Research

'Place bonding' in children's hospice care: a qualitative study

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ABSTRACT

Background Limited knowledge exists of parents' perceptions and experiences of children's hospices and how these contribute to the varied access and uptake of services.
Aim This study aimed to explore parents' perspectives and experiences of a hospice, to understand the barriers and/or facilitators to accessing a hospice, and what characteristics parents wanted from hospice provision.
Methods A two-phase qualitative study underpinned by a constructivist grounded theory methodology was employed. Phase 1 used focus groups to collect data from parents of children already accessing the hospice (n=24). Phase 2 used in-depth semistructured interviews with parents of children who did not use the hospice (n=7) and with parents who had previous experience of using a hospice (n=7).
Results A grounded theory of place bonding was developed which illustrates the cognitive journey taken by parents of children with life-limiting conditions considering/receiving hospice care for their child.
Conclusions Finding a place where they belonged and felt at 'home' made the decision to accept help in caring for their child with a life-limiting condition more acceptable. The theory of place bonding offers children's hospices a new perspective from which to view how parents access, accept and build relationships at the hospice.

INTRODUCTION

Much of the earlier work[1 2] exploring the meaning of place and place experience concentrates on the image of the 'home' as a dwelling place. However, the evidence suggests[3–5] that there are many places which are important in people's lives and terms like place bonding and place attachment are often used to describe the affective bonds which develop between individuals and places.[6–8] Around the world, there are many children with life-limiting conditions (LLCs) who could benefit from the provision of paediatric palliative care[9–11] and in some countries, for example the UK, children's hospices are central to the provision of this care. However, relative to the numbers of children with LLC who could use hospice provision, parents and professionals perceive barriers to accessing hospices[12–14] and subsequently the uptake of hospice services are low.[15–17] At the beginning of this study (October 2013), fewer than 10% of the estimated population of children aged 0–19 years with LLC living in the study region were accessing a hospice.[18]

This study aimed to explore parents' perspectives and experiences of a hospice in the UK, to understand the barriers and/or facilitators to accessing a hospice, and what characteristics parents wanted from hospice provision.

METHODS
Study design
As little was known about the views of using/accessing hospice services from the parents of children with LLC living in the region, a qualitative study underpinned by a constructivist grounded theory methodology was undertaken, enabling the researcher to engage with participants and encourage them to recount their experiences for the purpose of generating a theory which was 'grounded in the data'.[19] Aware that there were two separate groups of potential participants, those who used hospice services and those who did not, a two-phase qualitative study was designed. Phase 1 would use focus groups as a data collection method for the interaction and sharing of ideas and differences of opinions from parents who were all hospice users (HUs). Following this, phase 2 would use one-to-one interviews, selected as being a means of sensitively exploring the views of hospice care with parents with little or no experience of using a children's hospice.

Table 1 Categorisation of children with LLC, Association for Children's Palliative Care[20]

Categories	Definitions
Category 1	Life-threatening conditions for which curative treatment may be feasible but can fail, for example, cancer, cardiac anomalies.
Category 2	Conditions in which there may be long phases of intensive treatment aimed at prolonging life, but premature death is possible, for example, cystic fibrosis, muscular dystrophy.
Category 3	Progressive conditions without curative treatments, for example, progressive neuromuscular conditions.
Category 4	Conditions with severe neurological disability which may cause weakness and susceptibility to health complications but are not considered progressive, for example, severe cerebral palsy.

Sample and recruitment

Parents who had a child with a LLC, as defined by the Association for Children's Palliative Care (ACT),[20] (table 1) and were living in the identified study region were invited to participate. In phase 1, all parents using the hospice (n=258) were invited to participate in focus groups. Knowing that 6 to 10 participants is an ideal number and takes into account the potential for participants to fail to turn up on the day,[21] the study was designed with the intention of recruiting 8 participants to each focus groups. In phase 2, parents of children who did not use the hospice but were known to collaborating community nursing teams were identified by lead nurses from seven children's community health teams across the region and invited to participate in one-to-one, face-to-face interviews.

