FORUM

Children's Palliative Care: Considerations for a physical therapeutic environment

Julia Downing, Joan Marston, and Edwina Fleming

J Downing (corresponding author): International Children's Palliative Care Network, Makerere University, P.O. Box 7072, Kampala, Uganda; julia.downing792@btinternet.com

J Marston, **E Fleming**: International Children's Palliative Care Network, Assagay, South Africa

Keywords: palliative care, children, need, service delivery, physical environment, architecture

INTRODUCTION

Access to children's palliative care services varies greatly around the world. While some countries, such as the United Kingdom, are leading the way in service development, service provision does not meet the need — over 65 percent of countries have no recognized children's palliative care service provision, and only 5.7 percent are moving toward integration of services (1).

Access to palliative care is a human right for all people, young or old (2). Advocacy efforts to increase the availability of, and access to services are underway. In describing its vision, the International Children's Palliative Care Network (ICPCN) states, we should "live in a world where children's palliative care is acknowledged and respected as a unique service, and every child and young person with life-limiting or life-threatening conditions and their families can receive the best quality of life and care regardless of which country they live in" (3).

It is important for those who are working to develop children's palliative care services in different countries with different resources to consider the physical environment in which children are to be provided with care. In this article, we define children's palliative care and discuss who should receive it. We examine the need for this care and discuss the importance of the therapeutic environment. Finally, we review planning considerations related to the physical environment and describe the implications for service delivery.

PALLIATIVE CARE FOR CHILDREN

Children and young people with life-limiting or life-threatening conditions have unique palliative care needs, which are often different from those of adults. For example, their understanding of death and dying is not the same as that of adults, and the pharmacokinetics and pharmacodynamics of drugs differ between children and adults (4). The World Health Organization (WHO) defines palliative care for children as "the active total care of the child's body, mind and spirit, [which] 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" (5). While different organizations and countries employ different working definitions of palliative care, the WHO definition is generally accepted worldwide, and it is understood to be applicable to anyone younger than 18 (6). Palliative care is provided from diagnosis through to death and into bereavement. It is a concept and a philosophy of care that can be delivered in a variety of settings, including outpatient care, home-based care, and inpatient care. It can be delivered through the hospice — defined as "a nursing home that specializes in caring for the terminally ill" * — but this is just one means of delivery.

Eligibility criteria for pediatric palliative care will vary according to the specific service required and according to geography. Disease profiles of children with life-threatening and life-limiting illnesses differ from country to country. For example, in sub-Saharan Africa, most children accessing palliative care services have HIV and/or cancer (7), and the same is true for adults; in the United Kingdom, however, the breadth of the disease profile of children who can receive these services is broad (8) and very different from that of adults — the profile covers genetic conditions, birth asphyxia, and necrotizing enterocolitis of the fetus and the newborn (9). The stage of disease will determine the service required. Some children

* Collins English Dictionary, complete and unabridged 10th ed., s.v. "hospice."

Journal of Palliative Care 30:2 / 2014; 116–124

will need respite care and some long-term access to services, while others will have only a few days to live.

In order to help identify children in need of palliative care, the Association for Children's Palliative Care (now called Together for Short Lives) and the Royal College of Paediatrics and Child Health developed categories of children with life-limiting and life-threatening illnesses (10, 11). The categories act as a guide, but the most important factor is not identifying which category fits a child — it is ensuring that the child has access to palliative care. The four categories are: life-threatening conditions for which curative treatment may be feasible but could fail; conditions for which there may be long phases of intensive treatment aimed at prolonging life, but premature death is still possible; progressive conditions for which there is no curative treatment; and conditions that are not considered progressive but are characterized by severe neurological disability, which may cause the patient to deteriorate unpredictably.

