

Exploring the experiences and perspectives of families using a children's hospice and professionals providing hospice care to identify future research priorities for children's hospice care

Running title: Research priorities for children's hospice care

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Abstract

Objective: To generate a list of priority topics for children's hospice care research in Scotland from the perspective of its key stakeholders.

Method: Qualitative semi-structured interviews with families using hospice services (n=5), four focus groups with hospice staff and volunteers (n=44) and telephone interviews with professionals associated with the hospice (n=18).

Results: Fourteen broad themes emerged following thematic content and interpretive analysis of the interview data. Some of the research themes were specific to certain stakeholder groups, whereas other themes were identified unanimously across all of the stakeholder groups as being priority areas for future research. Increasing awareness of and improving access to children's hospice care, hospice and respite care needs of young people, community/home care and issues related to supporting the wider family arose, independently, in all three stakeholder groups as being priority topics for future research.

Conclusion: A greater evidence base is required in the field of children's palliative care and the topics researched should be identified and led by those most closely involved in the hospices. Engaging families and care providers in the process of identifying research priorities resulted in the development of an extensive research agenda, which will contribute to quality hospice care for children and families.

Key words: hospice care; palliative care services; research priorities; qualitative

Introduction

Palliative care for children with life-limiting conditions involves the provision of physical, emotional, social and spiritual support at every stage of their illness to ensure the best possible quality of life for the child and their family.¹ The principles of palliative care for children and adults are comparable yet there are many ways in which children's palliative care is unique and as such it has emerged as a specialist

field in its own right. Many life-limiting conditions experienced by children are extremely rare and while diagnosed in childhood they may survive into early adulthood. The time scale for their requirements for palliative care and access to these services is often prolonged, intermittent and at times unpredictable. Palliative care encompasses a holistic approach and involves supporting the entire family unit including siblings. As children continue to grow and develop throughout the course of the illness their understanding of both their disease and death will continuously alter as will their care and support needs. Children's hospices are one of the many fundamental palliative care services and they provide much needed specialist care and support to children with life-limiting conditions and their families. Within a holistic and family-centred framework, hospices offer a range of services including hospice and home respite, sibling support and activities, various therapies (art, play, music), symptom control, end-of-life care and bereavement care and support for families.

Whilst research in this new and rapidly evolving speciality has increased steadily over recent years, published outcome data to provide an evidence base on which care can be based is not adequate,¹⁻⁵ thus demonstrating the need for a clear research agenda to address key questions. Indeed criticisms have been levied that children's palliative care lacks a rigorous empirical basis¹ and that practice has developed through clinical experience, anecdotal evidence and modifications of adult palliative care management,⁶ creating an opportunity to move services forward by identifying and pursuing key research topics.

Government policy recognises the importance of involving patients and their families in both research and health service planning.⁷ Moreover, the involvement of families is important in evaluating and improving the quality of services provided by children's hospices,⁸ indicating a need to engage in research and evaluation that is inclusive in its design. Thus active participation of families in developing the future research

priorities for children's hospice care and engaging them in the research process is fundamental. Children's hospice care and wider palliative care are provided by a blend of services and agencies. In order to meet the needs of children and families there is a clear requirement for partnerships and joint working between health, social services and education and the voluntary sector. There are a variety of stakeholders involved in planning and commissioning children's hospice care and palliative care services, delivering the care and support and accessing the services and it is equally important to seek all these opinions when establishing key priorities for future research.

The Children's Hospice Association Scotland (CHAS) have a significant role in providing hospice care for children and young people with palliative care needs across Scotland. The organisation is committed to developing a programme of research based around the real needs of children, young people and families using the service, and keen to ensure that such research will facilitate the continued development and evaluation of the hospice care they provide. CHAS commissioned the research team to conduct an assessment to identify the research topics considered important to the future hospice care of children and families from the experiences and perspectives of key stakeholders groups involved with the hospice organisation.

Methods

Study design

A three-round Delphi survey was undertaken to explore the experiences and perspectives of families, hospice staff and associated professionals in order to identify research priorities for children's hospice care in Scotland. The Delphi technique has been previously applied to determine the priority areas for nursing,⁹⁻¹³ midwifery,¹⁴ and health research,¹⁵⁻¹⁷ and more specifically in identifying clinical and

nursing research priorities within the domain of palliative and hospice care.¹⁸⁻¹⁹ This paper reports on the qualitative first round focusing on the process of identifying research topics. The second and third round of the project involved a survey of over 200 participants who were asked to rate each of the research topics in terms of importance and attempt to reach consensus amongst stakeholders during the rounds as to which are the topics of highest priority for future research. The results of these rounds will be published in a subsequent paper.

