

**Title:** Working with communities to develop resilience in end of life and bereavement care: hospices, schools and health promoting palliative care

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**Abstract (130 words):**

This paper discusses research undertaken to explore and develop practice between a hospice and two primary schools. Action research was used to increase understanding about current practice in, and with, schools and to explore, implement and evaluate models of practice. Seven practice innovations were identified that are in various stages of being piloted. 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 the capacity of communities to respond to death, dying and bereavement. They demonstrate the diverse role that hospices, can play in developing how communities experience death, dying and bereavement and propose that a broader lens is employed to understand and facilitate end of life and bereavement services.

**Key words (up to 6):** end-of-life and bereavement care, school communities, hospices, public health approaches to palliative care, health promoting palliative care, action research

**Main paper (4703 words):**

**Introduction**

These are challenging times for palliative care services. Current service provision will not meet the needs of an aging population and this demands consideration about how care and support can best be delivered. Adopting public health approaches to end-of-life care, specifically health promoting palliative care, offers opportunities to address this challenge. It seeks to improve existing services alongside wider social reform that develops death and bereavement friendly communities (Rumbold 2011). An action research study was undertaken in my role as a hospice social worker to explore and advance education and support around death, dying and bereavement in school communities. This paper begins by discussing the context for this research, exploring how my profession and current practice shaped it. I outline how this experience links to public health approaches to palliative care,

focusing on health promoting palliative care and its relevance for both hospice and school communities. I go on to discuss action research as a tool for developing practice, describing the practice innovations that arose as a result of this research. I finish by discussing the practice innovations in relation to health promoting palliative care and the potential role that hospices can play in developing the resilience of school communities to support death, dying and bereavement experiences. Because my research was located in Scotland I have drawn primarily on Scottish legislation and policy, however, my discussion on the role of hospices and health promoting palliative care is inevitably broader than Scotland.

## **Background**

In 2007 I began working as a social worker in a hospice. The Hospice with whom I was employed provides specialist palliative care to a catchment area of almost a third of a million people across a rural area of Scotland. Palliative care is ‘an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness [...] This includes addressing practical needs and providing bereavement counselling. It offers a support system to help patients live as actively as possible until death’ (WHO 2015). Specialist palliative care thus involves working with individuals and families both during and after the illness.

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 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. I felt this focus would result in a more positive experience for children, whereby their experiences of death and bereavement were normalised, not pathologised, acknowledged and supported by people with whom existing relationships exist.

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). Since the introduction of these policies, a variety of advances have since been made that focus on creating more openness around death, dying and bereavement. In 2009, in England and Wales, 'Dying Matters', a national coalition to promote greater public awareness and discussion of issues relating to death, dying and bereavement was developed. This included the introduction of a 'Dying Matters' awareness week, 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 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). This was further emphasised by the Scottish Government in their *Strategic Framework for Action on Palliative Care (2015)*, which highlights the need to establish 'greater openness about death, dying and bereavement' and recognise 'the wider sources of support within communities that enable people to live and die well'. These developments go beyond developing discourse around death, dying and bereavement to involving the community in addressing end-of-life and bereavement care issues. Such

approaches 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). From this perspective, end-of-life and bereavement care is everyone’s responsibility, thus situating palliative care as a public health issue and identifying associated approaches as an effective way to improve and develop care.

### **Public health approaches to palliative care: health promoting palliative care**

Issues related to death, dying and bereavement have previously been excluded from public health discourse. Public health activities have historically been referred to as life-affirming, avoiding death and dying by focusing on preventing and controlling illness, disease, injury and premature death (Kellehear and Young 2007; Lupton 1995). Combining public health approaches with palliative care is, however, now recognised 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). This involves moving focus from traditional public health models, which concentrate on the cure and treatment of disease, to ‘new’ public health models that focus on equity of care ‘and on attempting to break down barriers between professional groups and lay people’ (Cohen and Deliens, p.11). From a ‘new’ public health perspective, public health approaches to palliative care thus involve working to promote openness and challenge stigmas related to death, dying and bereavement as well as empowering communities to draw on their own resources and community supports to adapt and cope. These principles are equally essential to the role and task of social work and I have argued elsewhere the relevance of a public health approach to palliative care for the social work profession (Paul 2013).