Assessment of the need for pediatric palliative care is a complicated process marked by uncertainty related to the patient population and the nature of palliative care as a specialty (8). A systematic review undertaken by Knapp et al. in 2011 (1) looked at the provision of children's palliative care around the world and concluded that it is not meeting the need. While we have information on the provision of such care, we lack precise estimates of the numbers of children worldwide who would benefit from palliative care, although Fraser et al. (12) have estimated that in the UK, 32 of every 10,000 children have a life-limiting condition. If we were to apply this statistic to the world's child population of approximately 2.4 billion, we would be looking at a figure of 7.7 million children with life-limiting conditions. However, the numbers would be higher in the developing world, where neonatal, infant, and child mortality is considerably higher, and where most children with cancer, HIV, tuberculosis, malaria, severe malnutrition, and other noncommunicable diseases live. A recent study by UNICEF and the ICPCN (13) demonstrated this, reporting that in Zimbabwe, 181 children per 10,000 required specialized palliative care, while in the UK, that figure was 32 per 10,000 (14).

THE NEED FOR A THERAPEUTIC ENVIRONMENT

Children with life-limiting conditions are cared for in a variety of settings — in their own homes, in clinics, in hospitals, and in intensive care units. In a few countries, such children may be fortunate enough to receive respite care in a freestanding children's hospice or have access to palliative care services. While many freestanding pediatric hospices, as well as children's palliative care services, hospital wards, and clinics, are decorated to create an environment that is as attractive and as nonthreatening as possible, the reality is that within these places children are often subjected to painful procedures (such as dressing changes and blood tests) performed by a changing roster of staff members. The environment in which a child is cared for has a strong impact on the child and can affect the ability of the child's family members to deal with the situation; it can even affect the child's immune system (15). Few settings are designed to support patients therapeutically. Often, the buildings in which treatment is offered were originally built for another purpose and have been adapted for their current use.

National and regional standards of palliative care — for example, those of Australia (16), South Africa (17), Africa (18), and Europe (19) — specify that a child-friendly and safe environment is required for the provision of pediatric palliative care, but the actual design of the building or unit in which care is delivered is not taken into account. According to Smith and Watkins (20), a healthcare environment is therapeutic when it supports the physical, psychosocial, and spiritual needs of the patient, the patient's family, and staff and has a positive effect upon all concerned.

Families of children with life-limiting and life-threatening conditions in the UK often have negative experiences in accessing medical care (10). Studies such as one by Vickers and Carlisle (21) suggest that the preference of most child patients and their families is that the child die at home or in a palliative care service, but most children with a life-limiting or life-threatening condition die in hospital (22). It is therefore crucial that the environment in which the child is cared for is given due consideration and made as therapeutic as possible.

ARCHITECTURAL CONSIDERATIONS

Architectural considerations in any context involve more than just the design of the physical envelope. A successful building will meet the needs of the organization it houses and those who use the organization's services; the building should also inspire its occupants in that it is beautiful, engages the senses, facilitates positive interactions, and — most of all — is relevant (23).

The role of architecture in palliative care and healthcare design is a growing area of study and one that has been explored in a variety of ways over the years (24, 25). Since the 1980s, researchers in the field of evidence-based design, which is

closely related to the field of evidence-based medicine, have been working to help designers establish an approach to decision-making that is based on existing evidence (qualitative and quantitative data) of the impact of solutions on people, costs, and management (26, 27). There is evidence to suggest that well-designed physical environments improve safety, are more healing for patients, and are better places for staff to work (28). Worpole (29) maintains that architectural spaces are created for both living and dying. In his exploration of the architectural dilemmas of palliative care facilities, he examines a series of questions: Should these facilities have a domestic or a professional appearance? Are they the final destination for patients or treatment centres? Should the buildings be large or small? What are the differences between facilities for adults and those for children? Although he does not specifically answer many of these questions, Worpole does show that there are different solutions to different problems, and what might be right in one context or culture may not work or be appropriate in another. Tofle (30) also suggests that designers and palliative care providers need to think about how architectural factors can create meaning and fulfill patient preferences in the palliative care context. In her book *Healing Spaces*, Sternberg (31) maintains that in creating a therapeutic environment, it is essential that we consider design and the physical space.

