Downing *et al. BMC Palliative Care* (2025) 24:89
https://doi.org/10.1186/s12904-025-01653-1

BMC Palliative Care

**REVIEW** **Open Access**

# Children's palliative care and public health: position statement

Julia Downing[1,2*], Duncan Randall[3], Katrina Mcnamara-Goodger[4], Peter Ellis[5], Gayatri Palat[6], Zipporah Ali[7], Jenny Hunt[8], Rut Kiman[9], Marie Friedel[10] and Sue Neilson[11]

## Abstract

A public health approach to palliative care has been developed in adult palliative care over several years. Despite the concepts of health and wellbeing, and palliation, dying and death appearing at first to be contradictory, a cogent argument has been made to understand palliative care in the context of promoting public health. However, the application to children's palliative care has not been articulated in depth. The need for and development of children's palliative care is well documented globally, with the public health model, and more recently the WHO conceptual model for palliative care development being key to ongoing development and progress in service delivery. Engaging communities to influence care provision is essential and important to ensure provision of appropriate and sustainable care. Positioning children's palliative care within the public health perspective transforms care and service provision and centres around the child, their childhood and their carers, as part of the community and the wider population. Access to healthcare is vital, of course, but so is access to childhoods which guarantee children's human rights and access to being a child living a childhood, whether that childhood is long, short or leads to an adulthood. Uncovering differing perspectives on the intersection of public health and children's palliative care that varied between global regions, led to the development of eight statements. Our collaboration between colleagues in seven countries in different regions has allowed us to set out the context of the children's palliative public health approach. This reflects a balancing of medical/nursing professionalised care and partnerships, co production and participation of communities. The public health approach to children's palliative care is radical, it is transformational, and means changing how we do things in order to improve the lives of children with palliative care needs and their families around the world.

**Keywords** Palliative care, Public health, Children, Paediatrics, Community, Global, Co-production

*Correspondence:
Julia Downing
julia.downing@icpcn.org
[1] Makerere/ Mulago Palliative Care Unit, Palliative care Education and Research Consortium, Kampala, Uganda
[2] International Children's Palliative Care Network, Bristol, UK
[3] Department of Nursing Sciences, Bournemouth University, Bournemouth, UK
[4] Retired Children's Palliative Care Nurse, Fellow of Association of British Paediatric Nurses, Wolverhampton, UK
[5] Retired Chief Executive, Richard House Children's Hospice, London, UK
[6] Department Pain and Palliative Medicine, MNJ Institute of Oncology, Hyderabad, India
[7] Public Health Specialist, Board Director African Palliative Care Association and Kenya Hospices and Palliative Care Association, Nairobi, Kenya
[8] Independent palliative social worker/ Bereavement therapist, Harare, Zimbabwe
[9] Instituto Pallium Latinoamerica, University of Buenos Aires, Buenos Aires, Argentina
[10] Department of Life Science and Medicine, Faculty of Science, Technology and Medicine, University of Luxembourg, Luxembourg City, Luxembourg
[11] Department of Nursing Studies, University of Birmingham, Birmingham, UK

## Introduction

There is very little documented on how the public health approach in palliative care can be applied to children and young people[1] with a life limiting[2] or life-threatening condition and their families, both for those living with their condition as well as for end-of-life care, death and bereavement. Death in childhood is often seen as a particular or special form of death and bereavement [1, 2]. The historical and current reality is that children die in childhood [3, 4]. In High-Income Countries (HICs), infant and child mortality has fallen since the late 1940's. However, in Low- and Middle-Income Countries (LMICs) although infant and child mortality rates have reduced, maternal mortality remains relatively high. Thus, while in HICs child death is rare, in LMICs, child death is common, and most families will have experience of it, if not in their immediate family, in families of close relatives, or friends.

What we do know is that caring for a child with a life-limiting condition along with the death of a child or young person in our society has a profound impact on their carers, family, friends, neighbours and community [5–9]. Further, this impact will last for many years; indeed, for the parents and siblings this may affect them for the rest of their lives [10–14]. How a child dies determines how a carer survives [15, 16]. End of life care is therefore important and can be effective in LMICs as well as HICs as the burden of mortality shifts with income toward prolonged illnesses where death can be prognosed in advance, such as cancer, but cultural and religious beliefs remain significant barriers [17, 18]. Thus, a public health approach is key. Death and dying, loss and grief is therefore everyone's business. Although we perhaps find it uncomfortable to talk about and acknowledge the death of an adult, the death of a child has added social stigma and may be seen as taboo.

Studies of child death portrayal in media and the lived experience of child death suggest that the public perceptions of death in childhood are shaped by similar conceptions as adult death, such as magical thinking [19], media portrayal and by personal experience of death in childhoods [20, 21]. Thus, while there are cultural and social perceptions there are also very personal narratives dependent on lived experience. Groups such as Heard [22] in the UK encourage the telling of such narratives in order to connect people living with childhood death in communities.

One of the challenges faced is the diverse use of the term 'public health' causing confusion and the need for clarification of what is meant by the phrase a 'public health approach' [23, 24]. Stjernsward et al. defined it as:

> *'A public health approach aims to protect and improve the health and quality of life of a community by translating new knowledge and skills into evidence-based, cost-effective interventions that will be available to everyone in the population who needs them' [25].*

It is concerned with the health of people on a population level, aiming to improve the health of communities, recognising that health is linked to social, political and economic factors [23]. Public health approaches come from a social justice perspective in which health is seen as a right for all, and resources are shared in the community in a sustainable way. Resources are (re)distributed, including sustainable human resources and material resources, as well as time and emotional effort/ labour.

