Approaches to community-based palliative care provision by children's hospices in the UK

Current approaches to providing community-based palliative care by children's hospices in the UK

Abstract:

Background: In the UK, the number of children living with life limiting conditions, and the demand for home-based palliative care is increasing. Children's hospices remain a dominant provider of children's palliative care. **Aims:** To ascertain the approaches taken by children's hospices to meet the needs of children and families who receive palliative care at home**. Method:** An inte

rnet-based survey was sent to all children's hospices in the UK, comprising ten questions exploring the size of the team, geographical areas covered, workforce composition, services offered and approaches taken to managing unplanned, out of hours care needs. **Findings:** 14 hospices responded to the questionnaire (26% of hospices). A total of 1,618 families were cared for by the hospices who took part in this study, of which, 825 families received care at home. Registered nurses constituted the greatest proportion of staff and were employed by all teams. Care provided at home can be broadly split into two categories: planned short breaks, and responsive palliative nursing, comprising advance care planning, anticipatory prescribing and dynamic symptom control. Out of hours support was usually offered in the form of telephone support. **Conclusion:** Models of community-based care are evolving to include nurses practicing at specialist and advanced levels, allowing more children with increasingly complex conditions to be cared for at home.

Key words: advanced level nursing; children; community; family centred care; palliative care; symptom management

Introduction

Children's palliative care is considered an '*active and total approach to care*' (Dickson, 2017: 13), defined in figure 1. Community-based palliative care by provided by children's hospices is a growing specialty. Although definitive numbers are unavailable, an internet search suggests that around two thirds of the 54 children's hospices in the UK offer elements of support in the community. Infants, children and young people (hereafter children) receive care from numerous professionals based in primary, secondary and tertiary health services, social care, education and from the voluntary sector. Children's hospices remain a dominant provider of children's palliative care in the UK, providing a range of services, including planned and unplanned (or 'emergency') short breaks, symptom control and end of life care, in addition to a range of services for family members, including pre and post bereavement, emotional and psychological support. Over recent years family demand for greater choice and more flexibility in the place of care has resulted in a number of hospices broadening the services provided to include a community-based offer. This has coincided with a drive for increased provision of home-based nursing care (Department of Health 2011) and community palliative care (National Palliative and End of Life Care Partnership 2010).

'Palliative care for babies, children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.'

Figure 1: Definition of children's palliative care (Dickson (2017: 13))

The lack of community-based palliative care services for children was highlighted in a number of papers (Quinn, 2012; Eaton, 2008; Hillis, Ling, Quinn and Brenner, 2016). Eaton (2008: 3197) notes the lack of consistency in community-based care across the UK, reporting that services are '*generally insecurely funded, often being very much the add on to another service*' and that they are frequently set up to relieve events that lead to social admissions to hospital. There has been an increase in the number of children living with life limiting conditions, owing in part to technological advances and medical understanding, resulting in the requirement for access to palliative care services across extended years (Brenner et al. 2016).

Brenner *et al.* (2016:3) found that parents deeply valued hospice at home services who could manage a child with an '*unpredictable trajectory'* and provide '*expert care'*, encompassing intensive emotional support for the family, at the same time as meeting the complex clinical needs of the child. Families widely praise the holistic approach taken by hospices, even when providing clinical care. Families talked about the attention paid to the whole child, rather than to purely clinical needs and to the family-focused approach taken by hospice teams.

Within the literature, the scope of community hospice care was discussed to a limited extent. The provision of planned care at home was more common, with teams moving towards providing specialist nursing care at home. The need for specialist short breaks and end of life care for children has been made for some time (Fraser et al. 2011; Department of Health 2008), and there is an emerging evidence base to support best practice (Bennett, McCarthy and McKinnon, 2016; Thompson, 2015). Despite the recommendations and

supportive evidence, there remains gaps in service provision, with variation in the availability of services.

Aim

The aim of this study was to determine the approaches taken by children's hospices across the UK in meeting the planned and unplanned health needs of children and families who receive palliative care at home. In addition, the survey aimed to identify the professional composition of community teams, and the number of children and families supported by each service.

