

Public Health Palliative Care Education: Children and Schools

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Public health palliative care recognises that illness, caregiving, death and loss are not just medical issues but social issues that affect every one of us, adults and children alike. Yet children are a population whose views, needs and capacity to both engage with and respond to these experiences are often unheard, unmet and unrecognised. This absence of children's perspectives poses a significant challenge in how we holistically understand, support and enhance children's experiences of illness, caregiving, death and bereavement. Public health palliative care education offers an important contribution to address this challenge by placing emphasis on children within wider social systems, specifically educational communities, that shapes how they engage with these experiences.

From this perspective, public health palliative care education with and for children is broad in its focus. It recognises the significance of meaningful support for children, their parents/carers and education staff, at times of illness, caregiving and bereavement, but looks beyond individual experiences to the role and capacity of education communities to proactively prepare its members to look after themselves and others. In this chapter, I discuss why children's experiences of caregiving, death and loss are relevant to public health palliative care. I then go on to highlight the role of school communities in public health, specifically focusing on the concept of Health Promoting Schools (HPS) and how this shapes our understanding of Health Promoting Palliative Care Schools (HPPCS). Lastly, I discuss some examples of public health palliative care education with children, considering some of the challenges and opportunities for developing work in this area.

Please note that the term child and/or children is used throughout the chapter to denote anyone of under the age of twenty-one. Whilst I recognise that it may be preferable to also use the term young people, or people in general, this term was selected for ease of reading.

Children's experiences of illness, caregiving, death and bereavement

Children are not immune to the experience of illness, caregiving, death and bereavement. On the contrary, research suggests that by the age of eight the majority of children have

experienced a bereavement of either a parent, sibling, grandparent or other close relative (Paul and Vaswani, 2020). Importantly, this figure is an underestimate of the true extent of childhood bereavement as it does not include deaths that occur in children's wider networks, such as the death of teachers, neighbours, distant relatives and so on (ibid). Moreover, it is based on Scottish data from 2004 to 2015 and does not reflect the occurrence of bereavement for children during COVID-19 or living in countries where there is extreme conflict, natural disasters, lack of access to healthcare, sanitation, and so on. Likewise, a considerable number of children look after someone living in their house on either a sporadic or regular basis, due to mental health, disability, substance use, long-term illness or frailty related to aging. As such the term young carer is used to define children who provide substantial physical, household, medical and/or emotional support (Smyth et al., 2011 p146).

Large-scale surveys suggest that between two to eight percent of children aged under 18 are young carers (Leu et al., 2019) and there is some evidence to suggest that this figure is as high as 22% (Joseph et al., 2019). These numbers, however, are also an underestimate due to the challenges associated with identifying children who are caring, such as children not recognising themselves as carers (Joseph et al., 2019) or that caring is often hidden because of concerns about stigma, family loyalty or family separation (Banks et al., 2002). Nonetheless, despite the challenges around identifying the actual number of children affected by bereavement or caregiving it is apparent that these experiences feature in children's lives.

Research related to children's experiences of caregiving and loss frequently focus on the negative impact that they can have on a child's social, emotional and physical health, educational outcomes and future functioning. For example, both experiences have been found to place children at increased risk of anxiety or depression, social isolation, school absences, bullying and academic underachievement (Cohen et al., 2012, Jamieson and Hight, 2013, Burns et al., 2020). As such, the significance of appropriate, timely and targeted support is recognised as important in developing improved coping and well-being (Jones et al., 2015, Ribbens McCarthy, 2006, Joseph et al., 2020). Professional services will be useful for some children, however, it is argued that this can result in a fragmented approach to support across health care services (e.g. in relation to somatic symptoms),