Services need to be developed, or co-produced with the community, with the people that they are serving – recognising that the people most affected can often provide the best solutions to the problem. In the public health context, health should be seen not just in terms of a curative approach to health, but in terms of a general feeling of well-being, and aiming for the best possible situation within a given context [26]. Cohen and Deliens [27] describe public health at the end of life as '*the efforts organised by society to optimize the circumstances of the dying and all those involved through collective or social actions*'. Thus, it embraces a wider perspective than that of the medical and biomedical models in developing palliative care [28] and includes all those involved such as communities, families, and professional caregivers.

A children's public health palliative care approach takes account of a community's response to child death. Attention is paid not just to medical aspects in individual children and families, but also to illness, disease and disability as it affects children in communities and populations. The political/social and cultural aspects of various childhoods is considered with communities working hand-in-hand with health professionals in order to provide a '*whole child*' approach, which embraces not just physical issues, but political/social, psychological, spiritual and cultural issues – all of which interact in and impact on the quality of life of shortened childhoods and bereavement. Spiritual and culture issues are particularly important and need to be recognised within the children's public health approach such that those with a faith, no faith or exploring religion and spiritual issues should be supported by the community.

---

[1] The World Health Organization defines palliative care for children beginning when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.

[2] Life limiting conditions in children and young people can be defined as conditions for which there is no reasonable hope of cure from which children or young people will die. Life-threatening conditions are those for which curative treatment may be feasible but can fail such as cancer.

Much of the work of public health involves engaging a community. However, there are aspects of community engagement which might not relate to a public health agenda, such as the design, delivery and evaluation of illness services, raising awareness of certain health conditions and the effective support for those living with a condition. For many "community engagement" is synonymous with fund raising for services. However, if community engagement is to reflect public health approaches, community engagement in children's palliative care needs to be embraced and include not only raising funds for palliative care services e.g. hospice, and public campaigns to improve access to palliative care services, but embracing and supporting the child and their carers in relation to living, dying and grieving in a community. Thus, the community needs to be engaged at all levels of the public health approach to children's palliative care such that we put children and their families first and making co-design a reality.

Medical/ nursing[3] care is important within public health palliative care, but should not be the dominant focus of care as it is focused on ill health. This work is dominated by a focus on the support and help offered to those living with altered health status and health conditions. As such it can be seen as a consulting activity - where individuals ask for help from "experts", or in other words they consult a healthcare professional [29]. This is in contrast to public health work which is focused on populations and where the work is to design interventions/campaigns to meet expressed, normative or comparative needs of a population who may or may not seek this from professionals (or anyone) [30].

These concepts also contain some intersecting and overlapping ideas, actions and interventions. Medical/ nursing care includes some public health work, which increasingly involves public patient involvement[4], including with children and young people [31]. However, the theories, which underpin these terms and concepts, differ. Public health theory differs from medical and nursing theory and these are not the same as community engagement theories. Thus, there is a theoretical inadequacy. As Pragmatists point out if a theory does not adequately reflect all aspects of a phenomenon then the theory has to be revised [32].

Within the context of palliative care development internationally, the public health strategy defined by Stjernsward et al. [25] has often been used as a guiding principle. It identifies the components needed to effectively integrate palliative care into a society and improve access and availability to services. The components include: (1) appropriate policies, (2) adequate availability of medicines, (3) education, and (4) implementation of services [25], with an additional underpinning activity of research added at a later date [26]. Whilst a useful framework, at times its focus can be seen to be more medical than public health. If the emphasis on access to medicines, and training health professionals is prioritised over the overall concept, with the focus on holistic needs, society and the community are at risk of being lost. A revised conceptual model of palliative care development was published by the WHO in 2021 [33] to strengthen Stjernsward et al.'s model [25]. It reflects international commitments to the Primary Health Care Approach recognising the importance of empowered people and communities, a key ingredient of public health. The conceptual model is made up of six components with its central focus, the core of the model, being that of people with life-limiting or life-threatening conditions (both children and adults). The foundational components of the model are empowered people and communities, and health policies, with research resting on these foundations and informing the use of essential medicines, education and the provision of palliative care to those in need [33]. Empowering communities is key and so raising awareness and training on children's palliative care is essential.

## Public health and children's palliative care

The WHO defines children's palliative care as "*the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological and social distress. Effective palliative care requires a broad multi-disciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's homes.*" [34]. Whilst variations in the definition of children's palliative care exist, e.g. from Together for Short Lives [35]; the revised International Association of Hospice and Palliative Care (IAHPC) definition of palliative care [36] and the Lancet Commission's concept of Serious Health-related Suffering (SHS) [37], the concept and philosophy of care is similar, with care being provided for children with life-threatening and life-limiting conditions and their families.

From the middle of the 20th century there has been a growing movement in HICs to recognise the work of caring for dying children and their carers/communities

---

[3] Here medical/nursing care is used to include practices of medicine, nursing and other disciplines allied to medicine for example physiotherapy, occupational therapy etc.

[4] Patient and public involvement (PPI) is the active involvement of patients and members of the public in the design and process of research (Mitchell et al. 2018) and/ or education and service development.

