Integrating palliative care into the community: the role of hospices and schools

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Abstract

Objectives: Palliative care services have, up to now, paid insufficient attention to social aspects of dying and bereavement and this has affected how patients and their families' experience end-of-life and bereavement within their communities. New public health approaches to palliative care offer a different way forward by seeking to develop communities that support death and bereavement. Such approaches are now a priority for the majority of hospices in the UK and work with schools has been identified as a key area of work. Practice that engages schools and children on issues concerning end-of-life care is, however, under-developed and under-documented. This research explored the role of hospices in working with schools to promote education and support around end-of-life and bereavement experiences.

Methods: Action research was used to explore the potential for hospices to work with schools and engage participants in change processes. The research was conducted in one hospice and two primary schools in Scotland. Participants included children, parents and school and hospice staff.

Results: Seven innovations were identified that were found to be useful for both the school curriculum and the relationship between hospices, school communities and wider society. A model for integrated practice between hospices and schools is suggested.

Conclusions: This research adds to knowledge about how hospices might engage in community engagement activities that encourage school staff to develop greater openness and support around end-of-life and bereavement care for their children. This will require a re-thinking of normal hospice services to also participate in community capacity building.

Main Paper

Introduction

The hospice movement has had considerable impact on end-of-life and bereavement care in the United Kingdom (UK) since the 1960's. [1] It stresses the significance of a shared and holistic approach to end-of-life care, where the physical, social and emotional experiences of the patient and their families are central. This approach can be viewed in parallel with the philosophy of integrated care whereby emphasis is placed on providing coordination and continuity in care by adopting a multi-disciplinary approach that is viewed through 'a patient-lens'. [2] [3] The rise of the hospice movement has been positive and hospice care is now widely available both in the UK and internationally. [4] Hospices, however, are unable to reach the majority of those needing palliative care [5] and, as the need for end-of-life care is forecast to rise, there will be increased strain on current service provision. Moreover, the hospice movement has been criticised for focusing on individual and interpersonal levels of care, neglecting the concepts of community involvement and social networks in dying, death and loss. [6] [7] This is significant given that the underlying principles of both hospice and integrated care address the shifting boundaries of a person's life and aim for care that is seamless and responsive to all dimensions of need. [2] Integration in palliative care therefore requires the narrowing of gaps not only between services, but also between individuals and their communities.

Adopting new public health approaches to palliative care offers one way forward to bridge this gap. They indicate a way to reform organisational policy and behaviour in a way that is more sensitive to the needs of people living with incurable illness and bereavement. [8] Similar to integrated care and hospice care, a public health approach to palliative care acknowledges the limitations of traditional models of health service delivery and focuses on a holistic view of health that recognises and responds to individual and community specific needs. [9] Such approaches have been given increased policy and literature focus and a survey recently revealed that public health approaches are a priority for most UK Hospices. [10] In this survey, a variety of activities were described. Work with schools was found to be the most common project undertaken: however, such work is under-documented and under-researched.

Children are a population whose needs around death and bereavement are often unmet. In Scotland, engaging educational establishments has been recognised as an important target for public health approaches to palliative care to ensure children are comfortable with and confident in talking about and managing death, dying and bereavement. [11] There is currently no evidence that explores developing work between a hospice and schools or the extent to which such work truly engages and develops school communities.

This research was a doctoral study funded by Strathcarron hospice (called the Hospice thereafter) in central Scotland with both Social Work and Palliative Care supervision. Hospice staff were keen to explore the role of the Hospice in working with schools due to an increase in referrals to the children's bereavement service and an intensifying number of requests from school communities to participate in a variety of work. Such work took a great deal of staff time and there was a need to find out how to work with schools more efficiently and effectively. The research therefore aimed to explore the potential role of the Hospice in engaging with school communities. It did so from a health promoting palliative care and a children's rights perspective, recognising the rights of children to be involved in conversation, education and support about death, dying and bereavement that proactively prepares them for all of life's stages. [12] It specifically sought to discover if there was a role for the Hospice in working with schools, how the values of hospice care might be integrated into school communities, and what developed practice might look like.

