:
- Lasts 45 minutes
- Confidentiality
- What we will be doing
- Introduce the questions I will be asking
- Okay to interrupt if don't understand etcetera
- Conversation guidelines (would they add anything?)
- Reasons for recording (is that okay?)
- What happens afterwards
- Consent and changing your mind

Fill in the consent form

Turn on digital recorder

Icebreaker: Go round circle saying name, age and one thing they are good at. Next person must repeat and then introduce themselves and so on.

1. Why did you want to take part in this research?
2. What do you think about this research topic? (strange, good idea?)
3. This project is based on thinking that adults find it difficult to talk to children about death and dying. Who thinks that's true? If so, why? (*Option – use agree/disagree/maybe cards*)
4. Has anyone ever talked to you about death and dying? (*Option – use agree/disagree/maybe cards*)
5. Was it helpful?
6. What about in school?

Prompt: Can you give an example? When? Why?

7. Is it something you learn about in class?

8. Post-it exercise:

3 reasons why it might be good to talk about illness, death and dying.

3 reasons why it might be difficult to talk about illness, death and dying.

3 things you would like to know more about illness, hospice care, death and dying.

Discuss

Explain: Death and dying a part of life and so some people think if we talk about it more we will be better prepared and it will be less scary when it happens to someone we love. Adults don't always know how to do this with children as they aren't sure what to say.

9. Top Tips exercise: What tips would you give to adults on talking to children about death and bereavement?

10. Ideas: Ideas for change

Prompt: Why is this important? How could it be done? What would be involved? What would make it difficult? When should this happen?

Closing Exercise: With ball go around the circle asking participants;

- How did you feel about today?
- What have you enjoyed about today?
- Is there something you found difficult today?
- What are you going to do when you go home tonight?

Remember: Consent forms, ball, guidelines, post-its, pens, Flip Chart paper, water, jug, cups, sweets, tissues, digital recorder (Spare batteries), note pad and pen, sticky dots.

Back up exercise: Agree/Disagree/Maybe statements: Teachers teach me about death and dying in school; adults talk to me about illness, death and dying; I would be interested to hear more about illness, death and dying; I would like to know more about the hospice; I can trust people to tell me if someone is very ill

4.2 Parent/carer focus group guide sheet

Introduction: Introduce myself
Thank people for coming.
Remind the group about the project.
Explain: How long group will last
Purpose of research
Confidentiality and anonymity
Reasons for recording or not
- Are people not okay with recording?
What will happen with data generated (and recording)
Discuss format and convention of focus groups process (encourage participation)
Introduce the questions I will be asking
Raise ground rules (i.e. everyone's opinion important, share and interact with each other etcetera)
Invite people to ask any questions

Fill in the consent forms

Turn on digital recorder

Questions:

1. Icebreaker/opening question: Ask group to introduce themselves, saying their name and how many children you have in the school and what age they are. It would also be really interesting to hear why you decided to participate in the group.
2. Research has identified a social taboo about talking about death and dying, particularly with regard to children and young people. How do you feel about this?
3. Do you have any recent experiences of talking with children about death, dying and serious illness? If so, tell me about this.

Prompt: Reason, Age, Gender, working with the school

4. What seemed helpful and unhelpful in this?
5. Health promoting palliative care aims to develop conversations about death and dying, believing that if we are open about it and treat it as a normal part of life we will be more emotionally and physically able to support ourselves

and each other through death and bereavement. What do you think about this?

6. Has anyone ever heard of health promoting palliative care before?
7. Do you think it makes sense in relation to primary-aged children? If so, why?
8. How do you think it might be achieved in schools?
9. It has been suggested that hospices need to work more closely with schools in their communities to break down barriers and encourage more openness about death and dying. What do you think of this idea?
10. How might it be achieved?
11. What challenges and obstacles do you think there might be?
12. How might it be promoted?

Closing: Thank people for giving up their time and participating

Reiterate what will happen to data

Invite people to ask any questions

REMEMBER:

Digital recorder
Spare batteries
Note pad and pen
Make note of who came

4.3 Hospice staff focus group guide sheet

Introduction: Introduce myself
Thank people for coming.
Remind the group about the project.
Explain: How long group will last
Purpose of research
Confidentiality and anonymity
Reasons for recording
- Are people not okay with recording?
What will happen with data generated (and recording)
Discuss format and convention of focus groups process (encourage participation)
Introduce the questions I will be asking
Raise ground rules (i.e. everyone's opinion important, share and interact with each other etcetera)
Invite people to ask any questions

Fill in the consent forms

Turn on digital recorder

Questions:

1. Icebreaker/opening question: Ask group to introduce themselves, saying their name and their role in the hospice and what contact they have with school children. It would also be really interesting to hear why you decided to participate in the group.
2. Research has identified a social taboo about talking about death and dying, particularly with regard to children and young people. How do you feel about this?
3. Do you have any recent experiences of talking with children about death, dying and serious illness in your role at the hospice? If so, tell me about this.

Prompt: Reason, Age, Gender, working with the school

4. What seemed helpful and unhelpful in this?
5. Health promoting palliative care aims to develop conversations about death and dying, believing that if we are open about it and treat it as a normal part of life we will be more emotionally and physically able to support ourselves

and each other through death and bereavement. What do you think about this?

6. Has anyone ever heard of health promoting palliative care before?
7. Do you think it makes sense in relation to primary-aged children? If so, why?
8. How do you think it might be achieved in schools?
9. It has been suggested that hospices need to work more closely with schools in their communities to break down barriers and encourage more openness about death and dying. What do you think of this idea?
10. How might it be achieved?
11. What challenges and obstacles do you think there might be?
12. How might it be promoted?

Closing: Thank people for giving up their time and participating

Reiterate what will happen to data

Invite people to ask any questions

REMEMBER:

Digital recorder
Spare batteries
Note pad and pen
Make note of who came

Appendix 5: Interview guide sheets

5.1 Adult interview guide sheet

Introduction: Introduce myself, the nature of the study
Thank for coming
Have read the information sheet? Any questions?
Explain: How long the interview will last
Purpose of research
Introduce the questions I will be asking
Okay to interrupt if don't understand etcetera
Reasons for recording. Is that okay?
Confidentiality and anonymity
What will happen with data generated (and recording)

Complete Consent From

Turn on digital recorder

1. For the purpose of the recorder please could you tell me your name, how long you have worked at the school and in what role?
2. Research has identified a social taboo about talking about death and dying, particularly with regard to children and young people. How do you feel about this?
3. Do you have any recent experiences of talking with children about death, dying and serious illness? If so, tell me about this.

Prompt: Reason, Age, Gender

4. Were there any special issues relating to gender, age, ability, ethnicity, or social class?

Prompt: Prior experience, type of death, relationship to person

5. What seemed helpful and unhelpful in this?
6. What can we learn from this?
7. Most literature discusses death, dying and serious illness as being discussed reactively in schools (in relation to bereavement). Has that generally been your experience?

8. Health promoting palliative care aims to develop conversations about death and dying, believing that if we are open about it and treat it as a normal part of life we will be more emotionally and physically able to support ourselves and each other through death and bereavement. What do you think about this?
9. Do you have any experience of working in this area?
10. Have you ever heard of health promoting palliative care before?
11. Do you think it makes sense in relation to primary-aged children? If so, why?
12. How do you think it might be achieved?
13. It has been suggested that hospices need to work more closely with schools in their communities to break down barriers and encourage more openness about death and dying. What do you think of this idea?
14. How might it be achieved?
15. What challenges and obstacles do you think there might be?
16. How might it be promoted?

Closing: Thank people for giving up their time and participating

 Reiterate what will happen to data

 Invite people to ask any questions

REMEMBER: *Digital recorder*

Spare batteries

Note pad and pen

5.2 Child interview guide sheet

Introduction: Thank for coming
Introduce myself
Remind the child of about the project
- Do you remember?
Explain why and how they were chosen
- Do you still want to take part?
Discuss what will happen today:
Last 45 minutes
Confidentiality
What we will be doing
Introduce the questions I will be asking
Okay to interrupt if don't understand etcetera
Conversation guidelines (would they add anything?)
Reasons for recording (is that okay?)
What happens afterwards
Consent and changing your mind

Fill in the consent form

Turn on digital recorder

1. Why did you want to take part in this research?
2. What do you think about this research topic? (strange, good idea?)
3. This project is based on thinking that adults find it difficult to talk to children about death and dying. Who thinks that's true? If so, why?

Option – use agree/disagree/maybe cards

4. Has anyone ever talked to you about death and dying?

Option – use agree/disagree/maybe cards

5. Was it helpful?
6. What about in school?

Prompt: Can you give an example? When? Why?

7. Is it something you learn about in class?

Post-it exercise: 3 reasons why it might be good to talk about illness, death and dying; 3 reasons why it might be difficult to talk about illness, death and dying; 3 things you would like to know more about illness, hospice care, death and dying.

Discuss

Explain: Death and dying a part of life and so some people think if we talk about it more we will be better prepared and it will be less scary when it happens to someone we love. Adults don't always know how to do this with children as they aren't sure what to say.

8. Top Tips exercise: What tips would you give to adults on talking to children about death and bereavement?

9. Ideas: Ideas for change

Prompt: Why is this important?
How could it be done?
What would be involved?
What would make it difficult?
When should this happen?

Closing Exercise:

How did you find today?
What have you enjoyed about today?
Is there something you found difficult today?
What are you going to do when you go home tonight?