Ethics

Ethics approval was obtained by the National Research Ethics Service and seven National Health Service organisations within the region who would act as participant identification centres for recruitment in phase 2 (14/EM/1004).

Data collection

Six focus groups, ranging from 60 to 90 mins, were conducted during the period July to October 2014 in parents' preferred location (four at the hospice and two in other respite locations). Despite contacting participants a few days before to remind them of the group time, offering options in different geographical locations, times which suited parents and the option of childcare, fewer participants attended each focus group than expected. Whilst the response rate for phase 1 of the study was 13.6% (n=35) the number who attended was 21 (8%). Following completion of six groups, three participants who were unable to attend their allocated focus groups still wished to participate. Although geographical limitations and their time restraints meant it was not possible to run another focus group, all three parents participated in one-to-one interviews. In summary, a total of 21 participants (four males) took part across six focus groups and three participants (one male) took part in an individual interview.

In phase 2, after 6 months when the health teams had invited all the parents they felt were suitable (n=48) recruitment was stopped. Building on a constructivist approach, drawing on the literature, advice from the steering group and patterns identified from the focus groups, an interview schedule was developed to aid data collection in phase 2 data. From November 2014 to April 2015, 11 interviews were conducted with a total of 14 parents (three males). The interviews ranged from 32 min to 60 mins. All focus group discussions and interviews were audiotaped and conducted by the study's principal investigator (HD).

During the interview process in phase 2 it became clear that half of the participants recruited (n=7) were not actually non-hospice users (N-HUs). Instead, these were parents who had either previous experience of the hospice or were using a hospice outside of the region, consequently this group of participants were labelled 'hospice aware' (HA).

Data analysis

The process of data analysis was grounded and consequently driven by the data and original transcripts of the participants. Informed by Charmaz's approach to data analysis,[19] a three-staged process of moving back and forth across the data, initial coding, focused coding and finally conceptual analysis and synthesis led to the development of categories and themes. Data collection and preliminary analysis occurred concurrently first in phase 1 and then in phase 2. Each transcript was uploaded into NVivo V.10 (QSR International, 2012) for initial sorting and coding of the data.

The second stage of analysis occurred concurrently while continuing to collect new data from subsequent focus groups. Relationships, patterns and variances in the data were identified by sifting through initial codes, comparing codes with each other and grouping these into smaller groups of focused codes. Analytic memos were written in order to record the relationships among the grouped focused codes and the interpretation occurring. While adding to the data, the three individual interviews which were conducted at the end of phase 1 were also an opportunity to clarify and affirm patterns that were emerging from the analysis of phase 1.

As this process of continuous comparison continued, analytical thoughts grew in complexity and clarity and theoretical sensitivity increased as patterns were developing. In the final stage of analysis, the process of theoretical coding was used to begin to theorise the preliminary categories which were emerging from the three data sets. The flexibility of grounded theory analysis meant that emerging thoughts, categories and themes were continually reviewed, refined and clarified. Table 2 is an example of how the theme Coming

Table 2 An example of the development of the theme Coming 'Home'

Coming 'Home': Depicts the sense of searching to try to find somewhere that, other than their actual home, can offer some respite from caring and the relief experienced when parents find that in the hospice	
To be able to _Cross the threshold_ parents were:	
▶ Getting 'Ready for respite'	"I don't know if I can do it yet, but I keep thinking maybe in time I'm going to need that break" (Parent 36, N-HU) "It took me three attempts to get here. I even drove up to the gates, and I said, 'No, not for me'" (Parent 17, HU)
▶ Overcoming many challenges and 'Internal battles'	"… so, any help that you get you always feel guilty because it's your responsibility" (Parent 32, N-HU)
▶ Then to find the only choice for help was 'Hospice the only option'	"…where else do we get respite from?" (Parent 13, HU) "They are shutting everything down" (Parent 5, HU)
Gateway to Belonging the search by parents for the right place:	
▶ When characteristics were present, they 'Created a sense of belonging'	"… he's safe" (Parent 3, HU) "It's always about consistency" (Parent 26, HA) knowing them that well to know their little cues and signs and things" (Parent 36, N-HU) "People are really important" (Parent 25, HA) "Finding the right space" (Parent 29, HA)
▶ However, the 'Paradox of belonging' was because of a diagnosis	"diagnosis that means you will ultimately die early" (Parent 24, HU) "… places like this sort of stamps you" (Parent 21, HU)
▶ And the recognition of another subtly hidden side to the hospice 'Disguise'	"… a hidden side" (Parent 27, HA) "… two identities" (Parent 7, HU) "… masking the real reason for the place" (Parent 22, HU)