Method

The research was initiated and led by a hospice social worker with experience in supporting individuals and their families at end-of-life and into bereavement. It took place in two primary schools, using an action research methodology. Action research was chosen due its focus on simultaneously developing knowledge and practice. This was important to the researcher, as a social work practitioner, and to the Hospice, because it was keen to see practice developed as a result of its investment. Action research aims to increase experience and understanding of a current situation and engage in a change processes. [13-15] It 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. [16] 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'. [17]

The research centred on primary school children aged nine to 12 years. This was based on a number of factors. Firstly, anecdotal evidence from Hospice staff identified their anxiety about talking to primary school children due to fears around causing unnecessary upset. The Hospice management team was therefore interested to bring about improvements in this. Secondly, children aged eight and upwards are considered as having developed a concrete understanding of death. [18-20] Although younger children will be aware of death, their understanding varies according to their experiences. [21] It was not an intention of the research to cause harm by introducing concepts to children that they were unfamiliar with, yet it was important to include children's views. Moreover, the focus of this study was on how adults engage with children on these issues, and therefore it was important to involve older primary school children who would be more able to participate.

Primary schools were invited to take part in the study due to their proximity to the Hospice and denomination: one non-denominational (NDS) and one Roman Catholic School (RCS) were then selected to see if this impacted on developed practice (in Scotland 14% of all schools are denominational, mostly Roman Catholic). Participants included those individuals who might be involved in potential practice innovations. This encompassed Hospice and school staff, children aged nine to 12 years and their parents. Potential adult participants were given verbal and written information about the research and invited to self-select as research participants. For children, after consultation and discussion with the head teachers, a letter was sent home informing parents/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. This was done in class groups. 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.

The action research was conducted over five phases. Phase one (preparation and scoping) involved a literature review, visits to other hospices and four focus groups with Hospice staff. The focus groups sought to determine the extent to which Hospice staff were currently involved in working with schools, the nature of this work, and ideas for improving current practice. Phase two (exploration) included a series of interviews and focus groups with children, parents and school staff to develop collaborative inquiry and engage in a process of change. This involved developing discussion and exploring ideas related to how education and support around death, dying and bereavement is experienced by children and generating ideas to improve current practice based on these experiences. These interviews and focus groups were piloted and were facilitated using an interview and focus group guide. At RCS, this involved seven interviews with staff, four focus groups with children and one focus group with parents. At NDS, this involved six interviews with staff, two focus groups with children and one interview with a child. The interviews and focus groups each lasted approximately 40 minutes to fit in with the school timetable. They were recorded digitally and then transcribed. Data from the initial two phases were analysed thematically under four broad headings identified from the interview and focus group schedules. The purpose of these headings was to provide an overview of the data so that participants, in subsequent phases, could use their own skills and experiences to further explore and analyse any emerging issues. Table One presents illustrative data from the school staff, parents, Hospice staff and children.

Adult Participants (school staff, hospice staff and parents)	
Theme: Ambiguities	**Examples**
Teaching and support is dependant on individual teachers	"I wasn't sure how to handle it properly and it was probably more myself that would have the hang-ups rather than the children but I didn't want to go there" (school staff, RCS)
Discussion/teaching/support is reactionary	"You tend to only do it if things come up in the newspapers or if you read about somebody that's died" (parent, RCS) "I just leave it up to the children to bring it to the fore for discussion" (school staff, NDS)
Parallels with sex education	"It's the same for that education for love, everybody was totally freaked out when they first heard about it, until they found out about how it was going to be done" (parent, RCS)
Need to balance education with support	"You want them to have an awareness, but the ones who do need support do get that" (parent, RCS)
Theme: Opportunities	**Examples**
Impetus for developing education and support	"Part of the health and wellbeing of the children is just dealing with transition and change and realising that folk grow older and that folk die and so it should be part of what we would cover […] that's not just done in a reactionary way" (school staff, RCS) "I think it would probably be good to have a bit, not too much, because you don't want them frightened, because its difficult, they're sensitive at different ages" (parent, RCS) "Education is about educating and developing the whole child, throughout their life, learning goes on forever, so perhaps it's quite important […] it's a reality isn't it" (school staff, NDS)
Flexibility within school curriculum	"Somewhere in amongst their science and their life programme, I don't know, but it might be easier to do if it's factual rather than emotional" (parent, RCS)
Relevant to all age groups	"It's okay to a certain point within each age group […] You do have to prepare them from young, […] because there is going to be children at that age that come across it very very closely" (parent, RCS) "What's wrong with starting it off early, at an appropriate level" (school staff, NDS)
Faith as a useful framework for discussion	"It's quite good for us in being catholic, I mean you've got an afterlife and it's good to explain to them [the children] that way" (parent, RCS)
Using the expertise of Hospice staff	"It's just reassurance that you are dealing with it properly" (school staff, RCS)