school personal (e.g. in relation to academic difficulties, absenteeism, behaviour problems at school) or community support services (e.g., specialist carer or bereavement support, mental health services) (Burns et al., 2020 p402). Moreover, not all children require specialist intervention (Currier et al., 2007, Aldridge, 2008) and, in relation to bereavement, it has been suggested that providing professional support too soon may result in the withdrawal of other support networks (Rumbold and Aoun, 2014). This is significant given that support from family, friends and schools are a key protective factor for children (Scott et al., 2019, Ribbens McCarthy, 2006, Gough and Gulliford, 2020). Children are more likely to seek support from their social networks, but a lack of social support can negatively impact on a child's coping, for example by compounding feelings of isolation and loneliness (Rowling, 2003, Andriessen et al., 2019, Gough and Gulliford, 2020). Moreover, a child's social context has also be found to influence exposure to bereavement and caregiving, for example low income is linked to higher rates of illness, caregiving and bereavement (Aldridge, 2008, Paul and Vaswani, 2020). Children's personal experiences of illness, caregiving, death and loss are thus influenced by the social, economic and environmental context and as such the associated risks to individual and community health arguably situate these experiences as a public health issue (Burns et al., 2020, Rumbold and Aoun, 2014, Paul and Vaswani, 2020).

Aside from personal experience, illness, death and loss are also part of ordinary life for children (Davies, 2017, Coombs, 2014, Paul, 2019). Children see, read or hear about the impact of illness and dying in relation to people in their wider community (such as neighbors, friends, schoolteachers and so on), as well as in books, movies, video games, history and science lessons and in the media (Paul, 2019). Yet, these experiences are not consistently acknowledged or recognised as a common part of a child's life by adults or in their education (ibid). It has been suggested that some adults often fear discussing death and bereavement with children believing such conversations might cause unnecessary harm or upset (Smith and Hunter, 2008, Puolimatka and Solasaari, 2006, Jackson and Colwell, 2001). This is significant given that the importance of informing, including and promoting self-efficacy when someone is ill or dies has been found to support children's coping (Monroe and Kraus, 2005, Smith and Hunter, 2008, Gough and Gulliford, 2020). Moreover, children are not systematically taught about death and grief, despite such education being

argued as essential in preparing children for loss (Rodríguez Herrero et al., 2020) and that children can, and want to, talk about these issues (Paul, 2019). Thus, children's exposure and engagement with death and loss is influenced by wider social norms, relationships and individual needs (ibid). This reflects literature on children and childhood more broadly, which recognises that the experiences and perceptions of children are not only shaped by their personal involvements and individual characteristics but also by "the attitudes, ideas and expectations of both the immediate and wider social context' (Hill and Tisdall, 1997p3). This is significant because other research suggests that attitudes and behaviors developed during childhood can follow into adulthood (Langford et al., 2015). Thus, if children are not systematically engaged with or taught about illness, caregiving, death and loss this could have future implications for how they both understand these experiences and look after themselves and others. There is then a need to move beyond understanding and responding to these experiences as individual and psychological processes or experiences to recognising and responding to them within the context of their social environment: for most children, after the family, this social environment involves their school community (Rowling, 2010). Public health palliative care draws attention to the significance of social context in shaping children's experiences of illness, caregiving, death and loss and as such offers an important contribution to how we understand and support these experiences.

Schools and public health

It is estimated that 90% of children worldwide attend primary schools and 80% of children attend secondary schools (UNICEF, 2021). Schools are therefore viewed as one of the most important settings for enhancing children's intellectual, social, emotional and physical growth and evidence suggests that doing so not only improves children's ability to learn but also that education improves future health (Langford et al., 2015). Moreover, promoting healthy behaviours through school settings has been found not only to benefit children themselves but also their families, peers and wider school community (Lee et al., 2019). This draws attention to schools as working environments for a variety of staff (teaching staff, administrators, caretakers, social workers, educational psychologists, nurses, librarians and so on) and an interface between the public and private lives of families. As such, schools are recognised as anchor institutions: that is trusted leaders in their communities due to their deep connections (economic, social and cultural) with the communities they are both

located in and serve (Taylor et al., 2014). Schools are thus well positioned to promote health and tackle health inequalities and have a long history as settings for public health interventions. This has included more traditional public health measures, such as the provision of preventative health care services through immunization programmes, hearing and vision assessments and oral and dental care, as well as interventions typically associated with new public health, such as health education and promotion activities in relation to malnutrition and obesity, sexual health, substance abuse and so on (Gard and Pluim, 2014).