Method

An internet-based questionnaire was developed to ascertain how children's hospices in the UK manage their community nursing provision, in order to inform the development of the services offered by Martin House Children's Hospice. The questionnaire was emailed to the Directors of Care (the most senior care role within a children's hospice, most frequently fulfilled by a registered nurse or allied health/social care professional) of all 54 children's hospices in the UK, inviting those who offer community-based care to respond.

Design

The questionnaire comprised ten open and closed questions, designed to explore the size of the team, geographical areas covered, workforce composition, services offered and approaches taken to managing unplanned, out of hours care needs. Key stakeholders from services across the region were consulted in the design of the questionnaire, which were piloted by one hospice community team and discussed at a regional network meeting. The

final version of the questionnaire was informed by comments made by practitioners. Example questions from the survey are shown in figure 2. Respondents were not incentivised to respond.

Thinking about the children and young people on your caseload

- How many children and young people do your hospice care for **in total**? (Please exclude bereavement services)
- How many children and young people receive **community-based care**?

How do you organise the following types of care *(who provides the care, what hours do you operate, how are these sessions planned?):*

- **respite/short breaks at home**
- **unplanned, 'emergency' care at home**,
- **end of life care at home**,
- **specific clinical input at home** (e.g. syringe driver changes, reviewing changes in condition, medicine reviews etc.
- Please tell us about **any other care you offer at home** that is not captured above. *(Please exclude bereavement care and support)*

Figure 2: sample questions

Ethical approval

Health Research Authority (HRA) approval was sought (IRAS Project ID: 249304), however it was concluded that HRA approval was not required. Approval was sought and granted from the Clinical Effectiveness Committee at Martin House Children's Hospice, who oversaw the process.

Data analysis

Data from closed questions were entered into an Excel spreadsheet. Responses to open ended questions were collated and analysed using deductive content analysis (Elo et al. 2014), as described by Elo and Kyngäs (2008). The structure of the questionnaire was used as a guide to the grouping of the data (Elo & Kyngäs 2008) to facilitate the exploration (Loft et al. 2019) of the lines of enquiry listed in the aim, above.

Findings

Fourteen hospices who provide residential and community-based children's palliative care from across England, Scotland and Wales responded to the survey between September 2017 and February 2018 – a response rate of 26%. A total of 1,618 families were cared for by the hospices who took part in this study, of which, 825 families received care at home. This represents 51% of families who use the hospice care services.

With the exception of a small number of multi-site hospices, children's hospices are individual organisations, with services and approaches to care varying between them. There was great variety in the approaches taken by individual organisations to meet the needs of the children and families that rely on their services, and much of this data needs to be considered in the context of specific organisations. The findings are presented in three groups, namely staffing, care offered, and out of hours care, giving a picture of the services offered by hospices across the UK.

Staffing

Services were asked about the staff employed to work in the community. There was significant variation in the approaches taken to the skill mix and staffing levels, which appeared to correspond with the numbers of children receiving care, the geographical area covered by the hospice, the levels of care offered, the hours of standard operation and whether or not the hospice provided out of hours support, including on call services to families.

Three of the 14 organisations that responded to the survey employed an integrated community/hospice care team, and therefore could not provide specific numbers of community-based staff. Registered nurses constituted the greatest proportion of staff, with all teams employing nurses, comprising both community specialist practitioners (health visitors, school nurses or children's community nurses) and staff nurses. Five teams employed non-medical prescribers.

Care support workers, members of the team without professional registration, were employed by seven teams. Lower numbers of registered nurses were seen where care support workers were employed. Allied health professionals were employed by three hospices, although four others noted that access to physiotherapy and occupational therapy was available through the inpatient services. Play staff were employed by three hospices, either as nursery nurses, or play specialists, as shown in figure 3.