Maggie's Cancer Caring Centres are situated throughout the UK. A lot is expected of their buildings and hence their architects. According to a 2012 architectural brief, the centres are intended to be,

> places where people draw on strengths they may not have realized they had in order to maximize their own capacity to cope. We need buildings where people can read themselves differently…We need our buildings to feel safe and welcoming…they should rise to the occasion, just as you, the person needing help, is having to rise to the occasion of one of the most difficult challenges any of us is likely to have to face. At the very least they should raise your spirits…so we want the architect to think about the person who walks in the door. (Quoted in Worpole [29, p. 41])

Maggie's Cancer Caring Centres aim to provide support in an environment that inspires each visitor. This is attempted by means of an architecture that reflects the value of the individual. A postoccupancy evaluation of the Dundee Maggie's Cancer Caring Centre in Scotland found a positive correlation between many aspects of the building design and visitors' sense of health and well-being (32). Thus, the architect's basic philosophy should be to consider first the people who walk through the door and understand that the buildings should be interesting enough for them to want to enter. The centres and their design should facilitate a sense of connectedness among people. They should reassure their occupants that they are not alone and encourage them to move on after a cancer diagnosis (33).

Dame Cicely Saunders, founder of the modern hospice movement, has said that during her internship at St. Joseph's Hospice in Hackney, the facility provided her with both spiritual and architectural inspiration. Worpole writes that palliative care facilities have become settings in which "emotions can be orchestrated creatively by good design" (29, p. 36). While much of the work on this type of architecture and design has been done in the UK, the United States, and Australia, examples can be found in many other countries. In Paris, in 1987, while children's palliative care was still in its infancy, Degrémont (33) became passionately interested in the question of whether an architect could help improve patient management, particularly in the field of palliative care. In Ghana, a hospice facility design was developed that would reflect and accommodate Ghanaian cultural traditions and utilize the country's resources (34). Recently, in Iceland, hospice design was addressed as a means of providing dignity in palliative care (35). Jaskiewicz explains: "The physician administers pain relief, the building has the ability to administer a kind of relief the patient may not even cognitively perceive. Through the eyes of a terminally ill patient, the architect should consider the views, connections and relationships the patient has with their surroundings. Keeping the patients' experiences at the forefront of all design decisions, the architect can promote a sense of dignity within the patients that seems to be lost in most modern health care facilities" (35, p. ii).

While pediatric palliative care can be provided in a variety of settings, including the child's home, we focus here on the architectural considerations for hospital-based and freestanding palliative care services, to which we can apply a similar philosophy. Several key issues must be considered in this context.

The concept of palliative care is rooted in the centuries-old tradition of offering a place of rest or hospitality to travellers. The children's hospice has been defined as "a residential structure alternative to a hospital, providing palliative care built on a children's scale with spaces, places and child friendly furnishings in an environment that is very similar to a family one" (36). Beyond ensuring that a child is comfortable throughout the

course of treatment, those delivering pediatric palliative care must provide the child with psychological support as well as social and cultural development that is as close to normal as possible (36). These important considerations must be reflected in the facility's design. We know that architecture influences human behaviour — it can stimulate or suppress, and it can generate both joy and fear (24). Children entering a health facility are often under stress, in pain and anxious, so it is vital to create within the facility an environment that will encourage children and their families to behave as they would in their own homes; an atmosphere of familiarity engendered by the facility's spatial design will enhance their psychological experience (37). Salutogenic elements — such as natural daylight, good ventilation, connection to the outside, views (to a garden, for example) — all contribute to the healing process and are essential to the design of any healthcare facility (23).

In planning any children's palliative care facility, it is necessary to complete the following initial steps: assess the needs of the organization, the child, the child's family, the healthcare providers, and other staff members; designate the function of each space and each zone and identify the interactions among them; determine which activities will take place in each space and zone; and calculate space requirements, keeping in mind what equipment and furniture is needed in each room.

Apart from the spaces needed for clinical functions, spaces will be required in which to fulfill children's psychosocial needs — that is, spaces for learning, play, creative activities, and support. There may also be spiritual and cultural factors that need to be addressed in other kinds of spaces.