Following *The Ottawa Charter for Health Promotion* (WHO, 1986) the World Health Organisation (WHO) gave focus to a settings based approach to health promotion that identified the social and cultural role and impact of settings, such as cities, schools, colleges, hospitals, workplaces and prisons, in influencing health (Whitelaw et al., 2001). In 1992, the European Network of Health Promoting Schools specifically developed the concept of Health Promoting Schools (HPS) as a strategic response to affect the risks associated with education, economic, political and social conditions (Barnekow and Rivett, 2000). A HPS involves all members of the school community working together to strengthen its capacity as a healthy setting for living, learning and working (WHO, 1996). It is a whole school approach that moves beyond traditional approaches to health education by taking a broader focus to promoting health (Langford et al., 2015). WHO's (1996) definition for a HPS thus gives focus to the formal and informal health curricula alongside 'the creation of a safe and healthy school environment, the provision of appropriate health services and the involvement of the family and wider community in efforts to promote health' (p2). As such, WHO (1996) define six elements of a HPS, these include:

1. School health policies.
2. The physical environment.
3. The school's social environment.
4. Community relationships.
5. Personal health skills.
6. Health services.

Focus is given to a holistic approach to health that involves sustained positive changes, developing and embedding health education, policy and practice within specific cultural and community contexts.

The concept and practice of HPS has been adopted worldwide and is recognised as providing a useful framework for addressing loss and grief from a preventative, community owned perspective (Rowling 2003, 2010; Kennedy et al 2021). Nonetheless, HPSs continue to attract the same critiques of public health activities more broadly due to their narrow focus on preventing and controlling illness, disease and disability, and avoiding the experiences of death, dying and loss and their associated social epidemiology (Kellehear and Young, 2007). This can leave individuals and communities unprepared and socially unsupported to cope with the inevitability of illness and loss (ibid). Public health palliative care education draws attention to this omission by recognising death as part of the life span. It refers to a broader definition of health that is not defined by the absence or avoidance of illness, disease, injury or death, but instead situates well-being at the centre. This definition of health is what Huber and colleagues (2011) refer to as 'the ability to adapt and self-manage in the face of social, physical and emotional challenges' (p1). Public health palliative care education thus identifies the relevance of HPS's but suggests a reorientation of current practice to one that acknowledges the need for and capacity of school communities to address educational and support needs in relation to meaningful care and support at end of life and into bereavement.

A model for public health palliative care education: health-promoting palliative care schools

Public health palliative care education aims to support school communities to develop education on and for experiences of illness, caregiving, death and loss. It recognises that these experiences are fundamentally social and as such place's emphasis on both information giving (raising awareness about illness, caregiving, death and loss) and action (education for life and death). Public health palliative care education with children should not therefore only occur in school settings, but instead related activities should be addressed across the multiple social domains in which children live, play and interact.

However, school communities, as discussed above, provide a unique setting from which to support the health and well-being of children, their families and the wider school community. As such, focus here is given to the significance of, and capacity for, school communities to normalise illness, caregiving, death and loss and in doing so work towards creating lasting social changes which foster a shared responsibility for, and increased compassion around, end-of-life and bereavement (Kellehear, 2005, Kellehear, 2016a). Within this context, Health Promoting Palliative Care Schools (HPPCS) is a public health palliative care education approach that specifically works to promote openness and challenge stigmas related to illness, caregiving, death and loss that promotes community members to draw on their own resources and supports to adapt and cope. This requires embedding policy and practices, promoting skills and developing learning that proactively prepares children for all life’s stages. It recognises the agency of children to both influence and be influenced by their school community and emphasises community and collective responsibility for caring for each other at times of illness, caregiving, death and loss. As such, HPPCSs give focus to the importance of building on the strengths and the capacity of school communities, promoting positive decision-making and meaningful care and support.