HA, hospice aware; HU, hospice user; N-HU, non-hospice user.

'Home' emerged from the theorisation of the preliminary categories. In the same way, two further themes were developed which also represent the experience of the parents in this study: This is Living Now and Moving Forward.

Trustworthiness

Consultation and frank discussion with a steering group comprising local health professionals, hospice board members, parents, academics and a representative from Together for Short Lives offered guidance on the conduct of the study and added confidence in the veracity of the study. Trustworthiness was maintained during the process of analysis through reflexive discussions among the research team and by using participants' words when labelling codes, ensuring that the research remained grounded in the data. In the findings, anonymised quotations are used to illustrate key points; the following abbreviations are used to describe participating groups of parents: HU, HA and N-HU.
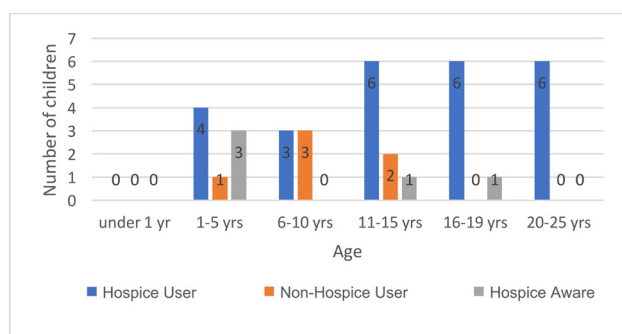
RESULTS

Participants

Thirty-eight parents participated in total: phase 1 (n=24; 19 females, 5 males) and phase 2 (n=14; 11 females, 3 males). The age of the children (n=36) whose parents participated in the study ranged from 1 to 25 years (figure 1), and their primary diagnosis according to the ACT criteria[20] were diverse (figure 2). In phase 1, the average length of time that the child had been attending the hospice was 8 years, (range 2 to 20 years).

Development of the theory: place bonding

Using the concepts developed from the grounded theory analysis of the findings and drawing on the literature, a theoretical understanding of the parent's search for a place, the journey of complex decision-making and the inter-relationships between the hospice and parents considering/receiving hospice care was developed (see
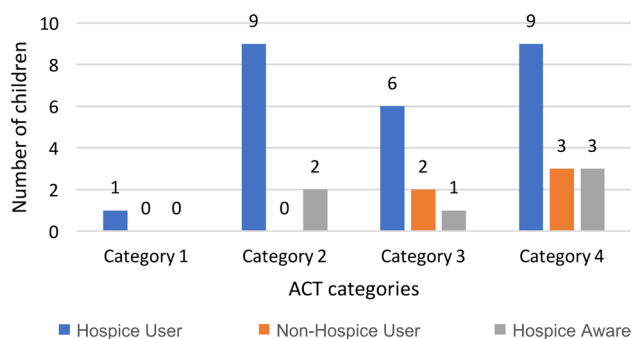
Figure 1 Ages of children whose parents participated in the study.