REMEMBER:

Consent forms
Ball
Guidelines
Post-its
Pens
Flip Chart paper
Water
Jug
Cups
Sweets
Tissues

Digital recorder (Spare batteries)
Note pad and pen
Sticky dot

Appendix 6: University of Edinburgh ethical approval forms

University of Edinburgh
School of Social and Political Studies
RESEARCH AND RESEARCH ETHICS
COMMITTEE



Ethical review form for level 2 and level 3 auditing

This form should be used for any research projects carried out under the auspices of SSPS that have been identified by self-audit as requiring detailed assessment - i.e. level 2 and level 3 projects (see <http://www.sps.ed.ac.uk/research/ethics>). This form provides general School-wide provisions. Proposers should feel free to supplement these with detailed provisions that may be stipulated by research collaborators (e.g. NHS) or professional bodies (e.g. BSA, SRA). The signed and completed form should be submitted, along with a copy of the research proposal (or a description of the research goals and methodology where this is unavailable) to the relevant person:

- For staff applying for external funding, the PI should submit the form to Research Office
- For Postdoctoral Fellows, the Mentor should submit the form to Research Office
- For PG Research (PhD or MSc by Research), the Supervisor should submit the form to Director of the Graduate School.
- For UG Dissertations, the Supervisor should submit the form to the Programme/Dissertation Convenor.

Research and Research Ethics Committee will monitor level 2 proposals to satisfy themselves that the School Ethics Policy and Procedures are being complied with. They will revert to proposers in cases where there may be particular concerns of queries. For level 3 audits, work should not proceed until Research and Research Ethics Committee (or the Director of Graduate Studies, in the case of postdoctoral research) has considered the issues raised. Level 3 applications should be submitted well in advance of a required date of approval.

Research Office may monitor the implementation of arrangements for dealing with ethical issues through the lifetime of research projects. Please ensure you keep a record of how you are addressing ethics issues in the course of your research (e.g. consent forms, disclosure processes, storage of data, discussion of ethical issues by project advisory board). Do contact the Research Administrator if any unanticipated ethics issues arise in the course of your research/after the completion of your project.

SECTION 1: PROJECT DETAILS

1.1 Title of Project

Let's talk about death and dying: An exploration of how primary schools and hospices can work together to address the social taboo of death and dying with children.

1.2 Principal Investigator, and any Co-Investigator(s) (Please provide details of Name, Institution, Email and Telephone)

Name Sally Paul

Institution: Social Work Department, School of Social and Political Science, Edinburgh University.

Email: sally.paul@nhs.net

Mob: 07737811420

1.4 Does the sponsor require formal prior ethical review?

YES

If yes, by what date is a response required

As soon as possible (hopefully by the 1st December 2011)

1.5 Does the project require the approval of any other institution and/or ethics committee?

YES

If YES, give details and indicate the status of the application at each other institution or ethics committee (i.e. submitted, approved, deferred, rejected).

Ethical approval is also required from XXXX Council and NHS Forth Valley. Both organisations require that ethical approval is granted from the university prior to an application being submitted.

The proposal has passed through the School of Social and Political Science end of year review procedures assessed by both internal and external examiners.

1.6 This project has been assessed using this checklist and is judged to be

LEVEL 3 (for discussion by Research Ethics Committee)

1.7 If Level 3, is there a date by which a response from the committee is required?

Name Sally Paul Signature.....

A response from the committee is required as soon as possible (hopefully by the 1st December 2011)

PLEASE ATTACH A COPY OF THE RESEARCH PROPOSAL (OR ALTERNATIVELY A DESCRIPTION OF THE RESEARCH)

SECTION 2: POTENTIAL RISKS TO PARTICIPANTS

2.1 Is it likely that the research will induce any psychological stress or discomfort?
YES

If YES, state the nature of the risk and what measures will be taken to deal with such problems.

Given that this research is focused on issues connected to death and dying it is likely that some participants could potentially experience some discomfort or distress. This may be influenced by a prior experience of bereavement and/or a complete lack of familiarity with such concepts. It will be difficult to predict these factors however steps will be taken to glean such information as part of the consent form as well as from staff and parents/carers in relation to children who are participating in the research. All participants will also be made fully aware of the nature of the research and will be able to self-select, at any stage of the research process, with regards to

participating or not. In the event that either a staff member or a child becomes distressed, existing supports within the school will be utilised as well as the hospice bereavement service where necessary. Moreover it is worth highlighting that the researcher has experience of managing distress related to such issues and is practiced in using related vocabulary that 'normalises' such experiences in a safe and supportive manner.

2.2 Does the research require any physically invasive or potentially physically harmful procedures? NO

If YES, give details and outline procedures to be put in place to deal with potential problems.

2.3 Does the research involve sensitive topics, such as participants' sexual behaviour, illegal activities, their experience of violence, their abuse or exploitation, their mental health, or their ethnic status?

YES

If YES, give details.

The research is concerned with developing open discussion around death, dying and bereavement. This can be perceived as a potentially sensitive topic given that it is an issue that affects everyone at some point in their lives. Some participants may have had recent bereavement experiences which may mean that they struggle with the research area and some participants may have previously avoided discussing such topics owing to the perceived difficulty they think it may cause.

2.4 Is it likely that this research will lead to the disclosure of information about child abuse or neglect or other information that would require the researchers to breach confidentiality conditions agreed with participants?

YES

If YES, indicate the likelihood of such disclosure and your proposed response to this.

If there is a real risk of such disclosure triggering an obligation to make a report to Police, Social Work or other authorities, a warning to this effect must be included in the Information and Consent documents.

It is not a purpose of the research to seek out disclosures of information about child abuse or neglect. It is possible, however, that disclosures may be made during the research specifically when the process of action research is to establish a trusting and supportive environment. In the event that a disclosure is made, child protection procedures will be followed in line with the school policy. This information will be obtained at the initial planning stage of the research so that the researcher is familiar with the process. This will be discussed verbally at the beginning of the research and reiterated in the consent forms and information leaflets. Such conversations are extremely common in the social work field and as such the researcher is practiced in this.

2.5 Is it likely that the research findings could be used in a way that would adversely affect participants or particular groups of people?

NO

If YES, describe the potential risk for participants of this use of the data. Outline any steps that will be taken to protect participants.

2.6 Is it likely that participation in this research could adversely affect participants in any other way? YES

If YES, give details and outline procedures to be put in place to deal with such problems.

It is unlikely that participation in the research would adversely harm the participants. As previously discussed, however, some participants may become upset by the subject matter. It will be difficult to predict who may become upset however steps will be taken to glean this information as part of the consent form and from staff and parents/carers in relation to children who are participating in the research. All participants will also be made fully aware of the nature of the research and are able to self-select, at any stage of the research process, with regards to participating or not. In the event that either a staff member or a child becomes distressed, existing supports within the school will be utilised as well as the hospice bereavement service where necessary. The hospice Director and Family Support Manager at the hospice have agreed that if bereavement support is needed it will be immediately accessible.

2.7 Is this research expected to benefit the participants, directly or indirectly?

YES

If YES, give details.

The research will provide opportunities for adults and children to express their views around the research topic in a safe, non stigmatizing and enjoyable way. Research has identified that people, including children, find it beneficial to learn and talk about death and dying (see research proposal). It has been identified as a method of harm reduction in that it is associated with a number of benefits that relate to emotional wellbeing . These include: the acquisition of knowledge, development of self-understanding and a clarification of values, meanings and attitudes towards death (Feifel 1977); enables and prepares people to manage individual experience of, and support those impacted by, death and loss (Kellehear and O'Connor 2008); assists in suicide and violence prevention (Wass 2004); enables better end-of-life experiences for people who are dying and their family (Scottish Government 2008); and equips people with the tools and language to address difficult aspects of loss and death (Jackson and Colwell 2001; McGovern and Barry 2000). .

Additionally the use of action research methods will enable participants to work with a range of people. Such methods have been argued as offering a means not only of generating knowledge but also for its ability for personal and professional development (Noffke and Somekh 2009). For professionals it is a way “to understand themselves and their work better” (Noffke in Noffke and Somekh 2009, p.10) exploring closer connections between personal beliefs and practice. For children, learning research skills can also provide “not only a means to deal with current issues but also develops a sense of agency in dealing with life issues over the long haul” (Noffke in Noffke and Somekh 2009, p.17). Both adults and children may also experience an element of personal growth, becoming more confident in, and comfortable with, managing and discussing issues related to death and dying, “strengthening a community’s inherent capacity to support [each other]” (Kellehear and O'Connor 2008, p.115). Participants’ advice with regards to how services can be developed will be genuinely valued and used in the planning for the action phase of research. It is intended that this participation will be an empowering experience.

2.8 Will the true purpose of the research be concealed from the participants?

NO

If YES, explain what information will be concealed and why. Will participants be debriefed at the conclusion of the study? If not, why not?

SECTION 3: POTENTIAL RISKS TO THE RESEARCHER/S

3.1 Is the research likely to involve any psychological or physical risks to the researcher, and/or research assistants), including those recruited locally?

YES

If Yes, explain what measures will be taken to ensure adequate protection/support.

Given the nature of the research area the researcher will be exposed to a variety of personal stories about experiencing and managing death and dying. At times some of these experiences may be difficult to hear which may have some impact on the researcher. The researcher will meet regularly with the supervisors to discuss both how the research is progressing and its impact on self. The researcher also has supervision with their line manager every 6 weeks. The line manager is the Senior Social Worker/Bereavement Services manager and has a vast experience of supervising staff who are working with people experiencing bereavement. The researcher has also worked in the field of death and dying for 5 years and as such has developed a number of coping strategies for managing this kind of work that include maintaining a healthy work life balance which involves time spent with friends and exercising. The researcher also meets on a monthly basis with other PhD students who are also researching around similar issues. This includes an element of peer supervision, providing space to share troubles and concerns.