Consideration should be given, as well, to the age of the children. A one-size-fits-all approach will not suffice, as age is directly related to space requirements. There is therefore a need for flexibility. Families must also be accommodated by the facility's design. Play areas for siblings and private spaces for family members should be provided, along with spaces in which families can be educated about the child's illness and trained to care for the child, spaces in which families can receive psychological support and counselling, and spaces in which families can pray or seek spiritual guidance or solace.

In order to reduce stress and enhance the working conditions of healthcare workers and other staff members, the design of the built environment must also address such needs as staff education and training, support, supervision, and resources. The number of staff members required by the facility and the types of services they offer will also have an impact on the facility's size and configuration. The staff roster should include: nurses trained in pediatric palliative care; specialists such as pediatricians, anaesthetists, oncologists, and neurologists; social workers and psychologists specializing in the management and care of children needing palliative care; therapists and other allied health professionals, such as occupational therapists, physiotherapists, dieticians, and teachers; religious personnel; administrative staff; and volunteers.

Space provision decisions must be based upon the activities that will be carried out within each space. Clinical activities in a children's palliative care facility focus mainly on medical, psychological, and social interventions, all of which must be taken into consideration; attention must also be given to support functions such as administration, cleaning, maintenance, and facility management.

The physical environment of a children's palliative care facility is divided into interrelated functional zones, which must be carefully considered in the layout planning stage (Figure 1). These zones include: the inpatient (residential) zone; the clinical zone (both inpatient and outpatient); the support services zone; and the education and training zone. Also important to consider are parking areas, gardens, playgrounds and other outdoor recreational facilities, meditation areas, and perhaps a therapeutic sensory garden. Table 1 lists some of the elements that could be included in each zone, along with suggested sizes for them. However, it will be up to the planners of each project to decide on the facility's requirements. What can be achieved will also vary according to what resources are available; some projects will be smaller than others, particularly in the developing world.

Each person's perception of the physical environment differs from that of the next person. A study conducted in Canada that looked at preferences of adult patients and those of their family members in terms of palliative care unit design demonstrated the need for a variety of different patient rooms and public places and determined that preferences often change as death approaches.

Figure 1 / Relationship of Different Zones

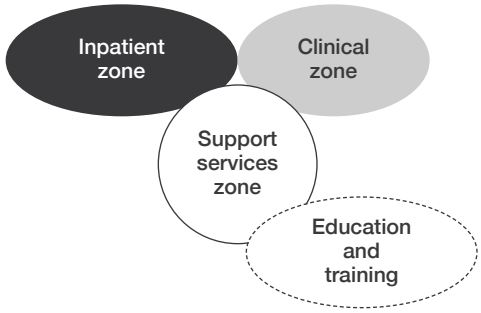

Table 1 / Example of the Space Allocated to Different Zones within a Children's Palliative Care Facility

Zone		Size m^2	Comments
1. Inpatient zone			
The residential component; a private zone specifically for the child, the child's family, and attending caregivers and staff. The area should resemble the home environment — domestic in character, familiar to patients and their family members, a place where they can undertake homelike activities. Space is required for patient care and therapy. It is preferable to have no more than 10 patient rooms.			
Single bedroom containing a small bed, crib, or cot and a single sofa bed, clinical wash handbasin, cupboard for personal effects, and medicine cabinet		20	
Single bedroom containing a small bed, crib, or cot and a single sofa bed, living/dining/ kitchenette area, clinical wash handbasin, cupboard for personal effects, and medicine cabinet		30	The preferred option
Family accommodation adjacent to the bedroom with couch, chairs, table, and television		20	
En suite ablution facilities with assisted shower and toilet		5	
Laundry		12	
Assisted toilet and bath		9	
Nurses' station		10	
Medicine, equipment, and clean linen stores		6	
Public toilet		4	
Dirty utility for waste and dirty laundry collection area		7	
Small leisure room		12	Optional
Kitchen		12	
Dining room		25	Size depends on numbers of people
Living room		30+	
Playroom and teenagers' room		16+	
Reading room/library/quiet space		16	
Garden area		Varies	
2. Clinical zone			
The zone for diagnostics, therapy, and rehabilitation for children, as well as counselling for children and their family members; both inpatient and outpatient care are offered here, and it must have a familiar, comfortable, homelike atmosphere.			
Offices for doctors and therapists, including spaces for counselling and art and music therapy		16	
Medicine, equipment, and clean linen stores		6	
Administration room with records		16	
Hydrotherapy room		16	Optional
Small lab for diagnostic tests		9	
Toilet facilities for patients and visitors		4	
Soft play area for toddlers		16	Separate
Therapy/recreation room for children and/or adolescents		20+	
Multisensory room for sensorial stimulation		12	Optional
Dirty utility for waste and dirty laundry collection area		7	
3. Support services zone			
This zone should have spaces for administration, organization, and management activities; it needs to be big enough to accommodate large groups — children, their families, support staff, and caregivers. It is important that there is a warm, domestic feel to the areas within this zone.			
Reception area	Reception lobby and desk	12	
	Lounge foyer	30+	
	Adjoining ablution facilities	8	
Offices	Secretary, manager, and volunteers	9	
	Administration, human resources, and finance staff	20	Open plan