[38, 39]. Arguably in accordance with feminist political action there has been a trend of bringing this "private" work of women in families and communities into a public sphere [40, 41]. As a consequence, there has also been an increasing professionalisation of this work and consequential disempowerment of communities in dealing with death and dying, and grief and loss, particularly in children. We can see this trend in the UK from the establishment of children's hospices from 1982 [42], community children's nursing services in the 1990's [43], the Royal College of Nurses (RCN) community on children's palliative care and the Association of Paediatric Palliative Medicine (APPM) as well as 3rd sector organisations such as Together for Short Lives. Education programmes and attendant qualifications on children's palliative care and employment roles have developed to serve the growing needs of the caring workforce [44].

The need for and development of children's palliative care has also been evident in LMICs with the integration of palliative care into existing health systems and community structures, and much more of an emphasis on public health than in HICs [45]. A review in 2010 identified that 65.5% of countries at that time had no known children's palliative care activity, with only 5.7% having provision reaching mainstream providers and that was in HICs [46]. Since then, provision of children's palliative care has expanded in many countries, with work being focused around the public health strategy. National children's palliative care organisations exist in a range of LMICs and HICs in all regions, with regional and international organisations such as the European Association of Palliative Care (EAPC) Children's & Young Peoples Reference Group, The Asociación Latinoamericana de Cuidados Paliativos (ALCP) Paediatric special interest group and the International Children's Palliative Care Network (ICPCN). In countries where there are no national children's palliative care organisations, some national associations have prioritised both adult and children's palliative care. These groups working together have been influential in raising the profile of children's palliative care at the World Health Organisation (WHO) resulting in position statements and other initiatives [47].

One of the challenges to global access to children's palliative care is competing global health priorities, not just in terms of palliative care vs. preventative or curative care, but also in terms of children's vs. adult palliative care. The Global Atlas of Palliative Care [48] for example identifies that only 7% of individuals needing palliative care globally are children (0–19 years of age). It is therefore important to situate palliative care development and the Public Health Strategy for children within current global priorities. Goal three of the sustainable development goals is about health [49] and palliative care is an important part of this. Likewise palliative care is included in the definition of primary health care through the Declaration of Astana [47], and is a core component of universal health coverage [50]. Each of these has a focus on improving the health and quality of life of the community with the public health emphasis on children's palliative care crucial.

The World Health Assembly (WHA) resolution on palliative care in 2014 [51] mandating member states to report on the development of palliative care, and the Lancet Commission report on alleviating the access abyss to pain and palliative care [37] highlight the need for palliative care, including children's palliative care. The WHO have also shown their commitment to the development of palliative care through dialogue with civil society about palliative care and a resulting work plan and the formation of the WHO Palliative Care Working Group which held its first in-person meeting in late 2023. Thus, it can be argued the time is right for the ongoing development of children's palliative care around the world within the constructs of a public health strategy.

Public health approaches to palliative care have grown over the past decade along with their acceptance [28]. The public health strategy [25] has become a widely used strategy for palliative care development [52] and more recently the WHO conceptual model of core components [33]. Examples of public health approaches such as that of compassionate communities can be seen around the world including in Kerala, India [53–55], Sydney Australia [56] and in the United Kingdom (UK) [57, 58]. Studies have also demonstrated the impact of the public health approach to palliative care, and that collaborating with key community stakeholders enables the provision of community driven support for people with palliative care needs [59]. Having said that, there is little published in relation to the public health strategy and children's palliative care. Rowse [60] discusses the role of a community children's palliative care team and their focus on health promoting and public health, reframing the delivery of a children's palliative care service within the public health agenda. Hexem and Feudtner [61] discuss some of the key tenets of children's palliative care, focusing on key public health concerns and how they apply to children's palliative care, such as: disease in populations and promoting patterns of health; promoting wellness; understanding the social determinants of health; considering nested levels of influence and impact; along with improving quality while promoting equity. They suggest that "providing an effective public health infrastructure that supports children and their families is a paramount goal for paediatric palliative care." (p171) Likewise Downing and Marston [45] situate the development of children's palliative care as a public health issue, stressing that the public health strategy and framework *'provides a sound basis from which to develop children's palliative care services'*.

This framework was further developed into a road map which emphasises the importance of co-production, and includes additional elements for successful integration e.g. having a national champion, educating the public about palliative care, conducting a needs assessment, stakeholders meetings and formation of working groups for co-production, and the development of clear goals for palliative care within a public health context [62]. Similarly the UK's children palliative care education and training (CPCET 2021) framework [44] has expanded on the commonly used three levels of palliative care education, the palliative care approach; general palliative care; and specialist palliative care, found in the WHA Resolution [51], and other frameworks, such as the EAPC white paper on the core competencies for children's palliative care [63] ; to four levels – public health, universal, core and specialist [64]. The inclusion of the public health level is key in the ongoing development of the public health approach within children's palliative care and covers "*… social attitude to death and dying in childhood and bereavement following a child death, … across education, health and social care and [involving] other stakeholder groups concerned with children, their experience of childhood, learning and support of children, siblings, parents and other family members as well as communities affected by child death (e.g. school communities)*" (p6).