SECTION 4: PARTICIPANTS

4.1 How many participants is it hoped to include in the research?

50 (18 Interviews and 4 focus groups with 6 – 8 people per group)

4.2 What criteria will be used in deciding on the inclusion and exclusion of participants in the study?

Owing to the design of the research only children aged 9 and 12 will be approached to participate in the research, as well as teaching and hospice staff. Potential participants will be given clear written and verbal information about the research and will be given the opportunity to ask further questions before deciding if they would like to take part. It will be important to emphasize that deciding not to be involved (for any reason) will not have an impact on the support they receive from the service they are involved in and does not exclude them from participating in the research at a later date. Participants will be able to self-select to be included as research participants and will be given opportunities to opt out of the research at any stage without any adverse effect.

See point 4.3 for more information on inclusion and exclusion of participants.

4.3 Are any of the participants likely to:

be under 18 years of age? YES

be looked after children (including those living in local authority care or those living at home with a legal supervision requirement)? YES

be physically or mentally ill?	NO
have a disability?	Not known
be members of a vulnerable or stigmatized minority?	YES
be unlikely to be proficient in English?	YES
be in a client or professional relationship with the researchers?	NO
be in a student-teacher relationship with the researchers?	NO
be in any other dependent relationship with the researchers?	NO
have difficulty in reading and/or comprehending any printed material distributed as part of the research process?	YES <input type="checkbox"/>
be vulnerable in other ways?	YES

If YES to any of the above, explain and describe the measures that will be used to protect and/or inform participants.

This research will involve conducting research with children aged 10 and 11 within a school setting. It is possible that some of these children may be living away from home, potentially with a legal supervision requirement and/or may be from a vulnerable or stigmatized minority. It is also possible that some of these children may not have English as their first language, which may impact their literacy and comprehension ability. Moreover, owing to the age of the children some of them may have difficulty in reading and/or comprehending any printed material distributed as part of the research process. A number of steps will therefore be taken to ensure that research participants are protected and informed about the research. These include:

An open dialogue will be created with the school so that any child who may be affected by participating in the research, perhaps due to difficulties in their home life, a recent bereavement or difficulties in comprehending English, is made known to the researcher. Steps will be taken to ensure that participation is open to everyone, despite such difficulties, if the child would like to do so. This may mean that additional information is supplied and/or external support is given, such as

- Bereavement support, to ensure that those who are identified are not put at any risk through participation.

- Information about the research and consent will be supplied both verbally and in written form. Consent will be kept a live issue, whereby participants will be reminded they can opt out at any time without giving any reason.
- Translators will be used where necessary.
- Research methods will be designed to be age appropriate. For example, strategies such as rating games and or creative writing.
- Consent for children to participate will also be sort from parents/carers.
- Every effort will be made to ensure that participants feel comfortable and secure. This includes: using venues which are familiar to research participants and where they feel confident; ensuring that refreshments are available; ensuring that support is available for those requiring it (eg participants whose first language is not English, those who would like to be accompanied by a friend, colleague or worker).’

It is also worth highlighting that, due to the nature of working with both adults and children, there is an element of unknown in terms of what ways someone may be deemed vulnerable. For example, some of the children may be experiencing bullying or some of the adults may be experiencing difficulties a home. The researcher therefore intends to practice reflexively in a way that is responsive to the needs of the participants, establishing trust and enabling participants to opt out of the research whenever they feel necessary. The researcher also intends to become extremely familiar with the school process and supports, keeping an open dialogue with the Head Teacher so that any unforeseen circumstances or issues can be managed effectively.

Do the researchers need to be cleared through the Disclosure (Protecting Vulnerable Groups) Scheme? See

http://www.disclosurescotland.co.uk/pvg/pvg_index.html YES

This was obtained in June 2010.

Will it be difficult to ascertain whether participants are vulnerable in any of the ways listed above (e.g. where participants are recruited via the internet)? NO

If YES, what measures will be used to verify the identity of participants, or protect vulnerable participants?

4.4 How will the sample be recruited?

Teachers, hospice staff, and children will be recruited by attending teaching staff weekly meetings, the hospice multidisciplinary meeting team meeting and school assemblies to discuss the research and give out information leaflets. A question and answer session will also be provided. Forms will also be circulated asking

individuals to indicate if they would be happy, or not, for the researcher to contact them further about the work. Parents/carers will be recruited by sending out information leaflets home with their children and holding an information evening at the schools for parents/carers to attend to hear more about the research. At this meeting, forms will be circulated asking individuals to indicate if they would be happy, or not, for the researcher to contact them further about the work. Emphasis will be placed within all of these meetings on voluntary participation, consent, anonymity and confidentiality, as well as explaining the purpose of the research and the possible reasons why people may or may not want to participate.

4.5 Will participants receive any financial or other material benefits because of participation?

NO

If YES, what benefits will be offered to participants and why?

Before completing Sections 5 & 6 please refer to the University Data Protection Policy to ensure that the relevant conditions relating to the processing of personal data under

Schedule 2 and Schedule 3 are satisfied. Details are Available at:

www.recordsmanagement.ed.ac.uk

SECTION 5: CONFIDENTIALITY AND HANDLING OF DATA

5.1 Will the research require the collection of personal information from e.g. universities, schools, employers, or other agencies about individuals without their direct consent?

NO

If YES, state what information will be sought and why written consent for access to this information will not be obtained from the participants themselves.

5.2 Does the research involve the collection of sensitive data (including visual images of respondents) through the internet?

NO

If YES, describe measures taken to ensure written consent for access to this information.

5.3 Will any part of the research involving participants be audio/film/video taped or recorded using any other electronic medium?

YES

If YES, what medium is to be used and how will the recordings be used?

Within the research interviews and focus groups there will be the opportunity to use a digital recorder if participants give their consent. It will be explained that the information will be listened to and transcribed by myself and I will not use real names. I will ask permission to use the participants' words. I will explain that anything they say that they later choose to retract will not be included in the data collection.

5.4 Who will have access to the raw data?

Myself, as the principal researcher, and this will be shared through the analytical process with my supervisors and the Hospice Director (although it will be anonymised at this stage).

5.5 Will participants be identifiable, including through internet searches?

NO

If YES, how will their consent to quotations/identifications be sought?

5.6 If not, how will anonymity be preserved?

Anonymity will be preserved by using pseudonym that will only be known by the researcher.

5.7 Will the datafiles/audio/video tapes, etcetera. be disposed of after the study?

YES

5.8 How long they will be retained?

The information will be destroyed five years after this study.

5.9 How will they eventually be disposed of?

The University of Edinburgh and the Hospice provide a confidential waste disposal service that can be requested.

5.10 How do you intend for the results of the research to be used?

The results of the research will be decided by the action research process. It is intended that the results will also be used by the hospice to inform practice with schools. It is also hoped that a number of journal articles will be written to share the research findings.

5.11 Will feedback of findings be given to participants? YES

If YES, how and when will this feedback be provided?

This feedback will be decided as part of the action research process by the participants.

SECTION 6: PARTICIPANT INFORMATION AND CONSENT

6.1 Will written consent be obtained from participants?

YES

If YES, attach a copy of the information sheet and consent forms.

In some contexts of ethnographic research, written consent may not be obtainable or may not be meaningful. If written consent will NOT be obtained, please explain why circumstances make obtaining consent problematic.

Administrative consent may be deemed sufficient:

- a) for studies where the data collection involves aggregated (not individual) statistical information and where the collection of data presents:
 - (i) no invasion of privacy;

(ii) no potential social or emotional risks:

- b) for studies which focus on the development and evaluation of curriculum materials, resources, guidelines, test items, or programme evaluations rather than the study, observation, and evaluation of individuals.

6.2 Will administrative consent be obtained in lieu of participants' consent?

NO

If YES, explain why individual consent is not considered necessary.

In the case of research in online spaces or using online technology to access participants, will consent be obtained from participants?

If YES, explain how this consent will be obtained.

If NO, give reasons.

All participants who are participating in the research will be asked to give individual consent. This requires that steps are taken to ensure that each participant has a clear understanding of what the research project, what it means to be a participant, and time to address any queries or concerns they may have prior to deciding whether or not they would like to participate.

Information leaflets and consent forms have been designed that provide clear, understandable and age appropriate information about the research. These have been piloted with children, teaching staff, hospice staff and parents/carers to ensure that they read well and give enough/appropriate information. Changes were made reflecting feedback.

6.3 In the case of children under 16 participating in the research on an individual basis, will the consent or assent of parents be obtained?

YES

If YES, explain how this consent or assent will be obtained.

Consent from parents and/or carers will be obtained via sending a letter home (see attached) that explains the purpose of the research and asks for consent for their child to participate. The letter was drafted in consultation with the Head Teacher of the participating schools. Parents/carers will also be invited to attend and information

meeting at the school that will provide an opportunity for any concerns to be raised and any questions answered.

6.4 Will the consent or assent (at least verbal) of children under 16 participating in the research on an individual basis be obtained?

YES

If YES, explain how this consent or assent will be obtained.

Informed consent will be sort from all children who would like to participate in the research. This requires that participants understand what the research project is about and have an opportunity and time to think, ask questions and discuss with others before making a decision. Information leaflets have been designed that provide clear, understandable and age appropriate information about the research. These leaflets also include details of how the researcher can be contacted so that any questions can be answered.