Health promotion is a central feature of the ‘new’ public health. It recognises health as a multidimensional concept involving physical, social and emotional aspects and 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’ (Bennett and Murphy 1997, p.7). 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)

Health promoting palliative care is thus a holistic approach that recognises and builds on existing strengths and skills within the wider community. Although it is only one public health approach, health promotion is usable in small settings (Kellehear 2005). 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).

A survey of UK palliative care services found that public health approaches to palliative care was a priority for the majority of services (Paul and Sallnow 2013). A review of 28 projects in England further revealed interest and commitment to the field (Barry and Patel 2013). In Scotland, schools have been identified as an important target for health promoting palliative care to ensure that children develop the skills and capacity to talk about, and cope with, death, dying and bereavement (Scottish Government 2010). Moreover, schools have been identified as key in supporting and responding to children’s bereavement experiences (Hemmings 1995; Rowling 2003). In the afore mentioned survey of UK palliative care services, working with schools was the most common type of work done in the community, identified by 73% of respondents (Paul and Sallnow 2013). 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 sharing this work and discussing the extent to which such activities are health promoting. Moreover, the practice of introducing health promoting palliative care occurs largely within clinical healthcare settings (Kellehear 2005). This indicates that health promoting palliative care activities are often 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 limited perspective 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’ site 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.

Kellehear (2005 p.156) offers a ‘Big Seven Checklist’ as a guide to understanding ‘genuine’ health promoting palliative care activities . 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?

The checklist highlights community ownership, collaboration and participation as essential to a health promoting approach to palliative care. This draws attention to the importance of working *with* communities, to engage them in a process of identifying and addressing end-of-life and bereavement care issues that are pertinent to their own specific needs, i.e. transferring power rather than maintaining it. The check-list also identifies the importance of developing activities that are based on early intervention and harm-reduction that involves normalising death, dying and bereavement and proactively preparing individuals and communities for related experiences. Nevertheless, there is little research that has used this checklist to help understand and define activities ran by palliative care services. In planning my study I identified a need for more research that explores and develops activities initiated by hospices,

specifically those with schools, using the checklist to critique the extent to which such activities confirm the fundamental principles of true health promoting palliative care.

### **Action research: a research approach to practice development**

I have confirmed 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. This prompted me to choose an action research methodology which 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 operational field research that deals with everyday issues of practice to increase effectiveness (McKernan 1996) and involves a spiral of steps composed of planning, action and evaluation/critical reflection of the action in order to plan subsequent events. It sits within participatory research paradigm that involves connecting people, subjects, objects and their environments (Hockley and Froggatt 2006). It is a developmental process in which participants resolve the issues in question. Theory in action research thus attempts to ‘bridge theory and practice but also generate new ways of understanding practice’ (Noffke in Noffke and Somekh 2009, p.10)

The research was undertaken in two primary schools in Scotland, starting in August 2011. Schools were invited to take part due to their proximity to the Hospice, size and denomination; one non-denominational school (NDS) and one Roman Catholic school (RCS) were selected to see if this impacted on developed practice (in Scotland 14% of all schools are denominational, the bulk of which are Roman Catholic). Participants included anyone who might be involved in potential practice innovations, including hospice and school staff, children and parents/carers. Potential adult participants were given verbal and written information about the research and invited to self-select as research participants. For children, a letter was sent home informing parent/carers that the research was happening in the school and that the researcher would be inviting their child to participate. They were then asked to opt their child out if they wished. For those children who were not opted out, the researcher provided written and verbal information about the research. The children were later asked to fill in a brief form indicating their interest in participating and/or if they had any questions. As a result of this process, 22 participants were recruited from the Hospice, 32 participants (seven staff, 21 children and four parents) were recruited at RCS and 18 participants (six staff and 12 children) were recruited at NDS. No parents/carers agreed to participate in the

research at NDS. Informed consent was sought from all participants. Owing to the duration of the action research, consent was kept a live issue so that participants were aware they could withdraw from the research at any time. Ethical review procedures were completed and approved at The University of Edinburgh, the Hospice and Local Authority (LA) in which the schools and research was based.