However, a broader awareness of the position of children's palliative care in relation to childhood in societies and the communities is needed [65]. Changing communities' views can be challenging, thus working with the community (individuals, key organisations e.g. churches, mosques, local authorities, schools etc.) in the co-production of public health models of children's palliative care is essential. Volunteers are often central in public health models. Whilst the use of volunteers engages local involvement, it often still retains the volunteer within an organisation, influencing culture and approaches. However, community engagement has the potential to empower individuals within their own community and enable the community to influence the culture and approaches to care. Thus, lessons need to be learnt from a variety of public health models of palliative care that can be applied to the children's palliative care context. Models of children's palliative care need to be appropriate for the setting and whilst models that rely heavily on professionals work well, particularly in HICs, they may not be possible or sustainable in the long term in LMICs. Such models that rely heavily on the professional approach may only be practical in societies with a developed professional care workforce. The sustainability of this workforce has also to be capable of managing the number of child deaths. This approach perhaps works in societies with low child death rates and high numbers of professionalised nursing, medical and other care professions. There is then logically a direct relationship between nursing/ medical/ care practitioner numbers and number of child deaths/ children likely to require palliative care. It also requires adequate wealth to sustain healthcare investment to educate and employ care professionals in sufficient numbers.

This approach also contains ethical/moral and political concerns. Firstly, there is the ethical dilemma that a professionalised approach can disrupt and may diminish a family/community response. As Randall [65] has pointed out, if the goal of children's nursing is to facilitate a child living with palliative care needs such that their childhood, despite being short, is as close to that of their peers in their community, then part of the nurses' work is to facilitate the relationships between the child and their carers (often parents). All children including those who are dying, are children. In the main, children have relationships with others who care for them, as they grow and develop their own self-care abilities. Children are part of a community, as we know *it takes a village to raise a child* (African proverb). We might rephrase this and accept it takes a village to make sure a child dies well. That for a child to die well the "village" has to mourn and recover from the death. If the responsibility for the child's good death is accepted by professional groups there is a risk that carers and communities may reject their responsibility. Moreover, that confusion arises as to who is responsible for which aspects of care (illustrating the need for training to manage and clarify boundaries). We can see these difficult dilemmas played out in high profile media stories such as that of Charlie Gard or Alfie Evans in the UK [66, 67]. Professional groups can also fail at a policy level to connect with communities and this disengagement can cause public/political concern as experienced in the UK with the Liverpool care pathway [68]. Of course, these are exceptional examples and in many individual cases the negotiation of responsibility for care results in shared, clearly defined responsibilities being accepted by children/carers and professionals. However, we cannot ignore the risk of conflict. Perhaps more importantly if less dramatically there are examples in the everyday care where professionals may disrupt child/carer relationships. Darlington et al. [69] found that many parents of neonates who died felt that they had to reclaim their child from the medical professions, by removing tubes and medical devices, only then could they hold their child and feel the child was their child. Many parents report that they needed to feel that they did everything they could for their child, who subsequently died. If some of the tasks are undertaken by other paid workers, then there is a risk parents are left feeling they missed out on certain experiences, chief amongst these might be being present at the time of death.

On the other hand, in the public health approach there is a risk that all of the responsibility for care is accepted by the child's carers. It is important that children are cared for in the place of care preferred by them and their families [70]. Whilst this is often at home, it may not be, and it is important that they have a choice of place of care. However, often societies do not provide alternative options as hospice and palliative care for children and this remains very limited in many countries, if it is available at all [46]. While many care givers find strength and capacities they may not have been previously been aware of, others will struggle and some may not be able to meet their child's needs. Even in communities where people may have experience of caring for the dying, caring for a child with palliative and end of life care needs may be less of a common shared experience. Communities may not develop strategies or understanding of care such as symptom control. There is then a risk that children and their carers are left to fend for themselves; some may be resilient and resourceful, others will not. In addition, it can be argued that children and their carers in LMICs are being denied the level of educated support that children in HICs can and do access. The benefits of professionalised palliative care enjoyed by some are not being shared with all and increasing technological support would seem to widen this divide further. Children's nursing as a specialty in nursing is only established in a few HICs countries with children's nursing not being recognised as a specialty in many LMICs, and where it is there are limited numbers of trained professionals.- For example a study in Kenya, Uganda, Malawi, South Africa, Zambia and Uganda identified just 3,728 children's nurses across the five countries, with 8/10 of those in South Africa [71]. Thus, the civic society effect of a critical mass of nurses and doctors who identify themselves not only as children's nurses/paediatricians, but as palliative care specialists is often not available. We therefore need to be 'thinking outside of the box', looking through different lenses, learning from and with communities, to ensure that children needing palliative care and their carers can access it in the most appropriate way, enabling the children to live as part of, and be a valued member of their community. This also extends to bereavement in the community. There is evidence that equipping communities with simple information regarding the grief process including how to support the bereaved within their cultural frameworks, provides significant benefits to not only bereaved families, but to the community as a whole [7, 72–74].

The importance of a good public health strategy has been seen throughout the Covid-19 pandemic, with a clear emphasis on the community and populations as a whole, not just the individuals within them. Many HIC societies reflect individualistic cultures which stress the needs of the individual over the needs of the community as a whole, and thus have tended to focus on the individual freedoms disrupted due to the pandemic. However, what has been seen in the Covid 19 pandemic is that what an individual does impacts the community, so we need to be looking at issues, including palliative care, through a public health lens, and address the premise that the whole community should take up a role in support of each other. The professional response must be complemented by the support available from families, friends, neighbours and others (e.g. schools, church, mosque etc.). The principles set out by the public health palliative care approach may offer a solution to establishing a sustainable model for meeting the ongoing need for care and support of children and young people, with their families; children or young people who have a life limiting/life threatening condition. This could be transformational, adopting new ways of working that require us (the professionals) to let go and share responsibility.

