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Exploring the role of children's hospices in caring for children, young people and families

Abstract

Children's hospices are central to specialist palliative care provision for the increasing number of children and young people living with life limiting conditions and their families. Although often believed to exclusively provide care at end-of-life (EOL), children's hospices provide holistic care for children, young people and their families, through a range of services from diagnosis, provision of ongoing care, at EOL and into bereavement. This paper explores the range of services children's hospices provide, whilst dispelling misconceptions, namely that children's hospices are solely for end of life (EOL) care and will highlight how services have responded as technologies have advanced.

Introduction

Children's hospices are central to care provided to the increasing number of children and young people with life-limiting conditions and their families, often over many years (Dunbar and Carter, 2021). Although children's hospices have been providing vital individualised holistic care and support for children, young people and families for over 40 years within the United Kingdom (UK), a lack of understanding about the range of services a children's hospice provides remains, with many professionals and also some of the public still assuming hospice solely provide care for children at EOL (Johnson, 2016). Evidence suggests that parents also have negative connotations of children's hospices (Pentaris et al., 2018), perceiving them as places for death and suffering. Such lack of understanding can mean that

children and young people eligible for hospice services may never receive them or receive them very late in their life trajectory (Twamley et al, 2014).

Development of children's hospice movement

The first children's hospice Helen House in Oxford opened in 1982, borne out of family need for respite care, and evolved from a relationship between Sister Frances Dominica and the family of Helen who had 24/7 care needs (Worswick, 2000). Helen House served as an exemplar for many subsequent children's hospices within the UK and further afield.

Children's hospices provide expert, individualised palliative care, with access to specialist facilities and hospice community-based services (CQC, 2022). Working alongside other health care providers hospices can support children and families at home (Together for Short Lives, TFSL, 2023a). Whilst children's hospices are still known for gold standard respite care, this is now offered alongside a range of services. Children's hospices and adult hospices have been described as half -sisters with their shared parent being a commitment to offer an environment conducive to holistic care based on individual need (Hain, 2019). However, differences exist, given the unique needs of children/young people and their families (See figure 1).

Further, it must be noted that the research base underpinning palliative care for children and young people, although increased in recent years, lags behind that of the adult population. The need for further research in the field on which to base practice is widely recognised (Fraser, Bluebond-Langer and Ling, 2020). Contemporary research evidence, specifically related to care/services in children's hospice is also limited. There are 54 Children's Hospices/ Services in the UK each providing a range of care and support to children, young people and families (Tatterton et al., 2023). Each children's hospice may

have varied referral criteria and their services configured slightly differently; however, most hospices will accept referrals from the antenatal period to age 18 with some offering specific support for young adults to age 25.

This paper draws on existing evidence, research and practice and examines the range of services children's hospices offer below, dispelling misconceptions.

Child/Family Support

Findings of a qualitative study, involving n=23 parents of children with non-malignant life limiting conditions reinforced how the diagnosis/recognition alters the lives of the child, parent(s) and family circle (Hurley et al., 2021). Recognising each child and family are unique, children's hospices provide individualized child/family centered care with tailored support to help children, young people and their families. Such care is provided from diagnosis/recognition throughout their life trajectory and into bereavement (TFSL, 2023a). The different forms of support offered, echo those identified in seminal work (for example Kaplan *et al.*, 1977; Gottlieb, 1978; House, 1981). Commonalities indicate three discernible forms of support, informational, emotional and instrumental. Informational support involves provision of advice and information, for example, providing information to help parents make decisions regarding place of EOL care. Emotional support involves empathy, trust and caring, for example one to one support from a specialist hospice nurse. Instrumental support involves providing tangible assistance and services, for example short breaks/respite, further explored next.

Short breaks/Respite

Since the main caregiving role, is often taken on by parent(s) this can have a huge emotional, and physical toll, thus ongoing parental needs are substantial (Gill et al,

2021). Respite care or short breaks (now referred to as more frequently) in hospice entail a period of interim care for the child in order that parents/carers can have a break (Whitmore, 2017). Whilst used interchangeably the word respite can carry a stigma/guilt for parents, as it could appear that parents need respite, and that caregiving is a burden. Short breaks are a much more positive term signifying a pause and can be more comforting for parents/child. Short breaks are highly valued by parents as demonstrated by Champagne and Mongeau (2012) who collected qualitative data from mothers and fathers who used hospice for short breaks. In fact, the need for respite was the driving force for Sister Dominica opening the first children's hospice as she recognised parental exhaustion and the need for a break (Worswick, 2000). Since then, technological advances have continued to develop with increased numbers of children with life-limiting conditions continuing to live longer often with very complex needs (Fraser et al,2021). Facilitating respite/short breaks is therefore central to quality care for children, young people and their families (Hizanu et al, 2024) and crucial support for parents providing ongoing care (Champagne and Mongeau., 2012). However, a grounded theory study involving 24 parents whose children accessed hospice services (Dunbar and Carter, 2019) highlighted parents can initially be reluctant to accept hospice-based short breaks. Reasons being negative perceptions of hospice and parental need for assurance of expert care for their child (Dunbar and Carter, 2019). The study also highlighted that perspectives changed having visited hospice.