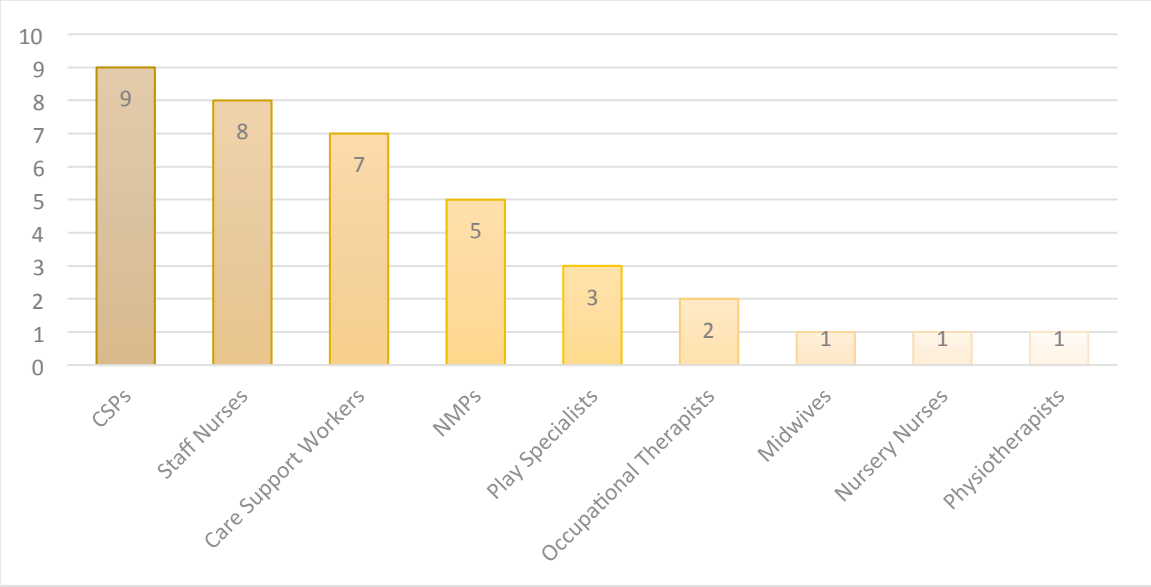

Figure 3: *staff groups employed by community hospice teams*

Care offered

Hospices offer a wide range of services in the community, caring for children with dynamic palliative care needs. The care provided at home can be broadly split into two categories – short breaks, including home-based respite, hospital visits and play sessions, and responsive, palliative nursing, comprising advance care planning, anticipatory prescribing, symptom control, end of life care and the verification of expected death, as illustrated in figure 4. In addition, therapies, including music, play and family therapy were discussed by some services, however these fall outside of the scope of this review.

Short breaks

The amount of care offered to families varied greatly between hospices, between two hours a month, to five hours per week. Most planned care is offered between 08:00 – 18:00, with preschool children, or children who are too sick to go to school given preference by services. Unplanned short breaks were offered less frequently, with the majority of hospices reporting to offer unplanned inpatient care.

Palliative nursing

Hospices reported an increased demand for these services by families and stakeholders alike. Three of the teams offered no palliative nursing as defined above, with other services offering variations of care to meet the dynamic needs of children requiring symptom management and end of life care. Four services reported to offer this on a 24/7 basis; a further two discussed how they work in partnership with NHS organisations to cover the 24 hour period. Advance care planning and symptom management was offered by almost 80% of services, however only a third of hospices offered anticipatory prescribing.