	"It not just about having them [the children] talk, but helping them with strategies and that's where the Hospice could really help" (school staff, NDS)
Children's natural curiosity	"If you can start that talking in school and they can take it home, then it gives them a starting point for them to talk about it (school staff, RCS) "A lot of the kids are really quite interested in the hospice" (Hospice staff)
Theme: Challenges	**Examples**
Controversial/taboo subject	"Its not something you can drop into conversation" (school staff, NDS)
Fear of upsetting parents/children/others	"That's the bottom line for teachers, you don't want to upset the children. That's my bottom line, I don't want to do damage" (school staff, RCS)
Lack of training and skills in school staff	"We don't have any training on that (pre and post bereavement support) whatsoever you know" (school staff, NDS)
Differing religious and cultural beliefs of children	"Not all of the children maybe have the same faith background so you're kind of aware of not wanting to cross a boundary that other folk wouldn't think is acceptable" (school staff, RCS)
Differing needs/experiences of children	"Tread[ing] carefully because different children react in different ways" (school staff, NDS)
Parents/carers	"I think a lot of parents are always worried that it's getting taken out of their hands and they don't have any control about it, if you want to try and help your kids or you know your child best" (parent, RCS)
Lack of focus in curriculum and school policy/procedures	"But when it's made a part of the curriculum, then they [teachers] just, they just have to get on with [teaching] it" (school staff, RCS) "you don't get any guidance on how to deal with bereavement in school" (school staff, NDS)
Practicalities of creating new activities	"There is a danger that you [the Hospice] 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 the schools in the area]" (school staff, RCS)
Lack of awareness on role of Hospice	"Certainly I didn't know what a hospice was until I had to go there with my brother" (parent, RCS) "The number of schools that do fundraising for us, but I often wonder how many of them actually realise where the money is going and what we're doing" (Hospice staff)
Theme: Suggested Innovations	
The Hospice and/or school nurse to give education on cancer; a one-off topic and/or project on palliative care and/or death and dying; enhance fundraising activities by providing education packs and/or projects; school take part in one off projects for the Hospice, such as the nursery	

children planting flowers and bringing them to the patients; Hospice staff providing education to staff and/or children and/or parents on bereavement and/or illness; develop a bereavement procedure; Hospice staff compile and share materials that stimulate discussion around bereavement; Hospice staff talk to children, parents and/or staff about what their role.	
Child Participants	
Theme: Benefits of teaching/support around death, dying and bereavement	**Examples**
Important learning about life, the future and emotions	"It helps you to prepare" (RCS) "It [death] is a key thing in life" (NDS)
Normalising	"I think teachers should talk about death and dying at school because then the children would get more used to it and then they'd feel more better" (RCS) 'If they [children] know about death, they can cope with an actual death" (NDS)
Enable positive experiences of pre and post bereavement support	"You can express yourself" (RCS) "The worst thing is when somebody dies and you come back to school and they all crowd around you" (NDS)
Theme: Challenges to teaching/support around death, dying and bereavement	**Examples**
Managing emotion	"Adults worrying how children will react" (RCS) "Because they [the children] might get emotional" (NDS)
Personal experiences	"[What] if it brings back bad memories" (RCS) "If you are currently going through a bereavement experience (RCS)
Worrying about the future	"It might happen to you" (RCS) "It may be scary and weird" (NDS)
Theme: Unanswered questions about death, dying and bereavement	**Examples**
Facts	"How can you be dead but you can donate lungs and stuff?" (RCS) "What's the difference between buried and cremated?" (NDS)
Spiritual and existential	"Why it happens? I would like to learn how to control death." (RCS) "To know if they can see you in heaven" (RCS)
Managing/responding to grief in self and others	"Why does the pain keep coming back like a swarm of bees all the time?" (RCS)