Champagne and Mongeau (2012) found that respite breaks at children's hospices allow parents to rest, focus on their other children, and alleviate caregiving stress while combating social isolation. Most children's hospices also provide specialist respite services within the child's home. A study evaluating a pilot hospice at home programme with parents

(Brenner et al, 2016) identified how expert hospice care at home was invaluable to them, their child and other family members. During hospice respite/short breaks a range of therapies can be provided for children, young people and families (TfSL, 2023a) for example complementary therapies, physiotherapy, music therapy, art therapy (memory making). Therapies can be provided at different stages throughout the child's life as well at EOL.

End of Life (EOL) Care

The National Institute for Health and Care Excellence (NICE, 2019) guidelines regarding EOL care for children, mandate a choice of place of EOL care and death, one choice being a children's hospice. Hospice may not be an option for every child. Further, the NICE guidelines for EOL care recommend advance planning, emotional/psychological support, managing symptoms, hydration and nutrition, and recognizing when a child is close to EOL (NICE, 2019). In keeping with the overall philosophy of hospice care, EOL care should be holistic, individualised and child/family centred. A systematic review examining 25 research papers suggests that parents have the profound need to fulfil their parenting role when their child is EOL and to be with their child (Barrett et al., 2023). Children's hospices have specialist teams including doctors, nurses, care team members and therapists to ensure that child and family care is holistic and that a partnership approach is adopted (TfSL,2013a). The family focused ethos of the children's hospice enables the provision of quality EOL care in a less medicalised environment (Mendizabal-Espinosa and Price, 2021) with clinical input nearby as needed. The often complex and challenging symptom management is an essential focus of EOL care (Benini et al., 2022) and hospices have experience in ensuring each child's symptom management plan must be individualised given the child/young person's condition, age and cognitive ability. The EOL phase with children and young people can be difficult to predict

(NICE, 2019). However, the benefits of children's hospice are such that continued assessment of the child and families' needs occur and open honest discussions with families to ensure they are informed and included in decision making (Barrett et al., 2023). Drawn up prior to deterioration a paediatric -Advance Care Plan (p-ACP) guides teams to be able to work towards achieving the child's, young person's/family wishes (Carr et al.,2022). Hospice teams support children and young people at EOL in the home setting also. Care in the home is often provided alongside statutory community teams which include nursing and medical support at EOL and after death in a hospice at home provision.

Care after death

Care of the child after death, alongside providing support to the bereaved family is a crucial aspect of the services offered by children's hospices (Tatterton et al 2019). Although eligibility and policies vary, UK children's hospices routinely use cold bedrooms/mattresses (Hackett and Beresford, 2021). Cooling facilities aim to slow down deterioration of the child's body providing families an alternative to traditional mortuary facilities (Tatterton et al., 2019). Research exploring the use of cold bedrooms indicates that they offer families space, privacy and time to say goodbye gradually to their child (Hackett and Beresford, 2021). Families also identify that cooling facilities permitted them opportunity to be together as a family (Norton et al., 2022). Caring for the child's body and supporting the family, is the role of the children's hospice team, although Hackett and Beresford (2021) report in an exploratory mixed methods study hospice staff often find this challenging. Such challenges arise from the necessity on occasions to manage deterioration (e.g. leakage, odour, disintegration).

The use of cold mattress's can be extended to the home, although findings (Hackett and Beresford, 2021) suggest uptake is low. If parents decide to use cooling facilities in the home, the community/hospice teams maintain regular contact checking on the child's body and discussing when it may be appropriate for funeral directors to take over the support.

Post death bereavement support.

The death of a child is life altering for a family (Pelacho-Rios and Bernabe-Valero 2022). Bereavement support is provided throughout the care pathway and through the child's death and beyond (TfSL, 2013). Bereavement support is provided for parents, siblings and grandparents and is core to service provision at children's hospices (Tatterton and Lyon, 2022). The bereavement team-consists of trained counsellors / therapists and may work with families for 1-2 years, sometimes longer. Bereavement support is provided through various means, for example one to one, group sessions with other bereaved parents or in couple/family groups. A systematic review (Ridley and Frache, 2020) examined interventions used with bereaved siblings, although hospices were not mentioned specifically the most common intervention identified were group sessions, often followed by a camp, individual support was also mentioned. Bereaved sibling groups are now offered by most children's hospices. These groups allow children to access support in a safe, nurturing environment alongside other children with similar experiences and may be delivered face to face or virtually.