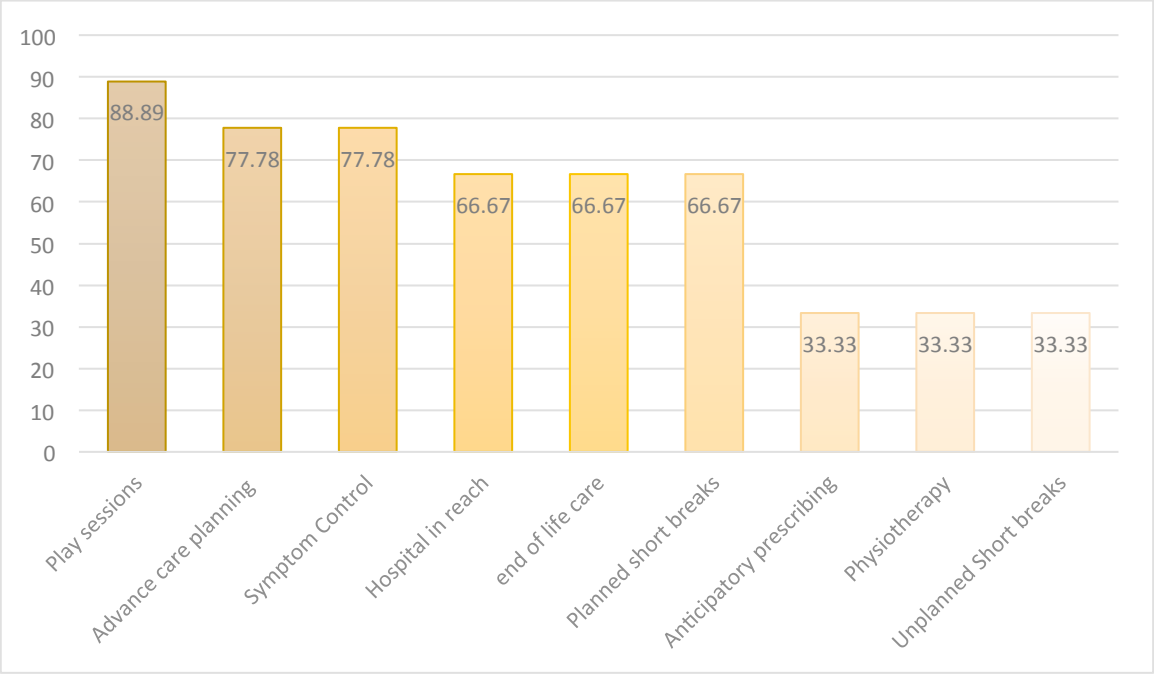

Figure 4: *types of care offered by children's hospices in the community*

Out of hours care

Community based services are routinely offered by most services seven days a week, inclusive of bank holidays. Out of hours '*on call provision*' by nurses varied, as shown in figure 5. Telephone-based nursing support was available to families using most services. Less than half of services offered home based care, or the opportunity for families to speak to a doctor. A number of services discussed medical on call for symptom control for families known to the hospice, or the ability of families to contact the hospice care team out of hours. Partnership working with statutory services was highlighted by two services, where on call provision was shared between hospice and NHS-funded community nursing teams at end of life.