Zone		Size m^2	Comments
Meeting room		16	
Counselling room		12	Separate but close to reception
Relaxation room for families		12	Separate but close to reception; quiet space for families to be alone or meet with staff
Staff	Staff restroom and lockers	12	
	Staff ablution facilities	6	
Large equipment store	Beds, cots, and equipment	20	
Mourning suite/bereavement room	Lounge and kitchenette	12	Independent access; separate from the rest of the facility
	Bedroom	12	
Sanctuary		12+	Room for meditation and prayer
Laundry	Clean and dirty laundry area	6	Separate areas
	Processing area	18	
Food store		12+	
Waste collection and disposal area		12	External, covered area
Garden maintenance store		9	External, covered area
Small shop		12+	Optional
Pets in therapy area	External	12+	Optional
4. Education and training zone			
This zone accommodates practical courses, seminars, and simulations, depending on the size of the facility; its inclusion depends on the size of the facility and its policies.			
Office	Secretary and manager	12	Optional
Meeting room		30	Optional
Conference room		16+	
Library		16+	
Photocopy room		6	
Practical learning room	Simulation facility	16+	Optional
Ablution facilities		8	

It also concluded that more research is needed on the stages of the dying process and how they affect preferences with regard to the physical environment (38).

An understanding of patient and staff flow patterns is also critical to the design of the facility's interrelated functional zones. Reducing the distance that staff must travel through corridors and passageways is essential for efficiency.

Ideally, a children's palliative care facility should be separate from, but close to a hospital. There should be easy access to diagnostic services and treatment areas, including an intensive care unit. It would be preferable to situate such a facility adjacent to a green area, such as a park (36).

The type and size of the facility will depend on a variety of factors: patient demographics, including cultural identification; patients' disease profile; the number of children who will access the facility; the availability of home care services in the area; resource and budget limitations; staffing; the parameters of the available site; the services that will be provided; and any government regulations pertaining to pediatric palliative care facilities.

Room requirements will vary according to patient needs and the size of the facility. It is criti-

cal that there be enough space to deliver a full range of palliative care services; adequate space will also be needed for equipment — wheelchairs, lifting equipment, bathing aids, and so on. However, many projects involve converting existing wards or structures to fulfill the requirements of palliative care, and it may be necessary to adapt to the resulting space restrictions.

First impressions count, so it is important that the facility's arrival area expresses the ideals of the facility and conveys a sense of security and support. Clear signage must be in place to give children and their families — and all visitors to the facility — the feeling of being welcomed and help them adjust quickly to the layout of this new environment. Children may be physically vulnerable and traumatized on their first visit, so, if possible, the external view of the building should offer them visual reassurance that they have nothing to fear. Pictures and sculptures that are appealing to children can help to reduce stress through distraction, particularly in the arrival and waiting areas. Children and their families should derive a sense of calm and an impression of order and supportiveness upon arriving in the entrance foyer. Inside, in the arrival and waiting areas, they should be met with fresh flowers and comfortable armchairs. The goal of the design should be to create an atmosphere of light, serenity, safety, and peace.