	"I'd like to know that other people cry" (RCS)
	"Why do adults not talk about someone who had died even though they say they have accepted it?" (NDS)

Theme: Practice Innovations
Do games in class that encourage children to talk about death and bereavement; ask children in assembly if they are sad because of a bereavement then talk to them about it; visit the Hospice; write personal stories about death in class and share them with others, if the children want to; get children to talk in pairs about people who have died in their lives; have a death and bereavement worry box; have a death club for anyone to join and talk about death; have an assembly in the school to tell people about death; do death as a science topic; do a memory poster [10] in class about someone who has died; do something monthly to remember people who have died; teach about death in religious and moral education/science/history; do class projects on death; hold a mass to remember people who have died; read story books in class that explains death.

Table One: Illustrative data from adult and child participants

Phase three (planning and developing) involved sharing findings from phase two with participants for feedback and analysis. This involved the dissemination of a written report to stakeholders from the research team whom were identified by the head teachers and the Hospice Chief Executive. At RCS, stakeholders included the Hospice Chief Executive, the head teacher and the researcher. At NDS, stakeholders included the Hospice Director of Operations, the head teacher, the six school staff involved in phase two and the researcher. Meetings with stakeholders were then held to discuss the themes arising from phase one and two and identify possible practice developments to take forward. Notably, no children were involved in the stakeholder groups as both head teachers felt that the adults were best placed to determine what activities could and could not be implemented in the school and/or Hospice according to resources. The children's views were thus given emphasis in the written report and by the researcher in the subsequent meetings with stakeholders. Identified practice ideas were then fed back to the wider research team for comment and discussion. This included negotiating who would be responsible for taking forward the ideas and how this might be done. This phase of the research was also shared with the LA Education Services, whom the head teacher a RCS felt should be aware and supportive of any developments. This paper reports on the research up to this stage. The findings from phase four (pilot developed practice) and five (evaluate developed practice) are ongoing and will be reported elsewhere.

Ethics
Ethical review procedures were completed and approved at The University of Edinburgh, the Hospice and the local authority (LA) in which the schools and research was based.

Practice Innovations
Both schools identified three practice innovations to take forward. An additional practice idea was identified by the LA Education Services. These innovations are outlined in Table Two, which for ease of discussion have been numbered from one to seven.

	Practice innovation	Description	Lead responsibility
RCS	(1) Curriculum Development	Create and implement an education programme ('The Resilience Programme') that integrates education on health, illness, death and bereavement into the curriculum across all ages.	School
	(2) Bereavement training	Design and deliver bereavement training for all school staff to raise awareness about childhood bereavement and develop appropriate skills to manage related issues.	Hospice Department of Education, Practice Development and Research (DEPDR) and Social Work staff
	(3) Provide information about the Hospice during the Hospice 'Go Yellow' fundraising event.	Develop specific materials to use with the Hospice 'Go Yellow' annual fundraising event to inform school staff and pupils about the role of the Hospice in the community and how money raised is spent.	Hospice Fundraising Team
NDS	(4) Carry out activities about the Hospice during the Hospice 'Schoolfriends' fundraising event.	Develop a series of activities for school children about the role of the Hospice to be carried out when participating in the Hospice 'Schoolfriends' fundraising event.	School
	(5) Bereavement training	Design and deliver bereavement training for all school staff to raise awareness about childhood bereavement and develop appropriate skills to manage related issues.	Hospice DEPDR and Social Work staff
	(6) 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.	Hospice DEPDR and Social Work staff
LA Education Services	(7) Bereavement policy	Develop a LA schools bereavement policy that includes specific guidelines on how to respond to bereavement in a school community.	LA Education Services and Policy Development Team