Participants

A purposive sampling strategy was employed to allow the identification of participants who would offer a breadth of perspectives and opinions on future research topics.

The three main participant groupings were:

- i. Families currently being supported by the hospice: The aim of this initial round of the project was to allow a range of families currently being supported by the hospice to be involved in generating topics for future research. All families currently being supported by the hospice would then be invited to participate in subsequent rounds of the Delphi survey to actually prioritise the list of research topics. A senior member of the hospice staff was requested to identify up to five families whose current circumstances would make it suitable to approach and invite to participate in an interview. Initial contact with the potential families was made through this senior member of the hospice staff, who requested the families' permission to be sent a project information sheet by the researchers. Families were advised to contact the researchers directly to discuss the project in greater detail and to obtain formal consent should they wish to participate. All five families approached agreed to participate in the interview and included new users (families using the hospice for one year

- ii. Staff and volunteers operating within the hospice: Posters were displayed at each of the two hospices inviting staff and volunteers to take part in the focus groups. Forty-four individuals agreed to participate and included representation from a selection of the various volunteer and staff groupings (Table 2).
- iii. Professionals linked to the hospice organisation: In consultation with the project Steering Group and hospice staff, key professionals were identified who had an association with the hospice and/or with families accessing the service (often as referrers to the organisation), and an informed interest or expertise in the care of children with life-limiting conditions and their families. Of the 23 professionals initially contacted 16 accepted the invitation to be interviewed and two recommended appropriate colleagues, producing a sample of 18. This sample included key strategic professionals in paediatric palliative care across the UK (Table 2).

Data collection

Data collection, involving interviews and focus groups, took place over a three-month period (January to March 2007). Semi-structured interview and focus group schedules were developed by the research team to guide the data collection. Topics for discussion included: describing their experiences of using the hospice and its services; experiences of providing palliative care to children with life-limiting conditions and their families; and identifying the topics they believed were important as future research priorities for CHAS.

Face-to-face interviews were conducted with five families. Three interviews were conducted with one parent present, one interview with two parents present and one interview with two parents, a sibling and the child with a life-limiting condition present. The interviews lasted between 32 and 51 minutes.

Four focus groups, with 44 participants in total were held with hospice staff and volunteers. The focus groups lasted between 55 and 70 minutes.

Eighteen telephone interviews with professionals were conducted. Interviews lasted between eight and 24 minutes.

All interviews and focus group discussions were audio-taped and transcribed verbatim.

Data analysis

Content and interpretive analysis of the transcripts was performed. Thematic content analysis is a useful approach for answering questions about the salient issues for a particular group of respondents or for identifying typical responses.²⁰ The member of the research team responsible for data collection read through each of the transcripts to identify key themes or topics for research. Some of the research topics were a direct answer to semi-structured interview questions, which asked participants to put forward their research priorities whereas others emerged during analysis and interpretation of the contextual data. To further ensure validity and reliability of coding, two additional members of the research team met to discuss, debate and refine the main themes.

Talking about research priorities was not a routine way of conceptualising their experience of the hospice and palliative care for many participants. Consequently while some ideas about research were clearly articulated in participants' speech, other ideas were less well developed. At times, themes emerged subtly in conversation about the services provided and people's responses to their role within the organisation. The research team's role was to identify those more subtly articulated ideas, and reflect them back to speakers within the conversation for confirmation, and to further develop them by the use of interpretive analysis of the transcribed discussions. The conversations were very different between the three stakeholder groups. Hospice staff and professionals were much more explicit in sharing research priorities whereas families' ideas came through more strongly during the interpretive analysis.

Ethical considerations

The project involved the participation of families with a child affected by a life-limiting condition so it was essential the project was conducted in accordance with clear ethical guidelines. NRES deemed that the project was service evaluation, rather than research, which does not require their ethical approval, therefore ethical approval was sought and approved via the Department of Nursing and Midwifery at the University of X (details to be added after peer-review process). CHAS' Clinical Governance Committee oversaw the project and received detailed progress updates on a quarterly basis. All participants provided written consent to participate and to the audio recording and subsequent transcription of the interview or focus group discussion.