Drawing on the WHO’s core features of a HPS,
Table 1 below sets out a range of indicators for HPPCS.

Core Features of Health-Promoting Schools (WHO 1996)	Health-Promoting Palliative Care Schools (HPPCS)
School health policies	<ul style="list-style-type: none"> • Curricula is inclusive of death and grief education that develops children’s knowledge, attitudes and skills around illness, caregiving, death, dying and loss and the factors that enable them to make positive choices to care for themselves and others through the life course. • Policies, procedures and practices are implemented that support helpful attitudes, values and support around illness, caregiving, death and loss. This includes specific policies in place for pupils and staff at times of illness, caregiving or bereavement that acknowledge diversity and difference. • Training, education and/or information is provided for children, teachers and parents/carers around how to talk about caregiving, illness, death, dying or loss, as well as how to support themselves and others when these experiences occur.

The physical environment	<ul style="list-style-type: none"> • A safe environment is provided to discuss and/or seek support about caregiving, illness, death, dying or loss. • Conditions and/or spaces are created within the school that are conducive to those who are ill, caregiving and/or experiencing loss. This might include: access to a safe and quiet place for children, staff or families; procedures which facilitate access to support; and opportunities to remember.
The school's social environment	<ul style="list-style-type: none"> • An ethos and culture are established in the school that creates openness around experiences of illness, caregiving, death, dying and loss. • Children, staff and parents/carers care for themselves and others at times of illness, caregiving, dying, death and loss. • Accessible mechanisms to seek support are developed.
Community relationships	<ul style="list-style-type: none"> • Positive relationships are developed among and between children, staff, families, palliative care service, carer organisations, bereavement services and wider community networks. • Community links are strengthened, through connections and partnership working with families, the community, schools, organizations and other stakeholders. • Expert support and advice is provided when needed both within, from and to school communities to support the wellbeing of children, their families and staff around illness, care-giving, dying, death and loss.
Personal health skills	<ul style="list-style-type: none"> • Capacity is developed amongst children, their families and staff, including death and grief literacy, to prevent mal-adaptive coping. • Children, their families and staff know how to offer support and get support for themselves and others at times of illness, caregiving and loss. • Learning outcomes and experiences are included in formal and informal curricula to develop children's knowledge and life skills for health and well-being at times of illness, caregiving and loss.
Health services	<ul style="list-style-type: none"> • Establishes partnerships with local palliative care services, carer groups and bereavement services to provide guidance, education and support as necessary. • Informal support networks within the school are co-created with children, their families and staff. • Referral pathways for informal and specialist support at times of illness, caregiving and bereavement are clearly mapped out and accessed as necessary for children, their families and staff.

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Table 1: Indicators for HPPCS's

The indicators identify the role that school communities play in promoting well-being at times of illness, caregiving, dying, death and loss for children, their families and school staff with early intervention and harm-reduction as key principles. They highlight the significance of policy, education and partnership working to co-create conditions within school communities, those in which children learn and staff work, that are conducive to children, their families and supporting each other at times of illness and loss. Implicit across the indicators is the role of leadership within the school, and education services more broadly, to provide strong support and governance to both adopt and roll out school agreed plans, policies and curricula. Whilst established policies and procedures can be critiqued for being a fundamentally a top-down approach, they also offer organisational support and reinforcement to encourage changes to both individuals and organisational behaviour (Patterson et al., 2018). Focus is thus given to health equity, recognising education as a social determinant of health, whereby developing death and grief literacy is integral to enhancing well-being.