Consent will be an ongoing process that continues throughout all stages of the research. The researcher will emphasise that children can 'opt out' and/or have 'time out' at any time if needed.

If NO, give reasons.

6.5 In the case of participants whose first language is not English, will arrangements be made to ensure informed consent?

YES

If YES, what arrangements will be made?

A translator will be used which can be accessed via XX council. The researcher would also make use of the Multi-Cultural Family Base in Edinburgh.

If NO, give reasons.

6.6 In the case of participants with disabilities (e.g. learning difficulties or mental health problems), will arrangements be made to ensure informed consent?

YES

If YES, what arrangements will be made?

If there are any adults or children that this applies to, discussion with the individual and the head teacher and/or hospice director will take place prior to participation to ensure that all the activities are planned in a way that is inclusive and any additional support needed is provided.

If NO, give reasons.

6.7 Many funders encourage making datasets available for use by other researchers. Will the data collected in this research be made available for secondary use? NO

If YES, what arrangements are in place to ensure the consent of participants to secondary use?

SECTION 7: Unplanned/unforeseen problems

7.1 Is the research likely to encounter any significant ethical risks that cannot be planned for at this stage?

NO

If YES, please indicate what arrangements are being made to address these as they arise in the course of the project.

SECTION 8: CONFLICT OF INTEREST

The University has a 'Policy on the Conflict of Interest', which states that a conflict of interest would arise in cases where an employee of the University might be "compromising research objectivity or independence in return for financial or non-financial benefit for him/herself or for a relative or friend." See:

http://www.docs.csg.ed.ac.uk/HumanResources/Policy/Conflict_of_Interest.pdf

Conflict of interest may also include cases where the source of funding raises ethical issues, either because of concerns about the moral standing or activities of the funder, or concerns about the funder's motivation for commissioning the research and the uses to which the research might be put.

The University policy states that the responsibility for avoiding a conflict of interest, in the first instance, lies with the individual, but that potential conflicts of interest should always be disclosed, normally to the line manager or Head of Department. Failure to disclose a conflict of interest or to cease involvement until the conflict has been resolved may result in disciplinary action and in serious cases could result in dismissal.

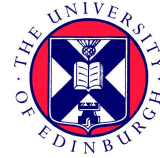
8.1 Does your research involve a conflict of interest as outlined above

NO

If YES, give details.

Appendix 7: Ethical review letter to LA

18th January 2011



Dear XXXXX,

I am writing to seek ethical approval from XXX Council for my PhD research study entitled:

Let's talk about death and dying: an exploration of how schools and hospices can work together to address the social taboo of death and dying with children.

Research has identified that there is a social taboo around talking about death and dying, particularly with regard to children. 'Health promoting palliative care' is an idea that has arisen to help tackle this taboo. It aims to develop conversations about death and dying, believing that if we are more open about it and treat it as a normal part of life we will be much more emotionally and physically able to support ourselves and each other through death and bereavement. This research intends to explore to what extent this social taboo exists in Scotland and how schools and hospices can work together to break down barriers and encourage more openness about death and dying with children.

I am currently employed by Strathcarron Hospice as a PhD researcher with Edinburgh University. I previously worked at the hospice as a social worker and the children's bereavement coordinator which involved facilitating one-to-one and group support for children and their parents/carers, as well as bereavement training for professionals in a variety of fields. In this position I was continuously aware of how adults sometimes struggled to discuss death, dying and bereavement with children, often meaning that children were excluded from information about significant aspects of their lives. The idea for this research came as an approach to help tackle this issue. It is supported by the hospice management team who are keen to explore better ways at working with schools to break down the social taboo that surrounds death, dying, bereavement and hospice care.

The following research questions will provide the focus for the research:

1. How is the social taboo about death and dying in relation to children in Scotland understood and experienced?
2. In what ways might the principles and practice of health promoting palliative care encourage and facilitate a new approach to death and dying for children in Scotland?
3. Should schools and hospices work more closely to try to achieve this?
4. If so, how can models of health promoting palliative care be developed? What can we build on and what are the challenges and obstacles?

In attempting to address these questions I intend on recruiting two primary schools to participate in this research. At each school I hope to:

- Interview six teachers to explore their experiences of talking about death dying and bereavement with children and identify possible ways that the school and hospice can work together.
- Speak to a group of parents and/or carers about their views on talking to children about death, dying, bereavement and hospice care.
- Speak to a group of children, aged 9 and 12, to discuss their experiences of having conversations about death, dying and bereavement. This group will be informed by the interviews with staff and parents/carers and will include a variety of age appropriate facilitation methods.
- Establish a small research team who will critique and explore new ideas, as suggested in the previous interviews and focus groups, for hospice and schools working together. It is hoped that one or two of these ideas will be tried out and evaluated. The team will hopefully include two hospice staff members, two teachers, two parent/carers and two children.

All of the above would be arranged at a time that suits the schools and is in line with their policies and procedures.

This research design is based on action research methods that seek to engage the experience and expertise of participants to inform, develop, and shape effective practice. It is also underpinned by the assumption that children have a right to be heard and their views taken in to account in the development of services, as outlined in Article 12 of the United Nations Convention on the Rights of the Child.

This research has been awarded ethical approval from both the School of Social and Political Science Research Ethics Committee at Edinburgh University and the Research and Audit Group at Strathcarron Hospice. This has included addressing issues of informed consent, confidentiality, anonymity and reporting abuse or neglect. Each person participating in the research will be asked to sign a consent form that identifies that they have understood the research and are aware that they can opt out at anytime. Consent will also be needed from the parents/carers of children participating in the research. All names will be changed in all research documents. All personal information will be treated as confidential unless a participant reveals that they, or someone they know, is at risk of harm. In this case the researcher will act as per school and hospice procedures.

The results from this research will be written up in a report. A short report of the findings will be compiled and shared with the participating schools and the Head of Education for XXX. The findings from the research may also be used for research publications to share the work that has been done with the wider education and hospice community. Direct quotes from the interviews will be used in these materials, however these will be anonymised.

If you would like to talk to someone else about the study please feel free to contact my supervisors at Edinburgh University: Professor Vivienne Cree, on 0131 650 3927; or Professor Scott Murray on 0131 650 9498.

If you have any concerns about the study, please contact XXX, Hospice Chief Executive, on XXX.

Thank you in advance for taking the time to consider this application for ethical approval. I look forward to hearing from you.

Kind regards

Sally Paul

XXX Hospice / Edinburgh University

Tel: XXXXX

Email: sally.paul@nhs.net

Appendix 8: Hospice presentation for ethical approval

Slide 1

**Let's talk about death and dying:
An exploration of how primary
schools and hospices can work
together to address the social
taboo of death and dying with
children aged 9 and 12.**

Sally Paul
Patient and Family Support Team
PhD Researcher
sally.paul@nhs.net

Slide 2

Background

- Experience of children's bereavement service
- Anecdotal evidence from school staff about managing bereavement and related conversations
- Interest from hospice to:
 - a. Work systematically with schools
 - b. Widen presence within the community to assist in breaking down associated stigma
 - c. Fulfil role in health promoting palliative care as per new policy making

Slide 3

Context (1)

- Bereavement is a universal experience
- Reluctance to talk about death (Conway 2007)
70% of people in Scotland feel that as a society we do not discuss death and dying (SPPC 2003).
- Communities less able and less prepared to support each other (Kellehear and O'Connor 2008)
- Most research and literature focuses on bereavement, specifically as a difficult and problematic experience.

Slide 4

Context (2)

Talking about death and dying can be seen as method of 'harm reduction':

- Allows acquisition of knowledge, development of self-understanding and a clarification of values, meanings and attitudes towards death (Feifel 1977).
- Better prepared for individual experience of, and more able to help those affected by ,death and loss (Kellehear and O'Connor 2008)
- Enables better end-of-life experiences for the person who is dying and their family (*Scottish Government 2008*)
- Introduces death as normal and non-frightening, giving the tools and language to address difficult aspects of loss and death (Jackson and Colwell 2001, McGovern and Barry 2000)

Slide 5

Context (3)

- Death education as in line with public health promotion, i.e. working WITH people to raise the health, safety and well-being of the local community (Kellehear 2007)
- Children viewed as a neglected and problematic group in death education (Wass 2004, Jackson and Colwell 2001)
- Know we should talk about death to children but little research on how to do this (Embedded in larger curriculum? Wass 2004, Jackson and Colwell 2001)

Slide 6

Context (4)

Recent shifts in policy making:

- End of Life Care Strategy (Department of Health 2008)
- Living and Dying Well (Scottish Government 2008)

Emphasis on action to promote awareness and change community attitudes and values around death and dying .

- In Scotland, recommendation 10 includes:
“Engage with educational establishments, planners and practitioners to ensure that children [...] develop the attributes, capabilities and capacities which will enable them to be comfortable and confident in talking about and dealing with death, dying and bereavement” ([Scottish Government 2010; 5](#))

Slide 7

Research Aim:

To explore practice in which hospices and schools can work in partnership to facilitate and promote discourse around living, dying and palliative care, with children, from a health promotion perspective.

Research Questions:

1. How is the social taboo about death and dying in relation to children in Scotland understood and experienced?
2. In what ways might the principles and practice of health-promoting palliative care encourage and facilitate a new approach to death and dying for children in Scotland?
3. Should schools and hospices work more closely to try to achieve this?
4. If so, how can models of health promoting palliative care be developed? What can we build on and what are the challenges and obstacles?