Table Two: Summary of practice developments

Given the scale of this research and the methodology used, the practice innovations do not provide any definite conclusions concerning the role of hospices in 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 (4) (use fundraising events as an opportunity to inform pupils and staff about the role of the Hospice) and (2) and (5) (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. It indicates that there were commonalities in how the different schools perceived working with the Hospice to be most helpful.

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 RCS and NDS, highlight that religion can provide a structure from which to develop conversation and education on 'the problem of death […] and the nature of the afterlife' [22] 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.

Based on the seven practice innovations three key themes were 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 Three, which offers a model for integrated practice with school communities.

Role of Hospice	Goal	Practice innovation(s)
Awareness Raising	Dispel myths associated with hospice care, end-of-life care and bereavement.	Develop existing fundraising campaigns and education and training opportunities that focus on raising awareness of hospice care.

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.	Plan and deliver bereavement training for school staff and bereavement awareness workshops for parent/carers.
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 palliative care issues. Work with school staff to develop a death and life-affirming curriculum. Work with school staff to develop bereavement policies and procedures.

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

Raising awareness involved using fundraising and education/training events as an opportunity for sharing information on hospice care, dispelling associated myths. This required a reorientation of normal service provision by broadening the remit of existing activities to also focus on raising awareness. For example, the research identified that if adult and child participants did not have personal experience of family members using the Hospice, the main reason they knew of the Hospice was via fundraising campaigns. There was, however, no guidance and/or direction from management staff in the school and/or the Hospice fundraising materials to use fundraising events to talk about hospice care. The school communities therefore fundraised for the Hospice without discussing what the Hospice is and does. This was viewed as a missed opportunity to seamlessly integrate education about hospice care into the curriculum. The role of fundraising was thus extended to raise money and also, in so doing, awareness.

Education and training involved Hospice staff educating school staff and parents/carers on childhood bereavement as well as the skills and techniques needed to meet the bereavement needs of children in a school setting. It simultaneously

sought to dispel myths associated with hospice care and ensure that any referrals for specialist bereavement support were appropriate. This was based on school staff and parents acknowledging that they may be the most appropriate person to support a child in bereavement but that they needed the skills and education to do so. Moreover, it was highlighted that because there are 160 schools in the Hospice catchment area, the Hospice could not help all children experiencing bereavement. The significance of Hospice staff transferring professional knowledge and expertise related to childhood bereavement and hospice care, with the aim of equipping school communities to manage death, dying and loss experiences, was thus identified. For example, school staff highlighted that providing bereavement support to a child whose religion was unknown was challenging. This was due to staff feeling that they needed to be "politically correct about everything" (school staff member) and not use any references linked to certain faiths that may conflict with what the child had been told at home. Thus, school staff identified the importance of Hospice staff 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.

Leadership in death education and bereavement related to the role of Hospice staff in influencing death and bereavement affirming activities, policies and procedures. This involved actively challenging death-denying policies and practices that may reinforce death and bereavement as a subject to be avoided. Activities under this theme sought both to develop a compassionate culture towards end-of-life and bereavement care and ensure that policies and procedures reinforced this culture. For example, the focus that the research, and researcher, brought to promoting the needs and rights of children in relation to death and bereavement drew attention to the lack of policies and procedures in place to support this. Participants recognised that although school staff can develop the necessary skills to support and educate children on death, dying and bereavement, if this was not enforced through policy making and/or the curriculum then such support and education may only happen on an adhoc basis according to the individual comfort level of staff. This prompted the development of a schools bereavement policy and curriculum programme that specifically addressed end-of-life and bereavement care. Both of these innovations are still in the process of being piloted. They attempt to ensure a well-informed response to bereavement

support and teaching that can be adapted to the individual needs of children and/or class groups. Moreover, these innovations enable a number of the practice ideas that were generated by child participants to be included and developed, such as creating opportunities as part of teaching for peer support, to have specific questions about death and bereavement answered and so on.