Results

A plethora of research topics were identified and categorised under 14 principal research themes (Table 2). Some of the research themes arose repeatedly in the

separate stakeholder groups whilst others were specific to certain groups. It should be noted that this does not indicate that they were of a higher priority than other themes (this was to be ascertained in rounds 2 and 3 of the Delphi survey). Due to the vast amount of data generated, a snapshot of the qualitative data will be presented in this paper focusing on those research themes which arose, independently, in all three stakeholder groups: (i) awareness of children's hospices, (ii) improving access to hospice services, (iii) community care, (iv) hospice and respite care needs of young people and (v) support needs of the wider family. Verbatim quotes from participants are provided to support the themes. The category to which the participant belongs is indicated in brackets following the quote.

(i) Awareness of children's hospice care

There was unanimous acknowledgement amongst participants that many myths and misconceptions concerning children's hospices continue to prevail amongst public and professionals alike. Recognition of the need to develop strategies that would promote a greater understanding of the hospice and assist to dispel existing misconceptions was made. It was felt very strongly across all of the participant groups that actively promoting the wide range of care and support provided by the hospice was necessary to increase awareness amongst the public and professionals and thus improve access to the service, tapping into unmet need:

"There is a big issue in terms of getting children and families across the threshold of a children's hospice, a) because of the terminology and b) because of professional misconceptions or lack of education and information that professionals have about what children's hospices do...." (Professional)

"Well for everyone I would think the first priority is making the health professionals more aware of the service that the hospice offers." (Family)

Conceptualising ‘awareness of the hospice’ thereby moves away from traditional concerns regarding the associations between hospice and death, and toward ideas where service demand and unmet need are prioritised.

(ii) Improving access to children’s hospice care

In order to improve access to the service participants felt it was necessary to undertake some initial scoping work to form a sound evidence base of the precise requirement for hospice care:

“The first one is to have evidence-based research about the number of families who fit the referral criteria who actually live in Scotland, a needs analysis.” (Professional)

The link between the level of awareness that professionals in health and social care have regarding the services provided to children and families and patterns of referral to the hospice was also expressed as a research priority:

“...so if they’ve got a perception that children’s hospices adopt the same model as adult hospices that they are there for end-of-life care, then they (professionals) wouldn’t necessarily perceive a family on their caseload would benefit from using a children’s hospice, so there’s work that could be done in identifying the sort of patterns of referral in terms of who refers to the hospice and who doesn’t...”
(Professional)

Participants thought that hospice services could be offered to families much earlier in the course of their child’s illness if professionals had a clearer understanding of the referral criteria:

“I think more professionals should know from the beginning like, my consultant didn’t offer use of the hospice to me, he just said we can give you help and support if you need it, and I think that it would be helpful if someone like my consultant or anybody’s consultant actually visited the place ...” (Family)

“I’m vague about the criteria, I tend to hear about the criteria through the families ... I’ve had no direct information...” (Professional)

Participants also suggested exploring the reasons families choose whether or not to access the hospice. There was acknowledgement that the decision to use a children’s hospice is a personal one and will not be the choice for all families of children with life-limiting conditions.

(iii) Community care

Community care was highlighted as an important topic for future research with an emphasis and recognition of the need to deliver hospice care as close to families’ homes as possible.

Within the current outreach service, hospice nursing staff visit families in their home, particularly during times of need where additional care would be welcomed, such as when a parent is ill. The service was described in staff focus groups as offering something special or different to the existing community care provided by statutory and other voluntary services. As this is a relatively new service within the organisation, there was agreement amongst the staff and volunteers, professionals and by one of the families that it should be a topic to research in order to inform further service development.

“...if home care is a need the family have, should [the hospice] be providing it, or should we be arguing for it to be provided for the family in the community and I guess that’s about researching what it is that we would be offering in terms of home care that would be special or different...” (Hospice staff)

(iv) Hospice and respite care needs of young people (age 16+)

Children with life-limiting conditions are living longer and continue to use the services of a children’s hospice into their late teens and early twenties. The issue of actively preparing, planning and managing the transition to adult services was raised by all of the participant groups as being a key research priority. This raised questions around the appropriateness of children’s services as the location of care for young people who are in the midst of psychological, relational and emotional transitions.

Participants discussed a needs-based approach to this issue, and the cultural shift between child and adult services:

“...that’s one of the big issues as well, as adult hospice services are so different from children’s hospice services and there’s this huge big chasm in the middle where nobody is meeting the needs of this client group.” (Hospice staff)

Conducting a needs analysis from the perspectives of young people themselves, their families and the professionals involved in their care to identify support services that will be of benefit to them was seen as crucial in developing the research within this theme and providing guidance for service development.