Slide 8

Research Design

Stage one: Preparation and scoping

- Literature review
- Identify current health-promoting palliative care projects involving children.
- Develop themes for interviews and focus groups from both the literature and existing projects
- Recruit two primary schools to participate (one faith school and one non-denominational school)

Slide 9

Stage two: Identifying challenges and possible approaches

- Interviews and focus groups to develop discussion and explore ideas related to how the social taboo of death and dying is experienced by children and exploring possible health-promoting palliative care practice with schools.
- 18 interviews in total: 12 with teachers (6 in each school) and 6 with hospice staff.
- Minimum of 4 focus groups; 2 with children and 2 with parents/carers
- Data generated from interviews and focus groups transcribed and thematically analysed.

Slide 10

Stage three: Developing a model(s) for possible interventions

- Focus groups with relevant stakeholders (teachers, children, parents/carers and hospice staff) to explore possible practice and generate ideas about ways forward.

Stage four: Piloting developed practice(s)

- Stage five: Evaluation of the new practice(s) in parallel with stage four.

Slide 11

Ethical challenges/considerations

- Sensitive area
- Anxiety from teaching staff
- Anonymity
- Involving children as researchers: Harm and benefits, confidentiality, child protection, keeping informed consent 'a live issue', possible payment (Cree et al 2002)

Slide 12

THOUGHTS/COMMENTS?

Slide 13

Dissemination

- Conference attendance and Journal Article(s) across Palliative Care Community
- Possible development of work-book about setting up the pilot project
- Also decided via research Process

Slide 14

References

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- Wass H (2004) A perspective on the current state of death education, Death Studies, 28: 289 - 308

Appendix 9: Letter home to recruit parents/carers and ask for consent for their child to participate [RCPS: for ethical approval]

Dear Parents,

Information & Permission for Participation in a Research Project with Strathcarron Hospice

It has been identified that there is a social taboo around talking about death and dying, particularly with regard to children. Due to this, the needs of children are sometimes ignored and they are often left ill-prepared to cope or support others with what is a natural and important part of life. Health promoting palliative care is an idea that has arisen to help tackle this taboo. It aims to develop conversations about death and dying, believing that if we are more open about it and treat it as a normal part of life we will be much more emotionally and physically able to support ourselves and each other through death and bereavement. This research aims to explore to what extent this social taboo exists in Scotland and how schools and hospices can work together to break down barriers and encourage more openness about death and dying with children.

My name is Sally Paul. I am currently employed by Strathcarron Hospice as a PhD researcher with Edinburgh University. I previously worked at the hospice as a social worker and the children's bereavement coordinator which involved facilitating one-to-one and group support for children and their parents/carers, as well as bereavement training for professionals in a variety of fields. In this position I was continuously aware of how adults sometimes struggled to discuss death, dying and bereavement with children, often meaning that children were excluded from information about significant aspects of their lives. The idea for this research came as an approach to help tackle this issue.

The research project has been approved by Strathcarron Hospice, Edinburgh University, XX Council Education Services and by the Headteacher of XXX primary school.

Two of the main purposes under the new Curriculum for Excellence in schools are to develop responsible citizens and confident individuals. As adults we know that illness and bereavement are part of the human experience and therefore if we want the best for our children it would be sensible to help them better understand these issues allowing them an increased chance to cope with these challenges when they inevitably come to them and their family. By doing this we increase their emotional intelligence and encourage their resilience as they grow and mature to adulthood.

As part of the project I would seek your support in allowing me to discuss these issues with your child within the supportive school setting. This would be done in agreement with your child who will have the option to decide not to participate if they wish, and without giving a reason. Furthermore I would ask for your own involvement in taking a little of your time in small group conversations to gain your views on how these delicate issues should be managed when talking to children.

There is a real opportunity to better understand the views of children and parents and thus form practical strategies that will be helpful to all in coping with illness and bereavement.

I hope you show your interest by completing the tear-off slip below and returning to the school. I will also be holding an information session to discuss the research in more detail and answer any questions you may have. The meeting will be held on *[date]* at *[location]*. If you would like to attend this meeting, please indicate on the slip below. Alternatively if you are unable to attend the meeting and still have questions please feel free to contact me on (01324) 826 222 or by email on sally.paul@nhs.net

Thank you for your support. Sally Paul

ADULT PARTICIPATION

As a parent I would like to join your focus group.

NAME: _____ TEL

NO: _____

CHILD PARTICIPTION

I give permission for my child to join your focus group.

NAME: _____

CLASS: _____

[please tick]

I am interested in attending the information session on *[Date and location]*

I am not interested in attending the information session.

I cannot attend the information session but would like to be contacted to discuss the research before giving my permission. You can contact me on

_____.

Appendix 10: Letter home to parent/carers asking them to opt child out of research [RCPS]

Dear Parents,

Information & Permission for Participation in a Research Project with Strathcarron Hospice

It is well known that there is a social taboo around talking about death and dying, particularly with regard to children. Due to this, the needs of children are sometimes ignored and they are often left ill-prepared to cope or support others with what is a natural and important part of life. Two of the main purposes under the new Curriculum for Excellence in schools are to develop responsible citizens and confident individuals. As adults we know that illness and bereavement are part of the human experience and therefore if we want the best for our children it would be sensible to help them better understand these issues allowing them an increased chance to cope with these challenges when they inevitably come to them and their family. By doing this we increase their emotional intelligence and encourage their resilience as they grow and mature to adulthood.

This coming term we are very excited to have Sally Paul working with us. Sally is employed by Strathcarron Hospice as a PhD researcher, with Edinburgh University. She previously worked at the hospice as a social worker and the children's bereavement service coordinator which involved facilitating one-to-one and group support for children and their parents/carers, as well as bereavement training for professionals. Her research project is looking at how people talk or don't talk to children about death and dying as well as coming up with new ideas to see how the school can work with the Hospice to help adults talk and educate children about death in a way which is helpful. The research project has been approved by Strathcarron Hospice, Edinburgh University and XXX Council Education Services, as well as my self at XXX Primary School. She has a vast experience of talking to

children about issues related to death and dying and is keen to develop new ways forwards in this area that keeps the needs of children firmly in focus.

As part of her research Sally hopes to speak to teachers, parents/carers, children and hospice staff. She has already begun approaching staff and on XXX will be coming to talk to classes P6 and P7 about her research. She will give the children information about the research and how they can be involved. At the end of the session each child will be given the enclosed information sheet and invited to participate. If a child decides not to participate in the research they will not be asked to give reasons.

As part of this project I would seek your support in allowing Sally to discuss this research with your child and invite them to choose if they would like to be involved, within the supportive school setting. There is a real opportunity to better understand the views of children and thus form practical strategies that will be helpful to all in coping with illness and bereavement. If, however, you would not like your child to be present during this session please let me know by tearing off the slip below and returning it to school.

If you have any questions or concerns please do not hesitate to contact either myself on (01324) 508 570 or Sally on either (01324) 826 222 or by email on sally.paul@nhs.net

Thank you for your support.

XXX

Head teacher

RESEARCH PROJECT WITH STRATHCARRON HOPSICE

I do not want my child to be present during the information session on the above research project.

CHILDS

NAME: _____ CLASS: _____

Appendix 11: Letter home to recruit parent/carers [RCPS]

Dear Parents,

Invitation to participate in a Research Project with Strathcarron Hospice

Last week I wrote to inform you about a research project we are involved in with Strathcarron Hospice. This project looks at how adults talk to children about illness, death and bereavement, focusing on developing new ideas to see how the school and hospice can work together to talk about these issues in a way that is helpful. Since this letter, the researcher, Sally Paul, has now discussed the project with the children and has received an overwhelming positive response. Over 70% of the children she told about the project are interested in participating and would like to share their views and ideas about what they have found, and would find, helpful.

I am now writing to invite you to be part of this exciting research project. I have attached an information sheet which gives more information about the research and what it would mean to be involved. Your views and experience on this issue are extremely important. It is a great opportunity to share your thoughts and ideas and assist in forming practical strategies that will be helpful to all in coping with illness and bereavement.

If this is something you would like to be involved in please fill in the slip below and return it to school by XXX.

Thank you for your support.

XXX

RESEARCH PROJECT WITH STRATHCARRON HOPSICE

Name: _____

Please tick:

I am interested in participating in the research project.

I am interested in being part of this research project but would first like to discuss some questions I have with Sally

Please contact me by [please tick]:

Phone: _____ Email: _____

Appendix 12: Findings from phase two [RCPS]

Overview of interviews and focus groups with adults (teaching staff, hospice staff and parents):

Provisional themes (ambiguities) re discussing palliative care, death and dying with children:

- Not something that is currently taught. Usually up to individual teachers.
- Most conversation and teaching about these issues is reactionary.
- Parallel with sex education
- Faith can give a useful framework for discussion.
- A reliance on parents to give permission to support children in bereavement issues.
- Lack of confidence with regard to talking about these issues (feeling out of comfort zone)
- There is a need to talk about these issues - it makes sense to do so as children are taught everything else.
- Such education is suitable across all ages. P6 mentioned a few times, however, as being a particularly good age.
- Such education may benefit from a national/local focus to get these issues forward into the curriculum.
- Education for staff may be needed.

Challenges to developing this work:

- Potentially a controversial subject for adults.
- Personal challenge. Some people feel they don't have the skills and language to do this work. Conversations are particularly difficult if it involves young people who are ill or who have died.
- Needs/wishes of the parents.
- Different religious and cultural beliefs.
- A lack of awareness from adults about what the hospice is/does.
- Some staff may not want to do this kind of work.
- Not enough hospices to go round if this kind of work is offered to every school.
- Different needs of children.
- Possibly contradicting what parents have told their children at home with regard to these issues.
- No training given to teachers on this area in university or continuing professional development.
- When parents don't give permission.
- Practical challenges – such as getting to the hospice, space for small group/1-1 work and so on.