Colour, form, shape, and scale are all important considerations in planning the facility. A child's scale is quite different from an adult's. For example, a small child will feel lost in an adult-sized bed, and an adolescent will feel disrespected if he or she is assigned a child's bed. A flexible design approach is needed to accommodate such differences.

The child's bedroom is the most important room in the facility. It is where the child is brought when he or she first arrives at the facility; it is a place of shelter within time and space. Both sides of the bed must be made accessible and adequate space allotted for equipment. However, it is important that the bedroom does not resemble a hospital room. It should look and feel as much like a typical child's home bedroom as possible; to that end, any required equipment should be stored in a cupboard or behind a screen. Where possible, clinical procedures such as dressing changes or blood transfusions should be conducted elsewhere in the facility to ensure that children's living areas are seen as places of safety and security.

Children need places in which to play and socialize. One 10-year-old South African remarked: "The things that make me excited at this hospital are the playing, meals, friends, our playing trees outside and myself playing in the yard" (39). Where possible, there should be an activity room for children where they can play games and watch television shows and DVD movies. Toys and games should be stored within sight and accessible to children. Such a space, which could also be used for educational activities, should be well lit, spacious, and relaxing. Designers of pediatric palliative care facilities should take the time to ask children what they like. They should look closely at what children buy, what they wear, how they play, what they play with, what they read, and what movies and television programs they watch and then incorporate what they learn into the plan.

Adolescents need a different type of recreation room — one designed with their specific preferences in mind. It should be a place they can go to de-stress, listen to their music, and watch the kinds of television shows and movies that appeal to them. In such a space, adolescents can gather to socialize with one another and spend some time away from adults.

Another necessity in a palliative care facility is a quiet room — a space in which one can comfortably contemplate, commemorate, or celebrate. Here, support groups for family members or staff can meet. Such a room can also serve as a sanctuary where one can remember a child who has passed away and/or engage in specific cultural practices or religious devotions. Children and their families can use the quiet room when they need to reflect and find meaning in what is happening to them.

Attention must also be paid to outdoor areas. Facility designers should explore ways of creating an inviting outdoor environment that gives children, families, and staff direct access to sunshine and encourages them to move about freely in the open air. A sensory garden may be considered — a natural space in which children of all abilities can benefit from sensory stimulation. A variety of foliage, trees, and flowers, as well as different colours, shapes, textures, and smells, can be used to create an enjoyable multisensory experience of nature. Ramps should be constructed throughout the garden to allow access to children in wheelchairs. Outdoor spaces can also be designed to accommodate pets, since animals have been proven to decrease patients' anxiety and pain and thus improve their quality of life (41).

When sourcing materials for their projects, designers should look for those that have resilience, durability, flexibility, malleability, and longevity. It is also vital to remember that all materials must be easy to clean and disinfect. The environment of the facility should engage the intelligence and the senses of those who occupy it through materials, finishes, and furnishings.

Colour is another critical element of designing for children. Colour schemes should harmonize with the purpose of each space and the experiences that will unfold within it — some colours encourage children to relax and some prompt them to play. Lighting is also significant; where possible, there should be a source of strong natural light. Large windows that admit direct sunlight, supported by artificial illumination, will help create a cheerful and positive atmosphere. As the natural light in a space changes through the course of the day, it will impart a sense of vitality and allow children to perceive the day's different phases.

Each pediatric palliative care facility will be different depending on the range of specific factors that influence its creation, but all will share some essential qualities. In speaking of the role of architecture in children's palliative care, the chief executive of Noah's Ark Children's Hospice in London sums up these qualities:

> We do not want the hospice to feel institutional or like a hospital, although at the same time it has to be an environment in which we can deliver the highest standards of medical and social care.
>
> We worked really hard with the architects to understand how people would be using the spaces and what would be happening, both inside and outside the building. We are trying to make this a really human space, providing a positive environment that feels like home and, much more importantly, is a place people want to come to.
>
> The design had to incorporate our basic requirements in terms of facilities, but it also had to be a fitting building for what is a wonderful environment. As a team we talked a lot about the link between the building and the nature that surrounds it. In the hospice we see the circle of life and this is also what is going on around the building, so we embraced this vision. (41)