The action research was conducted over five phases. Figure One describes the detail of these phases. The interviews and focus groups in phase 2 were piloted prior to this and were facilitated using an interview and focus group guide. The interviews and focus groups each lasted approximately forty minutes to fit in with the school timetable. They were digitally recorded and then transcribed. Data from these initial phases was analysed thematically with themes derived from the data.

### **Figure One: overview of research phases**

#### **Phase 1 (preparation and scoping):**

A literature review, visits to other hospices and four focus groups with Hospice staff to determine the extent to which they already engaged with primary schools, the focus of this work and areas for development.

#### **Phase 2 (exploration):**

A series of interviews and focus groups with children, parent and school staff participants to explore current practice in relation to death, dying and bereavement and engage in a process of change.

#### **Phase 3 (planning and developing model(s) for practice):**

Dissemination of written reports based on the findings generated in phases one and two and meetings with key stakeholders to discuss, identify and develop possible practice developments.

#### **Phase 4 (pilot developed practice):**

Pilot of the identified and developed practice innovations across hospice and/or school settings.

#### **Phase 5 (evaluate developed practice):**

Evaluation of practice innovations in partnership with key stakeholders. Practice is adapted and developed as per evaluation findings.

This paper reports on the research undertaken in Phases 1,2 and 3. The findings from Phases 4 and 5 are on-going and will be reported elsewhere.

### **Findings from phase three: the identified practice innovations**

Both research sites identified three practice innovations to take forward. An additional practice idea was also identified by the LA Education Services, as a result of the action research process at one of the schools. The activities are summarised in Table One, which, for ease of discussion, have been numbered from one to seven.

I have discussed elsewhere the main themes deriving from these innovations and what this suggests for the role of Hospices working with schools (forthcoming). Given the scale of this research, and the methodology used, it is hard to draw general conclusions concerning the role of Hospices working with school communities beyond this context. The innovations are site specific and as a result only describe the role of the Hospice working with that particular school.

Regardless there are some interesting characteristics of the innovations worthy of further examination. First, it is apparent that the majority of these practice innovations involve mobilising those already caring for, and interacting with, children to be actively involved in providing support and education around death, dying and bereavement. Second, not all the innovations focus on improving services run by the Hospice. Practice developments (3) and (4) involved improving current services ran by the Hospice, yet, the remaining practice innovations were concerned with transforming practice in school communities to better cope with death, dying and bereavement. Third, the focus of all the activities directly relate to the principles of health promoting palliative care and suggests that Hospices do play a key role in developing related activities.

To assess the extent of this role, I have explored how these practice developments address Kellehears' (2005) 'Big Seven Checklist' for health promoting palliative care activities, as identified in the literature and demonstrated through the research experience.