Opportunities to develop this work:

- Flexibility within new Curriculum for Excellence.

- Helpful to engage with children when they are not in the middle of a related experience.
- Visiting hospices could add a perspective to an education programme about the issues of death and dying.
- Faith may help to engage parents/get their support as death is a big part of Catholicism.
- Relationship with the hospice to use expertise in these areas and provide factual information.
- Children naturally inquisitive and want to know about these things.

Overview of focus groups with children:

Generally the children expressed that people do not talk to them about illness, death and dying in school. This was with the exception of one group, who said their teacher did talk to them about it once in relation to a book they had read.

Some of the children's parents talked to them about death, but only when someone had died. Some children were told by their parents when someone was very ill, but some were not. The children in this situation said it would have been helpful to know sooner.

Reasons why the children felt it is **good** to talk about illness, death and dying included:

- It helps you to prepare
- It helps you understand
- You can learn how to cope
- It is part of life
- You can express yourself
- It helps you to remember
- You can spend more time with people who are dying
- So you're not scared
- It is part of learning

Reasons why children felt it might be **difficult** to talk about illness, death and dying included:

- Managing emotion in class
- If you are currently going through a bereavement experience
- If it is a new experience
- If it brings back bad memories
- Worrying about the future ("it might happen to you")
- Not wanting to share personal stories
- Adults worrying how children will react

Each group was also asked **what they would like to know** about illness, death and dying. Answers seemed to come under three themes. These included: knowing specific details about illness, death and dying; spiritual and religious questions; and grief reactions.

Details:

- Why do our organisms survive for only around 100 years?
- How can you be dead, but you can donate lungs and stuff?
- What is the main cause of death?
- Why do guns kill you?
- Do people die every day?
- What is leukaemia cancer?
- Does it hurt when you die?
- How do you get cancer?
- How can smoking kill you?
- Why do people smoke?
- Is there a cure for cancer?
- Do you get brain cancer?
- How can drink kill you?
- How can smoking kill people?
- Can you die of smoking?
- What happens to the corpse?
- What [does] it feels like when you die?
- How death is caused.
- How to prevent death.
- How death apart [happens]?
- How painful is the pain?
- What happens to dead people's bodies before they are buried, burned, or have any other type of funeral?
- What happens to the bodies after they have been buried?

Spiritual

- Why do people murder each other?
- Is God real?
- Why it happens. I would like to learn how to control death.
- Why might it happen?
- Why can't we all just live?
- Why do people commit suicide?
- How to tell people about death without making them upset?
- To know if they can see you in heaven.
- Why do people get buried and some get cremated? (x2)

Coping with grief/managing emotions

- Why is it so sad?
- Why don't people talk about death? (x2)
- Why is it so upsetting?
- How can it make other people upset?
- Why does the pain keep coming back like a swarm of bees all the time?
- Why some people take it harder than others?

- I'd like to know that other people cry.
- How to move on?
- How talking to your kids about death frightens them [adults]?
- What would happen to the person who got told that someone died?
- How do you deal with death and dying?
- How should I respect other people's family members that die?
- Learn how to talk about death.

Ideas for practice between hospices and schools

Several opportunities for teaching about palliative care, death and dying within current curriculum were highlighted. This involved teaching as part of:

- RE
- Personal development
- Education for love
- Growing up programme
- Health and Wellbeing programme
- Science (in relation to drugs and alcohol)
- Go Yellow Day
- Including people who have died or who are ill in daily prayers
- Novels that are read in class (for example, linking the story lines to real-life situations, talking about how it felt, support etcetera)
- All Souls' and All Saints' Day
- Topics already being taught, such as teaching about the Egyptians, Jacobites and substance abuse
- Using Health jotters (such as writing about if someone has died and how this felt)
- Part of business studies (the hospice as a business)

These opportunities fell within three different strands that included: One-off projects; integration throughout the curriculum; and support/education for staff. A number of activities were discussed that could be developed within these strands to take forward work in this area. There were based on providing specific education on issues connected to illness, hospice care, death and bereavement to pupils, staff and parents as well providing opportunities to share feelings and experiences. Specific activities mentioned included:

- Give education on cancer (i.e. truth about diagnosis, treatments, survival etcetera). The school nurse could be involved or real people could be invited in (parents/grandparents/hospice patients) who have had cancer experiences.
- Have a topic and/or project on palliative care and/or death and dying. For example, Positive Palliative Care, which could include someone coming in from the hospice and speaking about real people or bringing a patient in to school or doing a power point with photographs. Homework could include bringing in photos of memories.

- Enhance 'Go Yellow Day'. This could include: providing education packs suitable for each age group that would say what the hospice is/does; providing a list of possible education projects; and asking different staff to go into the schools each year to talk about what they do.
- School doing one-off projects for the hospice (and discussing the hospice at the same time), such as the nursery children planting flowers and bringing them to the patients.
- The Hospice providing education to school staff on bereavement and/or illness. This could be part of CPD.
- The Hospice providing education to children on how to cope when people are ill or when someone dies, where they can get support, who can help, how to support other people and how to support their community. This could also be done with teachers.
- The hospice providing education sessions to parents on what they do and what services they have and so on.
- Small group work. Examples included: the hospice and/or teachers talk to P6 and P7 children about what they know (like that medication can work sometimes, but not always) and what questions they have; allowing an opportunity to express feelings together; children invited to bring in photos and talk about people that have died.
- Ask carers to come in to school and talk about what it is like to take care of someone who is very ill.
- School visits to the hospice as part a one off projects or integrated into the curriculum. Pupils could see the grounds, meet day care patients, learn what services they have etcetera. Staff could go in to schools before this. (Give away pencils, wrist bands, rubbers etcetera to prompt children to take their experience home to parents)
- Schools visits to the hospice WITH parents invited.
- Pupils teaching patients activities, such as arts and crafts.
- Interviews with hospice staff (children as a reporter, planning questions before they come as part of a project) using the different professions within the hospice (nurse, Dr, social worker, physiotherapist).
- Hospice or teachers running workshops on grief/feelings.

- Develop an ambassador programme (children selected from the school to visit the hospice and then to share what they have learnt with the rest of their class/school)
- Class quiz on hospice care
- Make a video of the hospice to show children and then send a hospice representative from the hospice afterwards to answer questions.
- If any money is raised, ask a class from the school to come into the hospice with the cheque.
- Have a special mass to think about the people who have died.
- Ask people in assembly if they are feeling sad and then talk to them individually.
- Have a worry box that children could put something they are sad about in and then someone could go and speak to them about it.
- Do a health exercise, such as getting into pairs and talking about if someone has died in your family.
- Make a poster of memories that you have of a person who died (someone you know or famous).
- Talk about experiences in a classroom so that you know it has happened to other people.
- Set dates each year when people talk about who has died and how they feel, for example, every month remember the people who have died in class.
- Putting together a list of fiction books that involve issues related to palliative care, death and dying that could be read in class.
- Develop a bereavement guideline/policy for when someone dies

Key themes discussed around the development of these activities were:

- An emphasis placed on ‘seeing’, such as showing photos of the hospice or bringing people into the hospice so that they see what it is really like.
- Not making education and conversation about these issues too serious, i.e. “talking with games”
- Giving people a choice to participate/opt out if they feel upset and providing support for this.
- Involve parents where possible.

- Simple message with younger children (e.g. keeping yourself healthy/life span) getting more complex (e.g. the role of medicine and when unexpected things happen).

Appendix 13: Letter home to parent/carer asking to opt child out of research [NDPS]

Dear Parents,

Information & Permission for Participation in a Research Project with Strathcarron Hospice

It is well known that there is a social taboo around talking about death and dying, particularly with regard to children. Due to this, the needs of children are sometimes ignored and they are often left ill-prepared to cope or support others with what is a natural and important part of life. Two of the main purposes under the new Curriculum for Excellence in schools are to develop responsible citizens and confident individuals. As adults we know that illness and bereavement are part of the human experience and therefore if we want the best for our children it would be sensible to help them better understand these issues allowing them an increased chance to cope with these challenges when they inevitably come to them and their family. By doing this we increase their emotional intelligence and encourage their resilience as they grow and mature to adulthood.

This coming term we are very excited to have Sally Paul working with us. Sally is employed by the Hospice as a PhD researcher, with Edinburgh University. She previously worked at the hospice as a social worker and the children's bereavement service coordinator which involved facilitating one-to-one and group support for children and their parents/carers, as well as bereavement training for professionals. Her research project is looking at how people talk or don't talk to children about death and dying as well as coming up with new ideas to see how the school can work with the Hospice to help adults talk and educate children about death in a way which is helpful. The research project has been approved by Strathcarron Hospice, Edinburgh University and XXX Council Education Services, as well as my self at XXX Primary School. She has a vast experience of talking to children about issues

related to death and dying and is keen to develop new ways forwards in this area that keeps the needs of children firmly in focus.

As part of her research Sally hopes to speak to teachers, parents/carers, children and hospice staff. She has already begun approaching staff and on XXX will be coming to talk to classes P6 and P7 about her research. She will give the children information about the research and how they can be involved. At the end of the session each child will be given the enclosed information sheet and invited to participate. If a child decides not to participate in the research they will not be asked to give reasons.

As part of this project I would seek your support in allowing Sally to discuss this research with your child and invite them to choose if they would like to be involved, within the supportive school setting. There is a real opportunity to better understand the views of children and thus form practical strategies that will be helpful to all in coping with illness and bereavement. If, however, you would not like your child to be present during this session please let me know by tearing off the slip below and returning it to school.