CONCLUSION

While the existing quantitative data is limited, there is clearly an immense need for children's palliative care facilities throughout the world. The specific needs of the local patient population, cultural factors, and available resources will vary; however, it is vital that each pediatric palliative care facility meets not only the physical needs of the children and families who enter it but also their psychosocial and spiritual needs. Careful attention must be paid to the design of each facility to ensure that the physical environment in which children and their families are cared for and supported is a therapeutic and healing one.

AUTHORS' CONTRIBUTIONS

All of the authors were involved in writing the paper. J.D. collated and finalized the manuscript. All authors critically revised the manuscript and read and approved the final document. There are no competing interests.

Received: June 19, 2013
Final version accepted: February 3, 2014

REFERENCES

1. Knapp C, Woodworth L, Wright M, et al. Pediatric palliative care provision around the world: a systematic review. Pediatr Blood Cancer 2011; 57(3): 361-368.
2. Brennan F. Palliative care as an international human right. J Pain Symptom Manage 2007; 33(5): 494-499.
3. International Children's Palliative Care Network (ICPCN). Vision, Mission & Aims. Assagay (ZA): ICPCN. Accessed Mar. 25, 2014. www.icpcn.org/about-icpcn/vision-mission-aims/
4. Amery J. Introduction. In: Amery J, editor. Children's palliative care in Africa. London: Oxford University Press; 2009.
5. World Health Organization (WHO). Effective palliative care for children. Geneva: WHO; 2014. Accessed Apr. 13, 2013. www.who.int/cancer/palliative/en/
6. United Nations (UN) Office of the High Commissioner for Human Rights (OHCHR). Convention on the rights of the child. Geneva: UN OHCHR; 1989.
7. Downing J, Marston J, Boucher S. Children's palliative care in Africa. Austr J Cancer Nurs 2010; 11(2): 3-10.
8. Hain R, Heckford E, McCulloch R. Paediatric palliative medicine in the UK: past, present, future. Arch Dis Child 2012; 97(4): 381-384.
9. Hain R, Devins M, Hastings R et al. Paediatric palliative care: development and piloting of a "directory" of life-limiting conditions. BMC Palliat Care 2013; 12(1): 43.
10. Wood F, Simpson S, Barnes E, et al. Disease trajectories and ACT/RCPCH categories in paediatric palliative care. Palliat Med 2010; 24(8): 796-806.
11. Association for Children's Palliative Care (ACT)/Royal College of Paediatrics and Child Health (RCPCH). A guide to the development of children's palliative care services: report of the joint working party. Bristol (UK): ACT/RCPCH; 1997.
12. Fraser LK, Miller M, Aldridge J, et al. 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. Final report for Together for Short Lives. Leeds: Division of Epidemiology, University of Leeds; 2011.
13. Connor SR, Sisimayi C. Assessment of the need for palliative care for children: three country report: South Africa, Kenya and Zimbabwe. London: United Nations Children's Fund (UNICEF), International Children's Palliative Care Network (ICPCN); 2013.
14. Fraser L, Miller M, Hain R, et al. Rising national prevalence of life-limiting conditions in children in England. Pediatrics 2012; 129(4): e923-929.
15. World Health Organization (WHO). Immune diseases and children. Children's health and the environment. WHO training package for the health sector. Geneva: WHO; 2011.
16. Palliative Care Australia (PCA). Standards for providing quality palliative care for all Australians. Deakin: PCA; 2005.
17. Council for Health Service Accreditation of Southern Africa (COHSASA)/Hospice Palliative Care Association (HPCA). Hospice palliative care standards. 2nd ed. Cape Town: HPCA; 2009.
18. African Palliative Care Association (APCA). APCA standards for providing quality palliative care across Africa. Kampala: APCA; 2011.
19. Craig F, Abu-Saad Huijer H, Benini F, et al. Steering Committee of the European Association for Palliative Care (EAPC) Task Force on Palliative Care for Children and Adolescents. IMPaCCT: standards for paediatric palliative care in Europe. Eur J Palliat Care 2007; 14(3): 109-114.