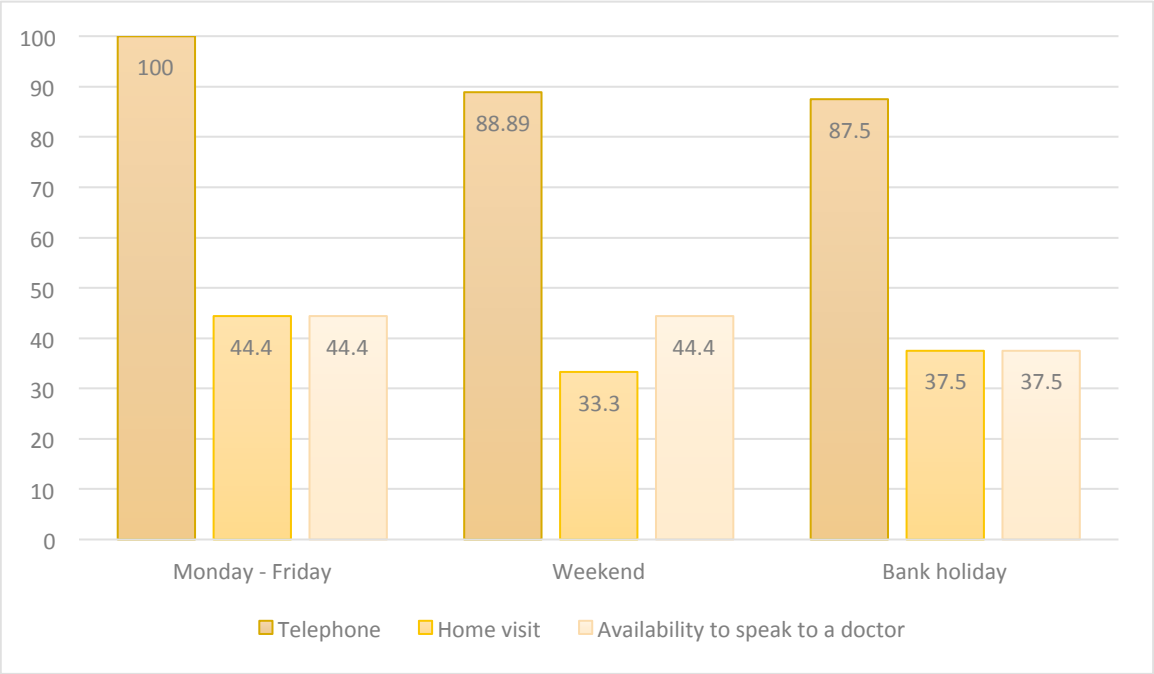

Figure 5: *out of hours 'on call' provision*

Discussion

Advances in medicine, interventions and technologies have resulted in children living longer, with increasingly complex conditions (Fraser et al., 2012). The demand for community-based children's hospice care is growing, and the scope of hospices evolving to meet the needs of children with increasingly complex needs at home (Spiers et al. 2012). Noyes et al. (2013) report the strong preference for home-based palliative care expressed by parents, as well as the need for flexible palliative care that allows families to change their preferences for preferred place of care between home, hospice and hospital. The provision of specialist care that is flexible and responsive to choices about where a child's care can be provided is therefore necessary (Parker et al. 2014).

Changes to the community based workforce enables hospices to provide specialist care to children who would have previously needed to be admitted to a hospice or hospital to receive the same level of care (van der Geest et al. 2017). Respondents discussed meeting local needs; the approaches taken to meeting the needs of children by individual organisations often correlate with local statutory service provision, where hospices provide services to meet unmet need. This allows hospices to ensure that the services offered are relevant and meaningful to the population served, grounded in the needs of those who rely on their services. In most instances, hospices provided services unilaterally, such as in the provision of home-based short breaks for children with palliative care needs, or community-based specialist nursing. However, examples of partnership working with NHS services was highlighted by some respondents, including out of hours 'on call' provision and joint funding in the employment of specialist and advanced-level nursing posts. Multiagency approaches are not uncommon within children's palliative care (Bainbridge et al. 2015), however care needs to be taken to ensure that universal and core services (Department of Health 2008) do not feel pushed out or replaced by specialist teams (Payne et al. 2017). Noyes et al. (2013) reported that access to specialist advice and support 24 hours a day was considered the most important element of palliative care for both parents and young people. Within this study, the provision of out of hours care appeared to depend on the availability of other out of hours support for families, predominantly children's community nursing services and inpatient hospice care. Where hospices provided 24 hour inpatient care, first line telephone support was available to families from hospice-based nursing staff. Less than half of the hospices included provide out of hours home visits, however they talked about the availability of emergency beds within the hospice, where families can be seen. The availability to speak to a doctor was also provided by the minority of hospices, although it

should be noted that most children's hospices are nurse-led services, and do not employ doctors on a 24 hour basis.

All services talked about service development being driven by family demand, with a desire to support and enable true choice in the place of care. The report by Sadler (2018:8) supported this, stating that '*for those who choose home, the reassurance of 24-hour nursing support is essential in situations* [when] *a child's condition deteriorates suddenly or they reach their final hours*'. It appeared to be particularly important for services to be able to offer choice in the location of symptom control and end of life care to the families who used their services, correlating with literature in both the children's (Dickson 2017; Department of Health 2011; Tatterton 2017; Mellor et al. 2012) and adult workforce (Dixon et al. 2015). The integration of hospice- and community-based staff was highlighted, where one group of staff work across both locations, with the rationale that families access care in both locations. Integrated teams offer families consistency, as well as helping staff to appreciate the needs and realities of families by visiting them at home, further improving the care offered (Payne et al. 2017). Family preferences surrounding the place their children's end of life care can fluctuate throughout the child's condition (Parker et al., 2014); an integrated, or well-coordinated service enables the flexibility of services to respond to this with a timely and seamless response.