The indicators refer to what Whitelaw and colleagues (2001) call a comprehensive model of health-promotion due to the recognition that solutions lie not only within direct and tangible activities (such as the development and delivery of death and grief education or bereavement policies) but also within 'the multitude of day-to day processes and practices which constitute the whole' (p344). Likewise, Kennedy and colleagues (2017) argue that 'in prioritising well-being for all school community members there is a need for these issues to be community owned rather than *only* individually evaluated' (p121). Thus, emphasis is also placed on influencing and/or changing established cultures within school systems about how caregiving and bereavement experiences are responded to and as such draws focus to the significance of relationships within and between children, families and staff.

Practice examples of public health palliative care education in schools and/or with children

This section builds on the earlier sections by discussing four practice examples of how public health palliative care education with children has been developed. The first two examples

highlight activities which use a HPPCS's approach, whereas examples three and four demonstrate different models of public health palliative care education.

Example One: Compassionate Schools Project, Plymouth, England

In 2018 Plymouth (the largest city on England's south coast) signed up to the Compassionate Cities Charter (Kellehear, 2016b) in which organisations and groups across the city work together to create a city 'informed and compassionate towards those facing end of life or experiencing bereavement' (St Lukes Hospice Plymouth, 2021a). As part of this commitment, St Luke's Hospice Plymouth, Plymouth City Council and the University of Plymouth created a schools' network to develop a whole school's approach to ensuring that children and the wider school community feel supported at times of illness, death and bereavement. The project was led by a community development worker, employed by St Luke's Hospice, Plymouth. Following consultation with participating local schools, the Youth Council, bereaved young people and other relevant stakeholders, several innovations were developed and piloted at five schools and colleges that included:

- Compassionate Friends Training: delivered to school staff by St Luke's Education Team about effective communication with those affected by death, dying and bereavement using the Listen Empathy Notice and Do (LEND) model (ibid).
- Compassionate Champions Training: delivered by St Luke's Education and Social Care Team to equip school staff with the skills and knowledge to deliver Compassionate Friends Training to other staff in their school communities as well as take a leadership role in this area.
- Compassionate Buddies Training: delivered to students by St Luke's Education Team in conjunction with other partner organisations, such as the University of Plymouth Conservatoire Forum Theatre Students, to build their skills and confidence in supporting peers who may be affected by death, dying and bereavement.
- Development of a school's bereavement policy.

- ‘Time Out’ cards that young people can give to teachers to let them know that they need time away from the class and allocated ‘safe spaces’ to access support material and take time out.
- Stickers for young people to place in their homework books to alert teachers that they are struggling and would like some support.
- Development of lessons plans, aligned with school curricula, to provide teaching and learning around bereavement, death and dying. This included: developing a session on loss and grief which can be adapted for primary and secondary aged children and young people using Forum Theatre sessions to talk about the signs of grief and helpful useful responses, using the LEND model.
- Development of an award scheme for schools to sign up to that met the full criteria of a Plymouth Compassionate School and is recognised as taking a whole school approach to death, dying and bereavement.

The initial evaluation of the project revealed that the compassionate friends and compassionate buddies developed increased confidence around talking about death, dying and bereavement and also knowledge of how to access support services (St Lukes Hospice Plymouth, 2021b). The work is ongoing, and forms part of the councils Healthy Child Quality Mark programme helping participating schools demonstrate safeguarding of bereaved children and young people. St Luke’s Hospice Plymouth hopes to recruit a full-time Compassionate Schools Coordinator to engage with all schools in the locality. This is dependent on funding being secured and includes finalising an online Compassionate Schools Guidance and Resource Pack and broader support for young people during school holidays through allocated safeguarded ‘Compassionate Cafes.