Sally will also hold an information session to discuss the research in more detail and answer any questions you may have. The meeting will be held on *[date]* at *[location]*. If you would like to attend this meeting, please indicate on the slip below. Alternatively if you are unable to attend the meeting and still have questions please feel free to contact her on (01324) 826 222 or by email on sally.paul@nhs.net

Thank you for your support.

XXX

Head teacher at NDPS

RESEARCH PROJECT WITH STRATHCARRON HOPSICE

I do not want my child to be present during the information session on the above research project.

CHILDS

NAME: _____ CLASS: _____

ADULT ATTENDANCE AT INFORMATION MEETING

Name: _____

[please tick]

I am interested in attending the information session on *[Date and location]*

I am not interested in attending the information session.

I cannot attend the information session but would like to be contacted to discuss the research before giving my permission. You can contact me on _____.

Appendix 14: Letter home to recruit parent/carers [NDPS]

Dear Parents,

Invitation to participate in a Research Project with Strathcarron Hospice

Last week I wrote to inform you about a research project we are involved in with Strathcarron Hospice. This project looks at how adults talk to children about illness, death and bereavement, focusing on developing new ideas to see how the school and hospice can work together to talk about these issues in a way that is helpful.

I am now writing to invite you to be part of this exciting research project. I have attached an information sheet which gives more information about the research and what it would mean to be involved. Your views and experience on this issue are extremely important. It is a great opportunity to share your thoughts and ideas and assist in forming practical strategies that will be helpful to all in coping with illness and bereavement.

If this is something you would like to be involved in please fill in the slip below and return it to school by XXX.

Thank you for your support.

XXX

RESEARCH PROJECT WITH STRATHCARRON HOPSICE

Name: _____

Please tick:

I am interested in participating in the research project.

I am interested in being part of this research project but would first like to discuss some questions I have with Sally

Please contact me by [please tick]:

Phone: _____ Email: _____

Appendix 15: Findings from phase two [NDPS]

Talking to children about death dying and palliative care: provisional themes and ideas

Talking with Adults [teachers and hospice staff]: provisional themes (ambiguities)

- Not something that is currently taught. It often depends on individual teachers.
- Most people felt that death and dying should be talked about with children.
- Talking and teaching about death, dying and bereavement can potentially help children to develop skills and can potentially help break down taboos associated with death and dying
- Most conversation and teaching about these issues is reactionary, i.e. when somebody dies. It is sometimes taught in RE (how different faiths/cultures cope with dying).
- No training is currently given to teachers on talking about bereavement and/or serious illness.
- General lack of confidence with regard to talking about these issues (feeling out of comfort zone, worrying that staff might upset the child or worry children unnecessarily).
- Teachers sometimes rely on parents to give permission to talk to and/or support children in bereavement issues.
- Some people unsure what the school procedure is when a child experiences a bereavement
- Sometimes parents need help before the child can be helped.
- Some uncertainty about how the hospice can help the school as they have previously only been involved in fundraising.

Specific Challenges:

- Teachers don't always know what is going on personally for children. Talking about these issues needs to be sensitive to families' needs.
- Parents may not agree with teachers talking to their child about these things.
- The personal experiences of teachers may impact on their ability to teach/discuss such issues.
- Not all teachers will feel this is their role (it is the job of the parents).
- Some teachers may lack confidence in this area.
- The curriculum is already busy and therefore it could be difficult to fit anything else in.
- It can be difficult to talking about death and dying whilst respecting individual family parental beliefs.
- Schools working with the hospice may be challenging as there are so many schools.

Opportunities for developing such work:

- Flexibility within new Curriculum for Excellence.

- Potential to integrate teaching about death and dying into a variety of aspects of the curriculum.
- Relates to health and wellbeing in the curriculum and building resilience.
- Links to teaching about life in general.
- Relates to building resilience.
- A relationship with the hospice would enable them to share their expertise in this area.
- Parents are generally supportive of school and trust teachers
- Builds equity of care/education – every child will get the same skills and/or knowledge
- Hospices could help facilitate and/or do generic training to reduce their workload of reaching all schools.
- Developing this area links to creating an open door policy where children feel free to share worries/ask for help
- Such education is potentially suitable across all ages if designed well.

Talking with children: provisional themes (ambiguities)

- Generally children said they were not spoken to about death, dying and serious illness at home or school.
- One person remembered their teacher telling them about their father who had died.
- Some children remembered doing a family tree in school, which meant they had to ask their parents about people who had died. Some parents found this difficult.
- Death was covered in some books (such as *The Boy in Striped Pyjamas*) and subjects (such as World War 2), but not talked about much.
- One group of children thought that teachers and/or parents did not talk to them about death because they were worried they might get upset or they might upset the child.
- Most children had experienced the death of someone important in their family (grandparents, a neighbour, a parent, a dog, uncles, an aunt, a sister's boyfriend). This was due to a range of circumstances including cancer, suicide and drug overdose. Not all children knew how the person had died.
- Two children discussed coming back to school after someone had died and being surrounded by a crowd of people who wanted to find out what had happened/where they had been. "The worst thing is when somebody dies and you come back to school they all crowd around you". The children said they would have preferred had their friends just "acted normal" or "left them alone".
- 1 child was experiencing someone close to their family who was dying. The person had not told their children and they thought this was wrong.
- 3 children had experience of the hospice through relatives that had been there, "It was a bit scary when I first went there [...], because I had never been there before".

- Some children said they were familiar with death through video games, books and films.
- Most children thought that people should talk to them about death and dying. It “should be encouraged [...] so that they know about death before somebody like they really love dies”
- They thought that children should be introduced to these conversations from ages 5 to 7.
- Some children worried that if the teacher didn’t know the children well they might say something that upset somebody. If this happened, they thought the child should tell someone like their parent, support worker or the teacher. One child said that a teacher would never mean to upset someone.

The children were asked why it might be **good** to talk about illness, death and dying. Answers included:

- So you can let it out before it gets really bad and start crying and that
- Because if they experience death there is a way to talk about it
- Let it all out. It really helps
- Make sure that kids are okay when they experience it
- If they know about death they can cope with an actual death
- It is what he [the deceased] wanted
- It will make you feel better and then you’ll feel much better, much more relaxed then.
- It’s a key thing in life
- So you can get ready for it and prepare (2x)
- We can learn more about it (2x)
- So they know that it will happen (2x)
- So people won’t get a shock when someone dies
- So you will not be so sad when someone passes away
- I think it is good to talk about it, because you would spend the last with them and you would be less sad
- We know we won’t have them around anymore
- So that can get over it and understand why it happens (2x)
- So that children will understand when someone does die
- I think it might be good to talk about death because people won’t be sad

The children were asked why it might be **difficult** to talk about illness, death and dying. Answers included:

- Because people don’t like death
- It may be scary and weird
- Because I don’t like talking about it (2x)
- “People are sometimes scared about death”
- Because the adult might be very emotional and it might not help, it might make it worse
- It might be difficult because sometimes the child might not understand
- It also could be difficult because the child could be very attached to the person who has died
- I think it will be difficult because you want them to stay a little longer

- Losing loved ones is hard to forget
- You hate them being in pain “You don’t want them to die in pain”
- Some people will be not be ready to talk about it (2x)
- Because they might get emotional (2x)
- It will make you all emotional (3x)
- Talking about death isn’t easy
- Loved ones are hard to let go

Children were asked **what they would like to know** about illness, death and dying. Answers included:

- What is the difference between buried and cremated?
- Why do you get buried?
- Why do you get cremated?
- How does cancer grow back?
- What do they do with your heart when your brain is dead?
“If you die brain-dead, what do they do with your heart that’s still beating”
- What is a brain tumour?
- Do you think people will ever find a cure for cancer?
- Where did you die in the old days, 600BC?
- Why do people get cremated?
- How does cancer start?
- Why do adults not talk to someone who has died even though they say they have accepted it?
- Why do I die?

Children’s experiences of participating in a research group:

- I am happy twice, well two times, for two reasons, because I let it out and we are not doing work
- I like this club [...] because you got to ask questions.
- I like the club and I felt happy because I was missing work and I felt happy because I got to say things about death so that I wouldn’t feel as sad.
- Okay. But I missed gym.
- I feel happy, because I got to say it all out loud about how I feel and stuff
- [I learnt] about death, about how death is, that it’s the same all over.
- I felt good to just like learn about death and dying, so I am well up for it now and I am going to be okay when it happens when I am older.
- I thought I was going to be a bit uncomfortable, but I was actually fine.
- I think it was good.
- I feel like I learnt a lot about death and dying and that and I enjoyed it
- It was fun. Better than a spelling test.