Advances in nursing scope and practice in recent years had led to hospices offering a greater range of nurse-led services, increasing flexibility and sustainability of care services, including the provision of a greater range of services in family homes. For example, the introduction of independent prescribing enables the provision of dynamic symptom management and

end of life care to be provided at home. Specific competencies (Royal College of Nursing 2018) have been developed that reflect the diversity of conditions experienced by children as well as the scope of nursing practice, defining supervised practitioners, practitioners, advanced practitioner and consultant practitioners, outlining the competence, performance criteria, expected knowledge, behaviours and attitudes of practitioners at each level. Government publications on specialist and advanced level nursing (Department of Health 2010) and the introduction of multi-professional toolkits for advanced level practice (Health Education England 2017) and prescribing (Royal Pharmaceutical Society 2016) have served as catalysts to further develop and consolidate the advancement of nursing scope in practice.

The utilisation of community-based specialist and advanced-level nursing enables hospices to provide care that is responsive to the dynamic needs of children and their families. Current literature supports this, recognising that advanced-level nursing practice can enhance care delivery, owing to the blurring of traditional boundaries between the disciplines of nursing and medicine (Kennedy et al. 2015). As highlighted already, contemporary home-based palliative care for children has grown to include symptom management and advance care planning, helped by the addition of non-medical prescribers to the community workforce. Together for Short Lives, the UK's leading palliative care charity for children, note that the effective management of distressing symptoms is the prime consideration for many families (Widdas, 2013), and that the care surrounding the child must be able to offer reassurance by effectively manging the pain and other symptoms the child is experiencing. This contemporary approach to community-based hospice care, which includes specialist and advanced nursing, results in the offer of services that are an

integration of short breaks and palliative care services (Smith et al. 2017; Whitmore & Snethen 2018). This leads to the availability of responsive support for families, that is highly valued, adaptive and trusted by families (Ling et al. 2016), demonstrated in the research by Brenner (2016: 6), who summarised desirable attributes of hospice at home staff as '*compassion, clinical precision and expertise, commitment to the child and family and taking time to discuss a child's care with the family*'. The importance of children receiving end of life care from staff that are known to and trusted by the child and family is widely published (Parker et al., 2014; Quinn, 2012; Tan, Docherty, Barfield and Brandon, 2012; Widdas, McNamara and Edwards, 2013; Wood, Simpson, Barnes and Hain, 2010). This important issue is met through the flexible provision of hospice- and home-based palliative care by organisations, as demonstrated by respondents.

Limitations

The results of this study need to be interpreted within the context of several limitations, particularly the sample size and generalisability of findings. 14 of 54 children's hospices responded to the survey, representing 26% of organisations; however, only those hospices that offered community-based services were asked to respond. Whilst it is accepted that not all hospices offer care at home, but there is currently no definitive number of hospices that do. The small number of respondents and the variation in terms of geographies and populations served, may mean that the findings are not representative of all hospices. Finally, the findings difficult to generalise. In spite of these limitations, this study has value in that it is believed to be the first study to describe the approaches taken to community-based care by children's hospices in the UK.

Conclusion

This study demonstrates the variety of ways in which children's hospices seek to meet the needs of children with palliative conditions, together with their families, in the community. One of the key reasons for success of children's hospices lies in their ability to evolve to reflect the needs of children and their families, in the context of local palliative care service provision. Hospices must continue to evolve by engaging with, and working either alongside or in partnership with other agencies, assuring that the care offered is relevant to both children and families, and the services they work alongside.

Models of community-based palliative care are evolving in children's hospices in the UK, resulting in an increased scope of nursing, where more children with increasingly complex conditions can be cared for at home, increasing choice and flexibility. This has been achieved through the introduction of nurses practicing at specialist and advanced levels, who are able to provide dynamic symptom control and end of life care to children and their families, in addition to short breaks provision, which has been established for some time. The integrated inpatient and community models of care identified in this research enable families to access services seamlessly and at short notice. Where dual services are available, families no longer need to balance decisions around their place of choice of care against the availability of services.

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