## Position statements

Positioning children's palliative care within the public health perspective transforms care and service provision; it centres around the child and their carers as part of the community and the wider population. Within a public health focus to children's palliative care:

1. Dying, death, loss and grief is *everyone's business*. Despite our anxieties in the professional world, we can empower the community.
2. No matter how long or short a childhood is, children are all children who have the right to live full and for filling lives as children.
3. The community and professionals supporting the child must complement each other, and offer regular, practical support, to enable children and their carers to continue living connected sustainable lives.
4. Theories of children's palliative public health must be coproduced by health, education and social care professionals and children, carers and communities.
5. Governments must incorporate children's palliative public health care into all levels of their health, education and social care systems. Communities must be involved through collective social action, and through co design, co-creation and co production.
6. We must be the change we want to see. Everyone involved has a role to play in delivering a radical and transformational change to build more sustainable and robust models of care and services.
7. Children's palliative public health must be embedded in all health and social care education curriculums, in particular in primary and community care.

8. More research and co evaluation into children's palliative public health care is needed to ensure the delivery of appropriate, individualised palliative care.

## Conclusion

Children's palliative care providers need to address the public health approach and adopt new approaches to working. The provision of palliative care for the child and their family should be based on co-production in order to better understand what matters to the child, their family and the community, and therefore provide appropriate care. This participatory approach is fundamental to the feasible implementation of children's palliative care within a public health framework. Evaluation of this approach around the world will help to provide evidence and give confidence for practitioners to take up this approach. No individual or group holds a complete answer. Whatever approaches are developed through coproduction will need to be implemented with regard to the specific context of where they are being used. No model can be applied uncritically across the world and progress can only be made by sharing understanding and resources. This approach is radical, it is transformational, it means letting go and working in completely new ways – importantly it means improving the lives of children and young people with palliative care needs and their families around the world wherever they and their carers live.

### Abbreviations

| | |
|---|---|
| ALCP | Asociación latinoamericana de cuidados paliativos |
| CPCET | Children's palliative care education and training |
| EAPC | European association of palliative care |
| HICs | High income countries |
| IAHPC | International association of hospice and palliative care |
| ICPCN | International children's palliative care network |
| LIMCs | Low and middle income countries |
| WHA | World health assembly |
| WHO | World health organization |

**Acknowledgements**
None

### Author contributions

JD led the development of the paper in collaboration with DR and SN. All authors (JD, DR, KM-G, PE, GP, ZA, JH, RK, MF, SN) contributed to the writing of the paper and all authors read and approved the final manuscript.

**Funding**
No funding was sought for the development of this paper.

### Data availability

No datasets were generated or analysed during the current study.

## Declarations

### Ethics approval and consent to participate

Not applicable.

### Consent for publication

Not applicable.

### Competing interests

The authors declare no competing interests.