While participants acknowledged that it may not be appropriate to care for young adults in a children’s hospice they stressed the fact that few other services exist to meet the hospice and respite needs of this population. The importance of working in

partnership with statutory and voluntary services in preparing for the transition to adult services was raised.

Identifying and meeting the support needs of young people with limited cognitive functioning emerged as specific concern from a family:

“One of the big issues for me is for children ... who have got very complex needs and have got very complex health needs, their care and everything should be needs led and not age appropriate.” (Family)

Exploring the psychological support offered to young people with an awareness of their life-limiting condition to develop clear evidence of what is required and what works was raised in one of the professional interviews:

“I’m sure there is much more we have yet to learn about what works and what doesn’t work in terms of offering good psychological support to children and young people facing these kind of issues ...” (Professional)

Recognising the lack of adequate alternatives for the care and support of young people, discussion turned to training and development issues for the hospice staff and volunteers so they are better able to support this age group and their families.

(v) Supporting the wider family

The hospice provides family-centred care extending beyond the child to include siblings, parents and significant members of the wider family. The issue of family support was identified as a priority topic for further research by two of the five families and six of the 18 professionals and was also raised in the staff and volunteer focus group discussions.

Exploring the impact of coming to the hospice on siblings and how they re-integrate into life outside of the hospice after their brother or sister dies was raised as a priority topic for research. Conducting a needs assessment to identify the specific support requirements of siblings at all stages of the child's illness including bereavement support was raised as a topic worthy of investigation by health and social care professionals.

Care of siblings emerged as an important topic for professionals, hospice staff and volunteers; with an emphasis on the potential for improved services to support siblings:

"I know they're probably doing work into siblings but from where I'm sitting siblings don't always get listened to and that's probably maybe to our own limitations. The needs of the siblings, no matter what age they are." (Professional)

There was also discussion amongst staff and volunteers regarding how gender mediates the experience of using and working at the hospice. Participants spoke of the specific support needs of male family members, and it was acknowledged that previously it has been difficult to attract more men to work at the hospice particularly on the care and support team. It was felt that having men on the staff team encourages fathers to engage with the hospice more, so increasing the gender diversity of the team will be important in supporting the families holistically:

"...because I have a group of bereaved parents and, traditionally, it's really hard to engage the men in that, I have no difficulty in getting the mothers to come but I have got a group of men who have asked specifically for the opportunity to meet as a group of men and I am not a man [laughs]..." (Hospice staff)

The wider issue of how male family members including fathers and grandfathers are supported was raised as a topic for future research by hospice staff and volunteers and by two of the families. Research would identify their specific support needs, including bereavement care:

“... it must be very, very difficult to get male members of staff but that’s one of the reasons that [Father] doesn’t go up a lot he says because it’s very female orientated”
(Family)

“I think that dads find it much more difficult to cope with the long term illness of their child, the fact that probably some day you know that they are going to die which is a really, really difficult thing to cope with, I think maybe more so for men. So maybe that is something that they [hospice] could think about.....” (Family)

Research reflecting the support needs of other key family members and carers was also raised as important for the organisation to consider:

“....impact on the wider family...I am always struck by the impact on grandparents who not only are mourning the loss of a grandchild, but they are also then trying to support their own child....” (Professional)

Discussion

A breadth of topics for future research emerged from interviews with key stakeholder groups and provide some insight into the areas of children’s hospice care that are of importance to families, service providers and relevant professionals. It is important to acknowledge to the reader that the research themes identified by participants relate to their experience with the hospice and do not indicate that participants had

concerns about these areas of the current service provision or were highlighting them as areas requiring immediate service improvement.

Families, in particular, talked at length about their own personal situation, about their child's illness and the resultant impact on their family. The researcher had to ensure the discussion was brought back to the focus of identifying topics for future research. This was sometimes challenging as it was crucial that the researcher determine what families understood 'research' to be and to have a clear understanding of their meaning or explanations of the future research topics.

Many of the research topics identified in this Scottish context connect with other opinion pieces which have described areas that would be fruitful in order to increase the evidence base in children's hospice care.^{1-2,5} The study reported in this paper, however is grounded in an extensive piece of research which (across all three rounds) consulted with over 600 key stakeholders to gain their views on the future of children's hospice research. Perspectives of families, hospice staff and relevant professionals interviewed support and add further weight to the essentiality of conducting research in these areas. The topics identified in this project are not exclusive to CHAS and are likely to be experienced by other children's hospices nationally and internationally thus providing an opportunity to develop partnerships in addressing the research agenda.