Figure 2 Primary diagnosis of children whose parents participated in the study defined and categorised by the Association for Children's Palliative Care (ACT).[20]
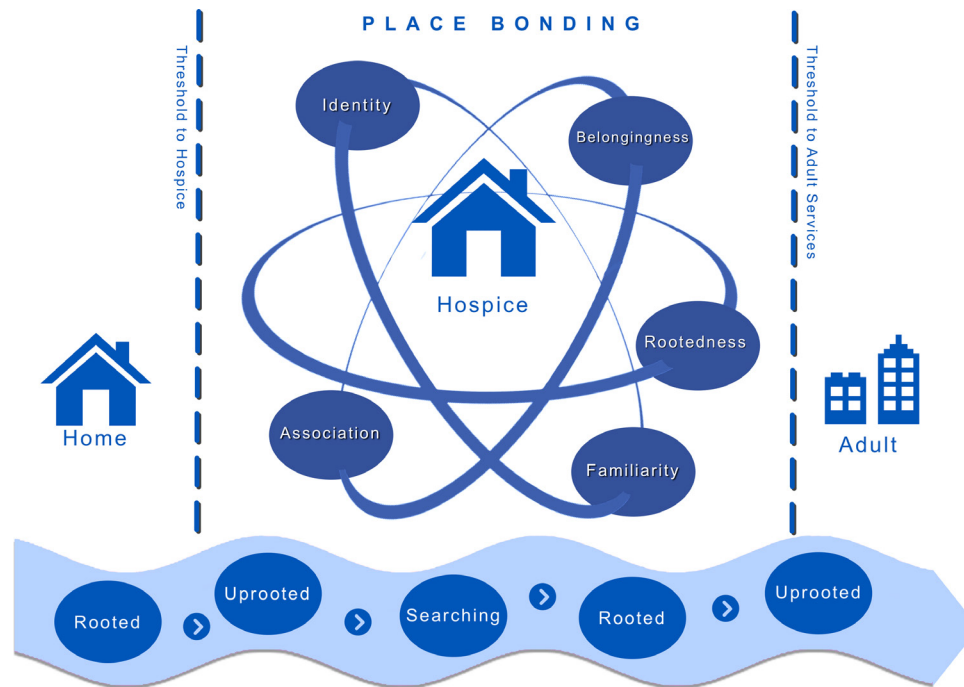
PLACE BONDING

Threshold to Hospice

Threshold to Adult Services

Identity

Belongingness

Hospice

Rootedness

Home

Association

Familiarity

Adult

Rooted · Uprooted · Searching · Rooted · Uprooted

Figure 3 Illustration of the grounded theory developed, 'Place Bonding': the cognitive journey taken by parents of children with life-limiting conditions considering/receiving hospice care for their child.

figure 3). While this theory of place bonding is specifically applied to a hospice setting, the nature of caring for a child with a LLC meant that across all three user groups (N-HU, HA and HU), parents recognised their current or future need for help in caring for their child. 'Moving Forward' portrayed the idea that living with a child with an LLC was akin to travelling on a journey, although a journey of uncertainty and many obstacles and one that was likely to be shorter for their child than usual. The parents were uncertain in terms of the progression and path of their journey and explained:

> sometimes times are hard, and the pendulum doesn't swing quite so fast, and sometimes it's all around the corner, we are sat there, a ticking time bomb effectively. (Parent 22, HU)

However, for others, similar to other studies,[22] the journey with their child was much longer than they ever anticipated:

> I didn't think we'd see sixteen without a doubt. I didn't see him carrying on this long. (Parent 24, HU)

In this study in order for parents to feel reassured about leaving their child they had to believe their child would be cared for in the same manner they were cared for at home. Therefore, becoming familiar with the hospice was an essential element of the bonding process.[4 8] Coming 'Home' describes the parents' search for the right place for their child to receive care, seeking somewhere that encompassed the characteristics of home. In line with other studies,[22] parents consistently stressed the importance of knowing their child was safe and secure, and how they wanted their child to

be cared for by familiar staff. For parents, consistency also meant that carers knew the intricacies of knowing their child and their child's routines, *'the routine of doing things the way you do them'* (Parent 26, HA). Parents' trust in staff was also dependent on whether they believed the staff were competent and sufficiently knowledgeable to care for their child.[22] When these characteristics were present it helped parents to experience some sense of freedom from the internal battles of guilt and separation.