In recent years, new areas of care have evolved within the children's hospice, one area being perinatal hospice care which is an emerging but vital service for families (Tatterton et al., 2023).

Antenatal and neonatal support

Enhanced antenatal screening and technological advances have contributed to a greater number of babies, being diagnosed before birth with life limiting conditions and also surviving birth (Pinney 2020). Increased numbers of under 1s with life limiting illnesses and death being highest in under 1s (Fraser et al., 2021) has resulted in a greater number of families being supported by children's hospices in the antenatal and neonatal periods (Tatterton et al 2023). A national UK children's hospices survey indicated variances regarding referrals to their perinatal/ neonatal service (Tatterton et al., 2023). However, most hospices provide support following a 20-week scan, which detected a baby may be born with a life limiting condition. The support provided is tailored to meet individual needs however, in infants known to have life-limiting conditions diagnosed in the antenatal period planning in advance is crucial to ascertain parents' wishes are respected at birth if achievable (Jackson et al., 2020). Parallel planning (an approach designed to ensure that the infant's needs are met regardless of how their condition progresses by ensuring simultaneous plans for life while also planning for deterioration or death, TfSL, 2015) is key during the antenatal period as despite advances in scanning technology it can still be difficult to predict prognosis of a baby in utero (Paize, 2019). Such planning may include a baby doing better than expected and possibly necessitating ongoing hospice care as well as preparing parent(s) for potentially worse outcomes.

Some families are not aware until after birth that their baby has a life-limiting condition. A study examining children hospice staff's experiences caring for babies from NNUs, suggests further collaborations between NNUs and children's hospices, alongside ongoing education of neonatal staff to ensure they can make families aware if hospice is a potential place for

their baby's care (Price and Mendizabal, 2019). Recently babies from NNUs and children/young people have been transferred to children's hospices for the removal of life supporting treatment focusing on a comfort pathway.

Compassionate extubation

Children's hospices provide specialist care for the whole family regarding compassionate extubation whilst, maintaining dignity and privacy in a homely environment. Careful planning with the multi-disciplinary team (MDT) is imperative ensuring safe and rapid transfer of the child (NICE, 2019). Choices available can include supportive compassionate extubation at home, with hospice and community services as well as in the hospice setting (Suryanarayan and Hills, 2017). MDT discussion in the planning stage is important to ensure all team members are aware of their roles and responsibilities. Parents should be central to all discussions. Transfer teams will transport the child from the Paediatric Intensive Care Unit (PICU) /NNU setting to the hospice/home setting (Menon et al., 2020).

Another important area of care which has become prevalent in recent years is transition from children's to adult services.

Transition

As care and treatment has improved young people with life limiting conditions are now often living beyond childhood (Kerr et al., 2018). Thus, children's hospices work with transition pathways and adult hospices to ensure that the care these young adults require continues to meet their needs (TfSL, 2023b). Some children's hospices have transition co-ordinators who work with the young adult to enable a planned, streamlined and timely move to adult services as described in (Ford, 2022).

Conclusion

In closing, children, young people with life-limiting conditions and their families, require intense and sustained support provided by specialist services not only for the duration of their child's life, but also for several years beyond. Children's hospices are instrumental in providing palliative care to children, young people and families-over many years. The expert service provision, care and support is individualised, holistic as well as child and family centred. Although, children's hospices have been providing care in the UK since the 80s, children's hospices have since developed and expanded services in response to the changing needs of this group of children, young people and families.

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Figure 1 differences between adult and children’s palliative care

- **Palliative care for children should start from the diagnosis or recognition of a life limited condition whether they are having active treatment or not**
- **A wide range of conditions specific to children and young people many of which are extremely rare require a palliative approach to care.**
- **The number of children dying is small, compared with the number of adults.**
- **Many of the illnesses are genetically linked thus there may be more than one child with the condition in a family.**
- **Parents/carers take on a huge responsibility for personal and nursing care, often very technical aspects of care over many years.**
- **A characteristic of childhood is continuing physiological, emotional and cognitive development.**
- **Adult palliative care is usually provided when death is imminent, while paediatric palliative care is generally delivered over a longer time frame often many years.**
- **Provision of play for all children is essential and education is a legal entitlement**