Example Two: The Resilience Programme, Falkirk, Scotland

The Resilience Project was initially developed as part of a doctoral study that used action research to explore, implement and evaluate models of best practice to promote education

and support around death and bereavement from a health-promotion perspective (Paul et al., 2019). The research was funded by Strathcarron Hospice due to the management teams' interest in exploring how to work more effectively with school communities. Two primary schools were recruited to take part and school staff, hospice staff, parents/carers and children, aged nine to twelve, worked in partnership to increase understanding about current practice in the schools related to death and bereavement and develop practices as appropriate. Several practice innovations were developed, and continued to be implemented, that were of relevance to the school curriculum, policy and training:

- Bereavement training

School staff participants recognised that were not educated on childhood bereavement yet believed that it was part of their role to acknowledge and respond to children's bereavement experiences (McManus and Paul, 2019). In response, research participants designed a 2.5-hour workshop to develop the capacity of school staff to respond to bereavement issues. This training was piloted and evaluated with the two schools involved in the research. In response to the initial evaluation, the hospice management team decided to roll out the training free of charge to all schools in the hospice catchment area. A subsequent evaluation of the wider training found that pre training 24% of participants (n195) rated their confidence as high in relation to acknowledging a bereavement with a child: post training this rose to 79% (ibid).

- Curriculum Design: The Resilience Project

Participants recognised that children were not systematically educated about death and grief as a normal part of the lifecycle and that children had a variety of related questions. One participating school established a working group to design an education programme on loss, death and grief. In 2015, this programme was delivered to all children in the school, from age three to twelve. Whilst the school deemed the pilot a success the working group noted that it failed to address the specific questions (about death) posed by children participating in the initial research. An offshoot of the programme was thus developed (The Resilience Project), for children nine to twelve, and is now a core part of the school's curriculum (Quinn and Paul, 2018).

- Policy Development

In the process of developing the innovations it was discovered that there was no bereavement policy for schools in the locality. The policy team within the education services subsequently established a team of school staff and designed a 'service circular' on how to manage bereavement in schools. The service circular was disseminated to all schools in the locality.

The expertise of hospice staff was input into each of the practice innovations at various stages of design, however, these activities now run independently from the hospice, unless the schools need to access training for staff or specialist pre/post bereavement support.

Example Three: Studio DöBra, Sweden

Studio DöBra was initiated as a doctoral study and is part of national research programme, DöBra (a pun which literally means 'dying well' but figuratively 'awesome'), which uses a health-promotion approach to support conversations about end-of-life issues at individual, community and societal levels (Lindqvist and Tishelman, 2016). It is a community-based intergenerational arts project that aims to create opportunities for children and older people to interact and exchange ideas and experiences about dying, death and loss. Using community-based participatory action research, Studio DöBra works with community organisations to co-create knowledge and ideas about developing intergenerational arts projects through collective reflective practice. The community organisations included after-school centres connected to primary schools, a library, activity centres for elderly, an artistic organisation, and municipal organisations for culture and elder care (Kleijberg et al., 2020). In partnership the organisations developed the content of the intergenerational workshops as well as supporting the recruitment of participants and the provision of a space to hold the project activities (ibid).

The Studio DöBra programme involved participants taking part in a series of five workshops encompassing a variety of collaborative arts activities, such as collages, sculptures, drawings and games, with end of life related themes (Kleijberg et al., 2019). This includes exploring questions such as "where do we end up after we die?" or "how does grief feel? The story of the project is then shared through a final exhibition of artwork (ibid). To-date two Studio DöBra programmes have been facilitated with a total of 32 participants (8 children and 8 adults per group). Community and academic partners have worked together to create a

‘toolbox’ that aims to support the development of similar initiatives (Donat Magnin et al., 2019).

The programme is undergoing evaluation as part of the action research methodology (Kleijberg et al., 2020, Kleijberg et al., 2019). The findings highlight that, whilst there were no predefined learning outcomes related to end-of-life issues, participants learnt from each other through sharing their own end-of-life experiences ‘on their own terms’ (Kleijberg et al., 2020: 2034). Moreover, the project enabled a developing sense of community through new activities and intergenerational connections which participants were keen to continue (ibid). Challenges, however, were identified regarding both the recruitment of elderly participants and the sustainability of the programme, both of which related to the dependency of children and older adults on what Kleijberg and colleagues (2019) refer to as the ‘adults-in-between’; who have a key role in both introducing the topic of death to these age groups, supporting the agency of the children and older adults, and maintaining the intergenerational spaces.