Engaging and involving families in setting the research agenda is essential so that hospice services can be directly tailored to meeting their specific care and support needs. Families of children requiring palliative care are seen as being a vulnerable population and as a result in the past, have often been excluded from research in efforts to protect them and avoid undue burden. However, being overly protective and discouraging the involvement or inclusion of families in research could limit

progress in the field. If optimal care and quality of life is to be ensured in children with life-limiting conditions and their families then research to more clearly understand the views and experiences of children and families is essential.²¹⁻²² Moreover, there is evidence that taking part in research interviews is viewed as a very positive experience by bereaved parents.²²⁻²³ In this project, families were happy to take part and engage in the discussion and communicated the importance of future research to ensure other families are privileged to the quality care they receive from the hospice. This project is unique in the fact that it addresses the views of both families and care providers in identifying areas for research. It is now important to take the next step forward in working together to engage both parties in other phases of the research process.

Gathering the views and perspectives of a range of key stakeholders including children and families who use the hospice was a key aim of this project. It is important to acknowledge the difficulty the research team encountered in including the views of children; both the child with a life-limiting condition and any siblings, in the research process. Despite the researchers inviting and encouraging children to be present during the interviews and to contribute to the discussion in generating ideas for research, only one of the five interviews was conducted with the parents, child and any siblings present. In the remaining four interviews, parents opted to be interviewed without their children being present. This was often for logistic reasons mainly the fact that parents requested the interview to take place during the daytime when the children were at school. In a further attempt to include children's perspectives, the researchers posted the interview schedule out in advance to give families the opportunity to discuss the issues together so the parent/s could then bring the views of their entire family to the interview. Future projects will be required to focus greater effort on obtaining the views and experiences of children and young

people with life-limiting conditions and their siblings and including them in the research process.²⁴

Conclusion

The findings from this work identify a breadth of topics for future research from the views and perspectives of families, hospice staff and volunteers and relevant professionals. Addressing the research topics identified would further contribute to the development of an evidence base in children's hospice and palliative care and delivery of children's hospice services that are underpinned by robust and valid research. In addition, these findings have wider implications, both nationally and internationally, for advancing children's hospice care and palliative care.

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Table 1 Distribution of family participants (n=5)

Family Category	Family unit	Length of time using the hospice
New user of the hospice	Mother, father, two siblings, child with LLC*	10 months
New user of the hospice	Mother, father, sibling, child with LLC	1 year
Longer-term user	Mother, father, sibling, child with LLC	2 years
Longer-term user	Mother, father, sister, child with LLC	9 years
Bereaved	Mother, sibling, child with LLC	5 years (family has been bereaved for one year)

* LLC = life-limiting condition

Table 2 Distribution of hospice and professional participants (n=62)

Participant Grouping and Roles	Number (n)
<i>Hospice staff/volunteers</i>	
Activities team	3
Administration	5
Care team (nurses)	16
Catering	2
Chaplains	4
Maintenance and housekeeping	5
Physiotherapy	2
Social work	3
Volunteers	4
Sub-total	44
<i>Professionals</i>	
General practitioners	2
Consultants (paediatric, neonatal, palliative care)	6
Special Needs Education teacher	1
Social workers	2
Nurses (community, palliative care specialists)	3
Representatives from hospice Board	2
Representative from voluntary organisation (ACH)*	1
Representative from national paediatric policy development	1
Sub-total	18
TOTAL	62

* The Association of Children's Hospices (ACH) is a national organisation/charity representing UK children's hospices.

Table 2 Research themes and the participant groups from which they were identified.

Research Themes	Participant Groups
Awareness of children's hospice care	Families, Hospice*, Professionals
Improving access to children's hospice care	Families, Hospice, Professionals
Supporting families who are new or potential users of the hospice	Families, Hospice
Community care (outreach)	Families, Hospice, Professionals
Hospice and respite care needs of young people (aged 16+)	Families, Hospice, Professionals
Spiritual and emotional care	Hospice
Bereavement and end-of-life care	Hospice, Professionals
Pain and symptom management	Professionals
Education of children and siblings	Professionals
Supporting the wider family	Families, Hospice, Professionals
Diversity	Hospice
Issues specific to hospice staff and volunteers	Hospice
Service development	Hospice, Professionals
Strategic planning	Professionals

* Hospice includes the hospice staff and volunteers participating in focus groups.