Received: 5 February 2024 / Accepted: 13 January 2025

### References

1. Hynson JL, Gillis J, Collins JJ, Irving H, Trethewie SJ. The dying child: how is care different? Med J Aust. 2003;179:S20–2. https://doi.org/10.5694/j.1326-5377.2003.tb05571.x
2. Hynson JL, Sawyer SM. Paediatric palliative care: distinctive needs and emerging issues. J Paediatr Child Health. 2001;37(4):323–5. https://doi.org/10.1046/j.1440-1754.2001.00674.x
3. World Bank. Mortality rate infant (per 1000 live births) https://data.worldbank.org/indicator/SP.DYN.IMRT.IN?end=2019&start=1960&view=map. Accessed 31st January 2024.
4. UN Inter-agency Group for child mortality estimation. Most recent stillbirth, child and adolescent mortality estimates. 2019. https://childmortality.org. Accessed 31st January 2024.
5. Pohlkamp L, Kreicbergs U, Sveen J. Bereaved mothers' and fathers' prolonged grief and psychological health 1 to 5 years after loss-A nationwide study. Psycho Oncol. 2019. https://doi.org/10.1002/pon.5112
6. Fraser LK, Murtagh FE, Aldridge J, Sheldon T, Gilbody S, Hewitt C. Health of mothers of children with a life-limiting condition: a comparative cohort study. Arch Dis Child. 2021. https://doi.org/10.1136/archdischild-2020-320655
7. McNeil MJ, Namisango E, Hunt J, Powell RA, Baker JN. Grief and bereavement in parents after the death of a child in low- and Middle-Income Countries. Child (Basel). 2020. https://doi.org/10.3390/children7050039
8. Suttle M, Hall MW, Pollack MM, Berg RA, McQuillen PS, Mourani PM, Sapru A, Carcillo JA, Startup E, Holubkov R, Dean JM, Notterman DA, Meert KL, Eunice Kennedy Shriver National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network (CPCCRN). Complicated grief, depression and post-traumatic stress symptoms among bereaved parents following their child's death in the Pediatric Intensive Care Unit: a follow-up study. Am J Hosp Palliat Care. 2022. https://doi.org/10.1177/10499091211015913
9. Morris S, Fletcher K, Goldstein R. The grief of parents after the death of a young child. J Clin Psychol Med Settings. 2019. https://doi.org/10.1007/s10880-018-9590-7
10. Dussel V, Jones B, O'Brien K, Williams-Platt M. Impact on the family. In: Hain R, Goldman A, Rapoport A, Meiring M, editors. Oxford Textbook of Palliative Care for Children. 3rd ed. Oxford: Oxford University Press; 2021;111–125. https://doi.org/10.1093/med/9780198821311.001.0001
11. Portney S, Ives-Baine L. Bereavement. In: Hain R, Goldman A, Rapoport A, Meiring M, editors. Oxford Textbook of Palliative Care for Children. 3rd ed. Oxford: Oxford University Press; 2021;126–34. https://doi.org/10.1093/med/9780198821311.001.0001
12. Hunt J, Takawadekar P, Friedel M. Anticipatory grief and bereavement support. In: Downing J, editor. Children's palliative care: an international case-based manual. Switzerland: Springer Nature; 2020;201–10. https://doi.org/10.1007/978-3-030-27375-0
13. Youngblut JM, Brooten D. What children wished they had/had not done and their coping in the first thirteen months after their sibling's neonatal/pediatric Intensive Care Unit/Emergency Department death. J Palliat Med. 2021. https://doi.org/10.1089/jpm.2019.0538
14. Rasouli O, Moksnes UK, Reinfjell T, Hjemdal O, Eilertsen MB. Impact of resilience and social support on long-term grief in cancer-bereaved siblings: An exploratory study. BMC Palliative Care, 2022; https://doi.org/10.1186/s12904-022-00978-5.
15. Neimeyer RA, Baldwin SA, Gillies J. Continuing bonds and reconstructing meaning: mitigating complications in bereavement. Death Stud. 2006. https://doi.org/10.1080/07481180600848322
16. Kars MC, Grypdonck MHF, de Kirte-Verhoef MC, Kamps WA, Meijer-van den Bergh EMM, Verkerk MA, van Delden JJM. Parental experience at the end-of-life in children with cancer: 'preservation' and 'letting go' in relation to loss. Support Care Cancer. 2011;19:27–35. https://doi.org/10.1007/s00520-009-0785-1
17. Amery JM, Rose CJ, Holmes J, Nguyen J, Byarugaba C. The beginnings of children's palliative care in Africa: evaluation of a children's palliative care service