20. Smith R, Watkins N. Therapeutic environments. Whole Building Design Guide. Washington: National Institute of Building Sciences; 2010. Accessed Apr. 27, 2014. www.wbdg.org/resources/therapeutic.php
21. Vickers JL, Carlisle C. Choices and control: parental experiences in pediatric terminal home care. J Pediatr Oncol Nurs 2000; 17(1): 12-21.
22. National Cancer Intelligence Network (NCIN). Place of death for children, teenagers and young adults with cancer in England. London: NCIN; 2011.
23. Exley S, Exley P. Design for kids. Victoria (AU): Images Publishing; 2007.
24. Dilani A, editor. Design and health III: health promotion through environmental design. Proceedings of the 3rd World Congress on Design and Health, June 25-29, 2003, Montreal, Quebec, Canada. Stockholm: International Academy for Design and Health; 2004.
25. Martin C. Putting patients first: integrating hospital design and care. Lancet 2000; 356(9228): 518.
26. Tranfield D, Denyer D, Smart P. Towards a methodology for developing evidence-informed management knowledge by means of systematic review. Br J Manage 2003; 14: 207-222.
27. Codinhoto R, Aouad G, Kagioglou M, et al. Evidence-based design of health care facilities. J Health Serv Res Policy 2009; 14(4): 194-196.
28. Ulrich RS, Zimring C, Zhu X, et al. A review of the research literature on evidence-based healthcare design. HERD 2008; 1(3): 61-125.
29. Worpole K. Modern hospice design: the architecture of palliative care. London: Routledge; 2009.
30. Tofle RB. Creating a place for dying: gerontopia. J Housing Elderly 2009; 23(1-2): 66-91.
31. Sternberg EM. Healing spaces: the science of place and well-being. Harvard: Belknap; 2010.
32. Stevenson F, Humphris G. A post occupancy evaluation of the Dundee Maggie Centre. Final report for SUST. Glasgow: University of Dundee, SUST; 2007. Accessed Apr. 27, 2014. http://sust.org/pdf/new_maggiecentre.pdf
33. Degrémont N. Palliative care and architecture: from hospital to people. Eur J Palliat Care 1998; 5(4); 127-129.
34. Anane-Binfoh T. Architecture for the terminally ill: a proposed hospice facility design for Ghana [thesis]. [Kumasi (Ghana)]: Kwame Nkrumah University of Science and Technology; 2008.
35. Jaskiewicz J. Dignity in palliative care: the hospice at Skogafoss Falls [thesis]. [Blacksburg (VA)]: Virginia Polytechnic Institute and State University; 2011.
36. Ferrante T. Architetture e design per l'hospice pediatrico/Architecture and design for the paediatric hospice. Florence: Alinea Editrice; 2012.
37. Chalmers DJ, Knight RG. The reliability of ratings of familiarity of environmental stimuli: a generalizability analysis. Env Behavior 1985; 17(2): 223-238.
38. Anderson D. Design and health scientific review. Palliative care unit design: patient and family preferences. World Health Design. 2008 Apr.: 62-67.
39. Ngu I, Kruger J. Phila Impilo! Izingane ziveza ezingakuthanda ngokulashwa kwazo/Live life! Children advocate best practices for healing. Overport (ZA): Young Insights for Planning; 2008. Accessed Apr. 24, 2014. www.icpcn.org/downloads/Phila_Impilo_7-9-08.pdf
40. Engelman SR. Palliative care and use of animal-assisted therapy. OMEGA 2013; 67(1-2): 63-67.
41. Makosinski J. Architects unveil vision of new sustainable paediatric hospital. Building Better Healthcare. Jan. 13, 2012. Accessed Mar. 25, 2013. www.buildingbetterhealthcare.co.uk/technical/article_page/Architects_unveil_vision_of_new_sustainable_paediatric_hospital/72516