Discussion

The DEMOS report *Dying for Change,* asks for a 'Big Society' response to improve end-of-life care experiences. [23] It identifies four kinds of public and social practice innovations to achieve this. These are innovations that improve, combine, reinvent or transform. In relation to hospice care: 'improving' is based on hospices developing existing service delivery; 'combining' involves hospices making better connections with community services; 'reinventing' involves hospices 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, only practice developments (3) and (4) (develop and improve existing fundraising initiatives) did this by seeking to embed consciousness-raising with the fundraising process and enhance fundraising. These activities involved broadening the goals of current fundraising activities to ensure that palliative care is accepted and integrated into communities. The remaining activities, however, are all concerned with radically transforming practice in school communities to better manage death, dying and bereavement. This suggests that the process of action research and the relationship with the researcher assisted in mobilising the school communities to consider and improve their response to death, dying and bereavement.

The research identifies that hospices can develop an important role with local school communities. This role goes beyond providing direct service provision, such as individual/group bereavement support and/or one-off education sessions on hospice care, to an empowerment model that focuses on promoting the skills and capacity of school communities to promote a more open discourse about death and loss and to help manage end-of-life and bereavement experiences. This dual role aligns itself with literature on public health approaches to palliative care that suggest palliative care services should operate two models of care: a clinical model that focuses on

providing services, and a reorientation model that focuses on community development. [24] The identified themes offer a model from which to understand and integrate hospice activities with school communities and a platform from which a broader range of activities can be planned. They focus on normalising death, dying and bereavement experiences and developing the capacity of school communities to manage such experiences. This process supports palliative care, which affirms life and regards dying as a normal process. [25]

A common denominator for integrated care is the purposeful working of independent elements that results in something better than the individual parts. [26] The research identified that partnership working with schools facilitated conversations to take place that enabled education and support around end-of-life and bereavement care in school communities to be realised. Only four parents were involved in the research and there are therefore limitations around the extent to which full partnership working was achieved. Nevertheless, by employing an action research approach, opportunities were created to bring voices, experience and skills together. This specifically included children whose voices are often absent from death, dying and bereavement experiences. The process revealed that without the guidance and expertise of hospice staff to promote and guide such work, the schools might not have provided the children with such opportunities. Moreover, the hospice may not have considered the opportunities available to integrate hospice care outside direct service provision. This highlights the importance of inter-disciplinarity, which has been argued as a vital part of integrated care [27].. This concept was central to the action research process which required working with school communities to share expertise, skills and experience to ensure that the needs of children are met. This involved recognising that hospice staff had expertise in end-of-life and bereavement care and a belief that hospice care should transcend the walls of a hospice building to develop community capacity around death, dying and bereavement. Moreover, it relied on working with school staff, children and parents to assess the relevance of this knowledge to their community and develop responses to how this knowledge could be shared.

Conclusion

Serious illness has physical, psychological, social and existential implications. Integration in palliative care must therefore cross these domains. This involves

acknowledging most people living with dying and/or loss spend their time in their communities and only a short amount of time in healthcare settings. Communities must therefore be equipped to deal with and support end-of-life and bereavement experiences. In the context of schools, this means that if a child, school staff member or someone important in a child and/or staff member's life has an incurable illness and/or is experiencing bereavement, the school communities should be able to acknowledge and manage these experiences appropriately.

This research demonstrates that hospices can develop conversations, education and support around death, dying and bereavement in school communities. The three themes identified offer a model for practice for integrating death awareness and bereavement support into school communities. To do this, there needs to be a reorientation of hospice service delivery to include a health promoting approach to palliative care that involves wider training in the community, support, awareness raising and advocacy. This recognises the importance of care networks and integrated care that can, and should, involve hospices developing the capacity of communities to actually deliver and support meaningful end-of-life and bereavement care.

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