Example Four: Public Awareness Campaigns

Globally there are numerous examples of public health awareness campaigns that aim to raise awareness of childhood bereavement and young-carers whilst simultaneously induce behavior change through supporting the public to better understand how to help children at times of caregiving and grief (Seymour, 2018). These campaigns are thus focused on improving outcomes for children at a population level and focus is frequently given to the role of school communities. They usually involve national and local collaborations to deliver a range of organised activities that recognise and address barriers to support at individual and community levels, such as unequal access to care or health literacy skills (ibid).

Children’s Grief Awareness Day is perhaps the most well-established example of a public awareness campaign, that happens annually in November. It was created in 2008 by the Highmark Caring Place in the United States of America (USA) to help children experiencing grief feel less isolated and more supported through transforming the culture around children and grief. It has since been adopted by organisations around the world, including Ireland, United Kingdom (UK), Canada and Australia, and ranges from a one-day campaign

to a whole week of activities that seek to recognise and take action around children's grief. For example, in 2021 the USA campaign saw the launch of *GriefTalk*, an initiative to encourage and support honest conversations around the topics of death and grief. Likewise, in the UK the theme *SayTheWords* was used to encourage a variety of activities related to identifying and acknowledging loss with and by children. This theme was supported by directing teachers to lesson plans on grief or encouraging schools to complete an audit tool aimed to support grieving pupils. Public awareness campaigns for young-carers are either part of wider annual Carer Campaigns, for example in Australia, or those specifically for young-carers, as in the UK. These campaigns aim to raise public awareness of carers, the associated challenges and the need for support. In the UK, from 2021 onwards, the focus of the campaign moved from awareness to action to give greater emphasis on encouraging the public to acknowledge and support young people involved in caregiving.

Challenges and opportunities

The examples outlined above demonstrate several ways in which public health palliative care education can engage with children about illness, caregiving, death and loss. The examples show that schools provide a useful site to connect with children about these issues but also to influence and shape behaviours, beliefs and supports, for both children and the wider school community. According to Rowling (2003) bringing death and dying into schools from a preventative, health-promotion perspective depends on several competing factors, including: curriculum priorities; the skills, comfort and motivation of teaching professionals; the learning environment; and the learning context. Curriculum priorities is a key challenge. Whilst education on, and for, death and bereavement can be incorporated at any stage of schooling, both as a discrete or transversal topic (Rodríguez Herrero et al., 2020), to-date evidence suggests that there is insufficient curricula focus to support such teaching (ibid, Paul, 2019, Tompkins, 2018). As such, education for and about death is not intentionally incorporated into school curricula but instead relies on the willingness and skills of individual teachers and/or schools which is, by essence, inequitable. This is against a back-drop of competing curricular priorities and a staff force which are not consistently trained in, or supported to, engage with such issues. Research regularly highlights that a key barrier for schools in engaging with illness, care-giving death and loss is that staff feel ill-

prepared and ill-equipped to do so (Rowling, 2003, McManus and Paul, 2019). Thus, while school staff clearly have skills in working with children there is a reticence to engage these skills around education and support relating to illness, caregiving, death and loss. As such, death and grief education necessarily involves self-development of teachers and cooperation with parents/carers as well as effective communication with children (Rodríguez Herrero et al., 2020). Embedding training for staff at all levels, including pre and post qualification for teachers, so that death and grief education and support can be fully embedded into the culture of education should therefore be a key priority (ibid). This, in turn, needs to be supported by distinct policy development in relation to support for staff and children. Death is a sensitive issue that can elicit powerful emotions and as such ensuring that staff, children and their families, can access meaningful support (social and specialist) if and when needed is essential, and a key focus within public health palliative care approaches.