	<b>Practice development</b>	<b>Description</b>
<b>RCS</b>	(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. To be led by school staff with some input from Hospice staff where needed.
	(2) Provide bereavement training for school staff.	School and hospice staff to jointly develop and design 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 will be facilitated by hospice staff and aimed at all school staff, including teachers and support staff.
	(3) Provide information about the Hospice during the Hospice 'Go Yellow' fundraising event.	Children and Hospice staff to jointly develop materials to use with the Hospice 'Go Yellow' annual schools 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.
<b>NDS</b>	(4) Carry out activities about the Hospice during the Hospice 'Schoolfriends' fundraising event.	Children and school staff to jointly develop a series of activities for school children about the role of the Hospice that can be carried out when participating in the Hospice 'Schoolfriends' fundraising event.
	(5) Provide bereavement training for school staff.	School and hospice staff to adapt the bereavement training programme designed with RCS (practice development two) to suit the needs of NDS. Facilitated by hospice staff with all school staff.
	(6) Provide a parent/carer bereavement workshop.	School staff to establish need for a parent/carer workshop on the bereavement needs of children and the role of the Hospice in the community. Hospice staff to develop and facilitate workshop.
<b>LA Education Services</b>	(7) Develop a bereavement policy	School staff, Hospice staff and children to develop a LA schools bereavement policy. The policy should include specific guidelines on how to respond to bereavement in school communities.

**Table One: summary of practice developments**

## **Practice innovations and the ‘Big Seven Checklist’**

Table Two outlines the ‘Big Seven Checklist’, 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 are in line with the checklist. This suggests they can be viewed as genuine health promoting palliative care activities. There are a number of gaps under practice development (6), primarily because during phase three it was intended that this activity would be discussed with parents/carers at NDS and a subsequent plan for advancing this activity produced. However, to date this discussion has not taken place and it is unknown if and how it might progress.

<b>'Big Seven Checklist'</b>	<b>Practice Developments:</b>				
	<b>(1) Death and health education in the curriculum.</b>	<b>(2) (5) Bereavement training to school staff.</b>	<b>(3) (4) Fundraising to raise awareness</b>	<b>(6) Parent/carer workshops.</b>	<b>(7) Bereavement policy.</b>
<p><i>In what way does/can the project:</i></p> <p>1. Help <b>prevent social difficulties</b> around death, dying and loss? or</p> <p>2. <b>Harm-minimize</b> difficulties we may not be able to prevent around death, dying, loss or care? or</p> <p>3. Be understood as <b>early interventions</b> along the journey of death, dying, loss or care?</p>	<ul style="list-style-type: none"> <li>- Health and death education is part of the syllabus <b>(1,2,3)</b></li> <li>- Open culture of talking about death and loss <b>(1)</b></li> <li>- Children aware of issues related to death and grief before they happen <b>(2,3)</b></li> </ul>	<ul style="list-style-type: none"> <li>- Develop skills and confidence of school staff to address bereavement <b>(1,2,3)</b></li> <li>- Develops culture on supporting bereaved children in school <b>(1)</b></li> <li>- Raises awareness of bereavement needs of children <b>(2)</b></li> <li>- Raises awareness of specialist support to be accessed when needed <b>(2)</b></li> </ul>	<ul style="list-style-type: none"> <li>- Introduces hospice care to school communities <b>(3)</b></li> <li>- Uses accessible, child friendly language <b>(3)</b></li> </ul>	<ul style="list-style-type: none"> <li>- Develop skill and confidence of parents/carers to notice and address bereavement <b>(1,2,3)</b></li> <li>- Raises awareness of bereavement needs of children <b>(2)</b></li> <li>- Raises awareness of specialist support to be accessed when needed <b>(2)</b></li> </ul>	<ul style="list-style-type: none"> <li>- Establishes culture of supporting bereaved children in school <b>(1)</b></li> <li>- Raises awareness of bereavement needs of children and provides guidance on how to meet these needs <b>(2,3)</b></li> </ul>
4. In what ways do these activities <b>alter/change a setting or environment for the better</b> 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 <b>participatory – borne, partnered and nurtured</b> by community member?	Action research	Action research	Action research	Action research	Action research
6. How <b>sustainable</b> 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 <b>evaluate</b> 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 Two: The practice developments and Kellehear's' (2005) 'Big Seven Checklist'**

I have asserted that the majority of the developments meet all of the first three questions on the check-list 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. Practice developments (3) and (4), use fundraising to raise awareness of hospice care, however, they can only be understood as an early intervention due to their focus on informing as opposed to empowering. Informing and educating are key features of all the innovations. This includes education that raises awareness of end-of-life and bereavement issues as well as developing capacity to support related 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. Practice development (7) (policy development), includes informing schools communities on the impact of bereavement on children and their responsibility to ensure that procedures are in place to support such experiences. Education on death, dying and bereavement experiences 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). Providing information and education on end-of-life and bereavement care has been a key feature of the hospice movement since it was first established (Hockley 1997). These innovations suggest however that education is provided by Hospice staff where needed (such as via fundraising and bereavement training) but is also designed and delivered by school communities.