How to introduce discussion and education in death, palliative care into the school: IDEAS

A number of ideas were suggested for ways to move this area forward in the school. These focused on: integrating teaching and discussion on death and dying into the

curriculum; holding one-off lessons and enhancing bereavement support and skills. Specific ideas were:

Ideas suggested by adults:

- Make explicit a bereavement procedure in the school so staff members know what to do.
- Hospice staff provide information/training/workshops to teachers on bereavement support (including how to answer any questions). This could be done on an in-service day.
- Hospice staff provide bereavement support to individual children where necessary and let the school know where they can get other support.
- Hospice staff share materials (films, books etcetera) for what to use to stimulate discussion on bereavement, for example as part of a book study.
- Hospice staff could come into school to speak to teachers/children about what they do and answer any questions (could use a video, website etcetera as a prompt before, after or during).
- Hospice to help with curriculum development.
- Visiting the hospice to speak to people who are there – either teachers or children.
- Use stories/narrative/drama to discuss death, dying and palliative care. For example: use books that discuss a child/parent not being well as part of a book study or ask children to share their experiences and make up a short drama sketch.
- Get hospice staff in to talk about what they do (either to children or teachers or parents).
- Develop a resource to be used - something similar to ‘Box of Feelings’ and ‘House of Emotions’ for death and bereavement (perhaps set around a courtyard where lots of people live with different stories, similar to Wellington Square story book). You could use it for individuals or with groups.
- Using fundraising for the hospice as an opportunity to talk about what happens.
- Part of business studies: examples of business; i.e. planning events; advertising.
- Interviews with staff (children as a reporter, planning questions before they come as part of a project, using the different professions within the hospice - nurse, doctor, social worker etcetera).
- Workshops on grief/feelings.
- Develop ambassador programme.
- Class quiz on hospice care.

Ideas suggested by children:

- Show a video that shows you about death and dying
- Have a club (Suggested name: A Death Club, but not everyone agreed as thought the name would put everybody off or they would think it was a death metal club).

- Talk about it in other subjects (like science and history)
- Talk about it in relation to “living well and feelings”
- Do it as part of a topic (like Jews, or hospitals, diseases, cancer)
- Do small group work, giving children the option to opt out if they want. This could be for anybody, not just children who had experienced bereavement.

Appendix 16: Update on practice developments

During the process of writing up this thesis, and whilst on maternity leave, the practice developments identified at both schools continued to evolve. Below I describe what took place during this time. I also include a discussion of an additional practice development identified by the LA education services as a result of the research in RCPS, which is also continuing to be developed.

- **Integrate death and health education throughout the curriculum (RCPS)**

A working party was established to design a curriculum that would introduce children to concepts of death, dying and bereavement, equipping them with the skills and support to manage such experiences. It was planned that this programme of work would be delivered throughout the children's whole school career in a way that was appropriate to their age and developmental stage. The working party consisted of one teacher, one Support for Learning Assistant, the acting deputy head and HT1. All of these staff members had been part of phase two of the research. I was also part of the working party. I initially attended all of the planning meetings. Once the curriculum was designed however, my involvement was led by the working party members who requested my support as and when they felt necessary. Initially the working party was called the 'death education working party'. Part way through the development process this name changed to 'the resilience working party' to better reflect the aims of the curriculum being designed.

During the school year 2012/13, the curriculum was fully designed with the intention that this would be piloted during the following school year, 2013/2014. In June 2013, HT2 announced his decision to retire and the acting deputy head accepted a permanent post elsewhere. This meant that both the working party and the management at the school changed significantly. Piloting the programme was therefore delayed until a permanent head teacher was appointed and a new working party recruited. The curriculum is now being piloted, starting August 2014. The teacher involved in the initial working party has been appointed acting principal teacher, with the remit of taking it forward. It is intended that the curriculum will be fully evaluated by June 2015.

- **Provide information about the Hospice during the Hospice's 'Go Yellow' fundraising event (RCPS)**

At the end of the school year 2011/12, several meetings were held with child participants at RCPS to determine how they would like to learn about the Hospice as part of the 'Go Yellow' fundraising day. Several ideas were generated, with the children coming to a consensus about designing a leaflet that could be given to, and sent home with, every child participating in the event. These meetings were facilitated by me, as there was currently no capacity within the fundraising team to participate in research. A draft leaflet was designed by the children. This was then given to the fundraising team, along with the children's comments about how they felt it would be appropriate for them to learn about the Hospice. The fundraising team took over developing the practice idea from this point. A copy of the leaflet was given to HT1 for his comments and adapted accordingly. His main comment was that the leaflet was written in a way that would also be very suited to being sent home for parents/carers to read. In May 2014, it was therefore decided to give a leaflet to all pupils in all participating primary schools, along with a 'Go Yellow' sticker. 12,000 leaflets were sent. No feedback was asked for. It was identified that if the same leaflet continued to be sent out to all children participating in the 'Go Yellow' events, they would receive the same leaflet year after year. Discussions are now being held to see if the leaflet should only be used with a specific age group. The fundraising team are also waiting to hear back from the resilience working party who designed a lesson about the hospice to be taught alongside 'Go Yellow day'. The evaluation of this may determine how this innovation develops.

- **Provide bereavement training for school staff (RCPS and NDPS)**

During the school year 2012/13, a focus group was held with RCPS school staff participants to determine what they would like to achieve from bereavement training (at this stage the research team at NDPS had not yet decided on what practice developments to take forward). This focus group was led by a staff member from the Hospice DEPDR and me, who incorporated the feedback into a draft training programme to be taught over two hours. This time had been decided by school staff,

who felt that they could only dedicate two hours due to a lack of time for training and competing training demands. The draft programme was shown to all staff at RCPS, who had an opportunity to make any changes. At this point, the research team at NDPS identified that they would also like to take forward bereavement training as a practice development. I made them aware that another school had been involved in designing a training programme. The NDPS staff participants said that they were happy to use this training, if agreed at RCPS, as a baseline from which to tailor their own training programme. The draft programme was subsequently shown to all NDPS staff research participants. No changes were deemed necessary and the bereavement training programme remained the same for both staff at RCPS and NDPS.

At RCPS, the bereavement training was facilitated to the whole school staff, including management, teaching and support staff (36 staff members) as part of an in-service training day in February 2013. At NDPS, the training was facilitated at an after-school training session for teaching staff in March 2013. 11 staff participated, ten of whom were teachers and HT2. The training was facilitated by a member of the DEPDR and me. It included a pre and post evaluation form in an attempt to determine the extent of participant learning. The feedback from these evaluations was analysed and presented to both the Hospice CEO and participants in June 2013. Based on this feedback, the Hospice CEO took the decision to roll out the training to all schools in the catchment area free of charge. This is currently being led by the DEPDR, and is in the process of being evaluated.

- **Carry out activities about the Hospice during the Hospice's 'Schoolfriends' fundraising event (NDPS)**

During phase three of the research it was decided that two of the school staff participants would be responsible for developing activities to discuss the role of the Hospice with the children as part of the Hospice's fundraising campaign they were currently involved in. At this meeting it was decided that these activities would include creating a 'memory Christmas tree', placed in the school garden for children to add the name of someone who had died, and facilitating a whole school assembly

on the role of the Hospice. It was arranged that the school staff members would contact either the Hospice DO or me for information on the Hospice and/or if they wished us to speak about our role in the Hospice. The DO also agreed that the Hospice could provide stickers to give to every child after the assembly. These activities were to be facilitated during the school year 2012/2013.

I was contacted by one of the staff members for information about the Hospice. I provided a slide show presentation that Hospice staff had previously used at other schools, along with Hospice stickers to give out to the children. The staff member said that they would contact me once they had a date set for the assembly so that either the DO or I could attend. I contacted the staff member after a period of several months to see if they had moved ahead with the assembly. The staff member said they were currently very busy with other school commitments and therefore had not had any opportunity to develop the assembly. As the 'schoolfriends' fundraising activity would be lasting the whole school year, they said that this was still on their agenda. I followed up this conversation with a number of emails, but did not get any response. I also contacted HT2 several times to see if a Christmas tree had been put up and used as a 'memory tree', but was unable to get in touch with her. The reception staff said that this was because HT2 was still continuing to work across two primary schools and was currently balancing a heavy workload. At the time of writing, I am unsure if either activity took place.

- **Provide a parent/carer bereavement workshop (NDPS)**

The decision to develop this activity was based on school staff participants identifying a need within the school's parent/carer population for information and education on childhood bereavement. It was felt that this could also be an opportunity to raise awareness of the role of the Hospice. It was decided that HT2 would liaise with parent/carers to determine the level of need for this workshop and then contact me so that a workshop could begin to be developed. I contacted HT2 several times following this decision to ascertain if she had spoken to parent/carers, but was unable to get in touch with her. As discussed previously, at this time HT2 was still continuing to work across two primary schools and was balancing a heavy

workload. I therefore wrote to HT2, asking her to contact me one she had scope to think about taking this activity forward. At the time of writing, I have had no further contact.

- **Develop a LA schools bereavement policy**

This practice development arose as a result of the research being conducted in RCPS. After participating in an interview during phase two of the research, HT2 decided to approach the LA education services to ask if there was a bereavement policy in place. There was currently no bereavement policy and it was identified by the Curriculum Support and Quality Improvement team that this was a gap that needed to be met. It was thus decided that a working party would be established to develop a bereavement policy for all schools in the LA. In the early stages of establishing this working party it was discovered that the LA policy and development team were already considering developing such a policy. This was due to a recent experience in a primary school where a pupil had died during the school holidays. Staff at the school identified that a bereavement policy would have enabled them to respond more effectively. Both departments thus decided to work together to develop a schools bereavement policy.

A working party was established in 2014. A Hospice volunteer, who was a retired teacher and volunteer for the children's bereavement service, and I were invited to attend the first meeting. This was in an advisory capacity to contribute our expertise on, and experience in, childhood bereavement. Tasks were identified and distributed amongst the LA staff so that the policy could begin to move forward. The working party is due to meet in the school year 2014/2015 to bring together the results of this work so that a policy can be developed and implemented. At this meeting, it was identified that bereavement training would be needed to support the implantation of the policy. The Hospice DEPDR agreed to provide this training as part of the LA continuous professional development courses offered to teaching staff. The training they will offer will be primarily based on the bereavement training designed with RCPS and NDPS (see above).

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