While public health palliative care education invites schools to proactively prepare children, and the wider school community, for illness, caregiving, death and loss, schools frequently attend to presenting problems. For example, it is common for school staff to engage with bereavement training or look at developing a bereavement policy once a bereavement occurs in the school, rather than proactively preparing for these experiences. This can result in a range of disjointed practice and policy provision both within and across school communities and thus there is a need to ensure that school communities can identify benefits of public health palliative care as part of their core business of education. Arguably this should not be difficult given the prevalence and impact of illness, caregiving, death and loss on children and within school communities; yet these issues are not common parlance and largely remain hidden. Moreover, the school setting is not an 'independent and controllable entity' (Whitelaw et al 2001 p343) but subject to a variety of competing political, social and educational demands and thus leadership is essential in promoting public health palliative care approaches. Specialist palliative care providers may have a role here. They are viewed as being in a unique position to initiate and/or provide leadership in developing public health palliative care activities due to their expertise in end-of-life and bereavement issues (Street, 2007, Kellehear and O'Connor, 2008, Paul et al., 2019). Moreover, in countries such as the UK and New Zealand, working with schools is a popular

form of community engagement for specialist palliative care services (Dempers and Gott, 2017, Paul and Sallnow, 2013). Yet there a number of barriers to developing such work due to funding, service vision and purpose, local need and clarity around the key goals of a public health approach (ibid). As such, whilst numerous examples exist of specialist palliative care services working with school communities, in line with WHO's definition of a HPS (1996), a consistent challenge remains in ensuring that positive changes are sustained and are not dependent on the service or the enthusiasm and commitment of a few staff members. The current focus in schools on addressing presenting issues potentially presents an opportunity for specialist services, such as those providing palliative care, bereavement support or support for carer's to engage with schools in these issues and to support and develop informal care networks. Moreover, the examples provided identify numerous opportunities for partnership working in relation to training, curricula and policy development, building social support networks and providing specialist services. Nonetheless, it is essential that external agencies with an intervention role create strong, supportive and enabling relationships, led by the needs of the school community.

Public health palliative care education in schools is a long-term process that requires attention to the development of policies, curricula, resources, staff training, and internal and external supports, alongside creating spaces and practices which acknowledge diversity and promote choice rather than prescribing certain behaviours. This relates to a change in ethos and culture as opposed to purely implementing practice strategies and as such Kennedy and colleagues (2020) argue that opportunities should be created for school communities to explicitly discuss their experiences and preferences for attitudinal and cultural change. It involves employing a participatory style of working rather than expert positions and includes fully recognising the rights and agency of children. This type of approach takes time and it is important to note that three of the examples provided were initiated by someone (a staff member or researcher) with a remit and resources to develop work with children as part of a public health approach.

Finally, while schools may provide a key site for public health palliative care education, it is important to acknowledge that not all children go to school and that children exist as part of other communities. As such, public health palliative care education needs to look both

within and beyond schools to the broader networks of children's lives. In relation to HPPCS's focus thus needs to be given to considering how related activities can transcend the school building and interact with the wider family and community lives of children and staff. To-date this expansion is currently underexplored.

Summary

This chapter has argued that illness, caregiving and bereavement are common features in children's lives and reframing these experiences as a public health issues places emphasis on a multi-layered approach to education, care, and support that firmly positions children within the families and communities in which they live. School communities provide a valuable setting for public health palliative care due to the link between health and education and the impact that schools have in mediating children's experiences. I have argued that HPPCS's offer a useful framework from which to develop meaningful engagement and holistic practices whereby children, and the wider school community, can gain information and skills to improve their health and wellbeing both now and into the future (Street, 2007). Reforms to school curricula, policy and training will be integral to promoting systemic change that fosters a compassionate school community at times of illness, caregiving, death and loss.

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