In relation to question four (alter an environment for the better), it is not possible to tell how the practice developments 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 either 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 the Hospice 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 developments were a result of action research which focuses on developing practice which is shaped and owned by communities members. Yet, although research participants identified all of the activities, parents/carers were not involved in choosing practice development (6) (parent/carer workshop). Instead, this development was identified by school staff whom argued that it would be a beneficial practice development for parents/carers. As no parents/carers were involved in this decision this practice development was therefore not genuinely participatory borne and does not meet the guidelines for health promoting palliative care. This identifies power within communities that can influence how practice is shaped by determining and responding to need without actually involving the people whom the practice is aimed at. It highlights that in designing and responding to end-of-life care and bereavement issues the Hospice must consider whose views are included and whose are not to ensure that practice is relevant.

It can be argued that all of the activities are sustainable, therefore meeting question six, as it is planned that all of the developments will continue without my on-going involvement. Nevertheless, at the time of writing it is not possible to say if this is the case as the majority of activities are still in the process of being piloted. Moreover, it is planned that the activities will be continued by those best placed to do so, meaning that I will not be in the position of an external facilitator to maintain the momentum of the work. Instead they rely on motivation, and time available, of the responsible staff. This is potentially in keeping with the multi-disciplinary, focus of health promotion, which places emphasis on cooperative relationships and involves action from all involved parties (Peterson and Lupton 1996). 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. However, a possible 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. Practice developments (1) (curriculum development) and (7) (policy development), will be incorporated into existing school frameworks and because of this is it likely that these two developments will be sustainable. This, however, is not a feature of all activities. 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 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, evaluating their success or usefulness is not necessarily included within these procedures. For example, the Hospice Department of Education, Practice Development and Research (DEPDR) always evaluate 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.

## **Conclusion**

This research set out to explore practice between a Hospice and two primary schools that advanced education and support around death, dying and bereavement experiences. It was a product of my practice experience as a hospice social worker coupled with an awareness and interest in the emerging field of public health approaches to palliative care, specifically health promoting palliative care. The research did not set out specifically to create health promoting palliative care activities: such practice and its significance to end-of-life and bereavement care was discussed as a basis from which to explore and critique practice developments arising from the research process. Yet, the majority of practice innovations that arose as a result of this research were not based on the Hospice delivering specific services to schools but mobilising those involved in caring for children to be actively involved in providing support and education around death, dying and bereavement. By discussing these innovations alongside the principles of health promoting palliative, community ownership, participation

and capacity building were highlighted. This, in turn, identified the significance of designing activities around the needs of school communities, which are led, but not owned by, palliative care professionals. I have argued therefore that the practice innovations can be understood as health promoting palliative care activities due to their focus on developing the resilience of school communities to cope and manage issues relating to death, dying and bereavement experiences. Furthermore, I have suggested that hospices are well placed to engage with and develop health promoting activities. With this focus, school communities are viewed by hospices as an equal partner in providing quality care and education around death, dying and bereavement for children and integral to providing meaningful support. Engaging with the social work task from a proactive standpoint was a key focus of this research. The identified activities engage proactively with death, dying and bereavement by concentrating on developing the education and skills of children, and those around them, to cope with experiences related to death, dying and bereavement. This highlights the relevance of public health approaches to palliative care for social workers and the important role that social work professionals have in developing practice in this area.

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