in Africa. J Palliat Med. 2009;12(11):1015–21. https://doi.org/10.1089/jpm.2009.0125
18. Downing J, Powell RA, Marston J, Huwa C, Chandra L, Garchakova A, Harding R. Children's palliative care in low and middle-income countries. Archives Dis Child. 2015. 10.1136.archdischild-2015-308307.
19. Bluebond-Langner M, Clemente I. Children's views of death. In: Hain R, Goldman A, Rapport A, Meiring M, editors. Oxford Textbook of Palliative Care for Children. 3rd ed. Oxford: Oxford University Press; 2021;66–74.
20. Bonoti F, Leondari A, Mastora A. (2013). Exploring children's understanding of death: Through drawings and the death concept questionnaire. Death Studies 2013;37(1):47–60. https://doi.org/10.1080/07481187.2011.623216
21. McPoland P, Grossoehme DH, Sheehan DC, Stephenson P, Downing J, Deshommes T, Gassant PYH, Friebert S. Children's understanding of dying and death: a multinational grounded theory study. Palliat Support Care. 2023;22(2):213–20. https://doi.org/10.1017/S1478951523000287
22. Heard. Shifting the narrative about care for very unwell children. 2024. https://heard.org.uk/articles/childrens-palliative-care-project-page/ Accessed 26th June 2024.
23. Kellehear A, Sallnow L. Public health and palliative care: an historical overview. In: Sallnow L, Kumar S, Kellehear A, editors. International perspectives on public health and palliative care. London: Routledge; 2013.
24. Dempers C, Gott M. Which public health approach to palliative care? An integrative literature review. Progress Palliat Care. 2017;25(1):1–10. https://doi.org/10.1080/09699260.2016.1189483
25. Stjernsward J, Foley KM, Ferris FD. The public health strategy for palliative care. J Pain Symptom Manag. 2007;33(5):486–93. https://doi.org/10.1016/j.jpainsymman.2007.02.01
26. Harding R, Selman L, Powell RA, Namisango E, Downing J, Merriman A, Ali Z, Gikaara N, Gwyther L, Higginson I. Cancer control in Africa. Research into palliative care in sub-saharan Africa. Lancet Oncol. 2013;14:e183–88. https://doi.org/10.1016/S1470-2045(12)70396-0
27. Cohen J, Deliens L. Applying a public health perspective to end-of-life care. In: Cohen J, Deliens L, editors. A public health perspective on end of life care. Oxford: Oxford University Press; 2012;3–20.
28. Harding R, Atieno M, Downing J. Growing and developing palliative care worldwide: assessing and developing public health approaches to palliative care. In: Walshe C, Preston N, Johnson B, editors. Palliative Care nursing: principles and evidence for practice. 3rd ed. UK: McGraw Hill Education; 2018.
29. Freidson E. Professional Dominance: the social structure of medical care. 2nd ed. New Brunswick: Aldine Transaction. Library of Congress; 2007.
30. Cragg L, Davies M, Macdowall W. Health promotion theory. Second edition. Maidenhead, Berkshire. Open University; 2013.
31. Mitchell SJ, Slowther AM, Coard J, Akhtar S, Hyde E, Khan D, Dale J. Ethics and patient and public involvement with children and young people. Arch Dis Child Educ Pract Ed. 2018;104:195–200. https://doi.org/10.1136/archdischild-2017-313480
32. Murphy PJ. Pragmatism from Peirce to Davidson. Colorado. West View; 1990.
33. World Health Organization. Assessing the development of palliative care worldwide: a set of actionable indicators. Geneva: World Health Organization; 2021.
34. World Health Organization. Palliative care for children. 2023. https://www.who.int/europe/news-room/fact-sheets/item/palliative-care-for-children#:~:text=Palliative care for children is,treatment directed at the disease. Accessed 26th January 2024.
35. Together for Short Lives. A guide to children's Palliative Care: supporting babies, children and young people with life-limiting and life-threatening conditions and their families. 4th ed. Bristol: Together for Short Lives; 2018.
36. Radbruch L, Liliana de Lima, Knaul F, Wenk R, Zipporah V, Ali Bhatnaghar S, Blanchard C, Bruera E, Buitrago R, Burla C, Callaway M, Munyoro EC, Centeno C, Cleary J, Connor SR, Davaasuren O, Downing J, Foley K, Goh C, Gomez-Garcia W, Harding R, Khanh QT, Larkin P, Leng M, Luyirika E, Marston JM, Moine S, Osman H, Pettus K, Puchalski CM, Rajagopal MR, Spence D, Spruijt O, Venkateswaran C, Wee B, Woodruff R, Yong J, Pastrana T. Redefining palliative care – a new consensus-based definition. J Pain Symptom Manag. 2020. https://doi.org/10.1016/j.jpainsymman.2020.04.027
37. Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Kwete XJ, Arreola-Ornelas H, Gómez-Dantés O, Rodriguez NM, Alleyne GAO, Connor SR, Hunter DJ, Lohman L, Radbruch L, del Rocío Sáenz Madrigal M, Atun R, Foley KM, Frenk J, Jamison DT, Rajagopal MR, on behalf of the Lancet Commission on Palliative Care and Pain Relief Study Group. Alleviating the access abyss in palliative care and pain relief – an imperative of universal health coverage: The Lancet Commission report. Lancet; 2017;391(10128):1391-1454; https://doi.org/10.1016/SO140-6736(17)32513-8
38. Fraser LK, Miller M, Aldridge J, McKinney PA, Parslow RC, Hain R. Life-limiting and life-threatening conditions in children and young people in the United Kingdom; national and regional prevalence in relation to socioeconomic status and ethnicity October 2011 Leeds University of Leeds. 2012. https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/01/ExRes-Childrens-Hospices-Ethnicity-Report-Leeds-Uni.pdf. Accessed 31st January 2024.
39. Grinyer A. Palliative and end of life care for children and young people: home, hospice and hospital. Chichester: Wiley-Blackwell; 2012.
40. Tronto J. Moral boundaries. A political argument for an ethic of care. New York – London: Routledge; 1993.
41. Tronto J. Un monde vulnérable. Pour une éthique du care. Ed La découverte. 2009.
42. Price J, McFarlane M. Palliative care for children- a unique way of caring. In Price J and Mcneilly P editors. Palliative care for children and families: An interdisciplinary approach, Palgrove McMillan; 2009;1–17.
43. Whitting M. 1888–2004: a historical overview of Community Children's nursing. In: Sidey A, Widdas D, editors. Textbook of Community Children's nursing. 2nd ed. Edinburgh: Elsevier; 2005.
44. Children's Palliative Care Education and Training (CPCET) action group. The Children's Palliative Education Standard Framework and Self audit tool. 2021. http://www.icpcn.org/training/childrens-palliative-care-education-standard-framework-and-self-audit-tool. Accessed 31st January 2024.
45. Downing J, Marston J, Ed. Oxford: Oxford University Press; 2021;361–72. https://doi.org/10.1093/med/9780198821311.001.0001
46. Knapp C, Woodworth L, Wright M, Downing J, Drake R, Fowler-Kerry S, Hain R, Marston J. Pediatric palliative care provision around the world: a systematic review. Pediatr Blood Cancer. 2011. https://doi.org/10.1002/pbc.23100
47. World Health Organization and the UNICEF. Declaration of Astana. Geneva: WHO; 2018.
48. Knaul F, Radbruch L, Connor S, de Lima L, Arreola-Ornelas H, Mendez Carniado O, Jiang Kwete X, Bhadelia A, Downing J, Krakauer EL. How many adults and children are in need of palliative care worldwide? In Connor S, editor. Global Atlas of Palliative Care 2nd Ed. London:WHPCA; 2020;17–32.
49. United Nations Development Programme (UNDP). Sustainable Development Goals. Goal 3. Good Health and Well Being. 2021 https://www.undp.org/content/undp/en/home/sustainable-development-goals/goal-3-good-health-and-well-being.html Accessed 13th May 2021.
50. World Health Organization. Universal Health Coverage.2023. https://www.who.int/news-room/fact-sheets/detail/universal-health-coverage-(uhc). Accessed 9th Jan 2024.
51. World Health Organization. WHA67.19. Strengthening of palliative care as a component of comprehensive care throughout the life course. Geneva:WHO; 2014.
52. Mwangi-Powell FN, Downing J, Powell RA, Kiyange F, Ddungu H. Palliative care in Africa. In: Ferrell BR, Coyle N, Paice JA, editors. Oxford Textbook of palliative nursing. 4th ed. Oxford: Oxford University Press; 2015.
53. Kumar SK, Kerala. India: a regional community-based palliative care model. J Pain Symptom Manage. 2007. https://doi.org/10.1016/j.jpainsymman.2007.02.005
54. Salins N, Bhatnagar S, Simha S, Kumar S, Rajagopal MR. Palliative care in India: past, present, and future. Indian J Surg Oncol. 2022. https://doi.org/10.1007/s13193-022-01556-0
55. Nair M, Augustine A. Understanding long-term outcomes of public health strategy in palliative care at micro level: impact of home-based palliative care services under local self-government institutions in Kerala, India. Indian J Palliat Care. 2022. https://doi.org/10.25259/IJPC_4_21
56. Horsfall D, Noonan K, Leonard R. Bringing our dying home—creating community at end of life. Sydney: University of Western Sydney; 2011.
57. Abel J, Bowra J, Walter T, Howarth G. Compassionate community networks: supporting home dying. BMJ Support Palliat Care. 2011;1:129–33. https://doi.org/10.1136/bmjspcare-2011-000068
58. Paul S, Sallnow L. Public health approaches to end-of-life care in the UK: an online survey of palliative care services. BMJ Support Palliat Care. 2013. https://doi.org/10.1136/bmjspcare-2012-000334
59. Peeler A, Doran A, Winter-Dean L, Ijaz M, Brittain M, Hansford L, Wyatt K, Sallnow L, Harding R. Public health palliative care interventions that enable communities to support people who are dying and their carers: a scoping review of studies that assess person-centered outcomes. Front Public Health. 2023. https://doi.org/10.3389/fpubh.2023.1180571

60. Rowse V. Palliative care for children: a public health initiative. Paediatr Nurs. 2006;18(4):41–5. https://doi.org/10.7748/paed.18.4.41.s19
61. Hexem K, Feudtner C. A public health framework for paediatric palliative and hospice care. In: Cohen J, Deliens L, editors. A public health perspective on end of life care. Oxford: Oxford University Press; 2012;168–72.
62. Callaway MV, Connor SR, Foley KM. WHO Public Health model: a roadmap for palliative care development. J Pain Sympt Manage. 2017. https://doi.org/10.1016/j.jpainsymman.2017.03.030
63. Downing J, Ling J, Benini F, Payne S, Papadatou D. A summary of the EAPC White Paper on core competencies for education in paediatric palliative care. Eur J Palliat Care. 2014;21(5):245–9.
64. Neilson S, Randall D, McNamara K, Downing J. Children's palliative care education and training: developing an education standard framework and audit. BMC Med Educ. 2021. https://doi.org/10.1186/s12909-021-02982-4
65. Randall D. Pragmatic children's nursing - A theory for children and their childhoods. London: Routledge; 2016.
66. Wilkinson D, Savulescu J. Hard lessons: learning from the Charlie Gard case. J Med Ethics. 2017;44:438–42. https://doi.org/10.1136/medethics-2017-104492
67. Wilkinson D, Savulescu J. Alfie Evans and Charlie Gard – should the law change? BMJ. 2018;361:k1891. https://doi.org/10.1136/bmj.k1891
68. Neuberger J. The Liverpool Care Pathway: what went right and what went wrong. Br J Hospi Med. 2016;77(3):172–4. https://doi.org/10.12968/hmed.2016.77.3.172
69. Darlington A-S, Long-Sutehall T, Randall D, Wakefield CE, Robinson V, Brierley J. Parents' experiences of requests for organ and tissue donation: the value of asking. Arch Dis Child. 2019;1–7. https://doi.org/10.1136/archdischild-2018-316382
70. Benini F, Pappadatou D, Bernada M, Craig F, De Zen L, Downing J, Drake R, Freidrichsdorf S, Garros D, Giacomelli L, Lacerda A, Lazzarin P, Marceglia S, Marston J, Mukaden MA, Papa S, Parravicini E, Pellegatta F, Wolfe J. International standards for pediatric palliative care: from IMPaCCT to GO-PPaCS. J Pain Symptom Manag. 2021. https://doi.org/10.1016/j.jpainsymman.2021.12.031
71. North N, Shung-King M, Coetzee M. The children's nursing workforce in Kenya, Malawi, Uganda, South Africa and Zambia: Generating an initial indication of the extent of the workforce and training activity. Hum Resour Health. 2019. https://doi.org/10.1186/s12960-019-0366-4
72. Hunt J. The nine-cell bereavement table: a tool for training. Bereave Care. 2002;21(3):40–1. https://doi.org/10.1080/02682620208657554
73. Hunt J, Andrew G, Weitz P. Improving community support for the bereaved in their communities. Bereave Care. 2007;26(2):26–9. https://doi.org/10.1080/02682620708657687.
74. Mutedzi B, Langhaug L, Hunt J, Nkhoma K, Harding R. Improving bereavement outcomes in Zimbabwe: protocol for a feasibility cluster trial of the 9-cell bereavement tool. Pilot Feasibility Stud. 2019. https://doi.org/10.1186/s40814-019-0450-5

## Publisher's note