However, the decisions to use the hospice or consider using it took different times to come to fruition. Similar to other studies[23 24] in most cases the decision by parents to take their child to the hospice was a planned one, often influenced by the desire to spend some quality time with other family members, to have some 'me' time and some needed rest. This had to be balanced against the anxiety parents experienced in being separated from their child and the sense of guilt they perceived in relation to their parental responsibilities during that separation. In his seminal work, Relph[1] referring to the concept of 'insideness' described how increased familiarity between an individual and a place led to a stronger sense of attachment and therefore the development of stronger bonds. The strongest sense of 'insideness' at the hospice was achieved where parents felt secure and ultimately safe. However, for those parents who chose not to come to the hospice they remained in a state of outsideness,[1] with no appreciation of what the hospice had to offer.

The irony was that for some of the parents, having finally made the decision to accept help, there was

limited choice in terms of the places they could access. This lack of choice and availability of respite services is reflected in the literature as one of the largest unmet needs in children with complex and palliative care needs.[17 25 26] For some of the parents searching for services led them to the hospice, a place whose identity presented them with particular challenges. This identity represented much of what they dreaded including their fear that their child would most likely die prematurely or the perception that accepting hospice care was seen as giving up.[13] Although parents recognised the respite benefits that the hospice offered, the reality was that entry to the hospice was by invitation prompted by their child's diagnosis and needs which were reminders of their child's LLC: *nobody wants a diagnosis that means you get invited to come here* (Parent 4, HU). While there was a strong sense of agreement across all three groups of the characteristics necessary to enable parents to accept respite, it was the group of HUs who described, how in the environment of the hospice, they felt they had found somewhere where their child belonged. However, there was a paradox to having a sense of belonging because the reality of entry '*stamps you, indelibly with that mark that you didn't have before, it's real and true then*' (Parent 21, HU).

Apart from the respite support offered, parents recognised that there was a hidden side to the hospice as it was also a place for end-of-life care:

> They've done a fantastic job in masking the real reason for the place, and you can't see any of it. It's there. And it doesn't matter how long you stay there, you still can't see it. (Parent 22, HU)

Parents believed that this side was subtly hidden by the hospice, and as a consequence, the hospice became a place of belonging, where parent and child experienced respite in a happy, vibrant environment:

> [the decision] we put off, because we didn't want to go to a hospice. It's the place where you go to die, and that's it. That stigma that's attached is so wrong. Because as soon as we went to look, we were like, we should have done this a year ago. (Parent 27, HA)

As reflected in other studies,[12 27 28] while it was evident that there were both positive and negative connotations associated with the concepts of palliative care and hospice, there was something about the hospice itself that made it feel like home and a place of shelter[29 30] rather than a clinical institution and these aspects drew parents in and drew them back.

Many of the parents in the study yearned for normality which they perceived parents with 'normal' (their terminology) children had. In line with other studies,[26 30] the hospice also gave parents the freedom to engage in normal family activities without tedious planning and to experience a sense of spontaneity in their lives. This association with normality at the hospice had a powerful therapeutic effect on parents enabling them to experience rest and restoration and it became a 'lifeline' for them.[31] They described the impact of the loss of 'normal' in their lives: loss of the 'normal' child that they expected, loss of their identity, loss of friendships and loss of the future they had envisaged.[32 33] Many found that their life was not their own, instead life was defined by the needs of their child and the multiple roles and identities[22] that they adopted in order to manage their child's care.

> To kind of be you again you just forget that you are, you know who you are, you're doing it without noticing just looking after … and you don't think about anything. (Parent 11, HU)

Parents also described how they felt their lives were closely timetabled, how everything needed to be well planned and organised and how there was little spontaneity. The pressure of constantly readjusting to the impact of these restrictions forced parents to try to balance the scales by creating their own normal and perceiving the need to take control of their lives.[34] By taking control, they achieved a life that was different from those around them in which they were '*living day by day*' (Parent 25, HA). For some parents this meant adopting new roles, such as key worker, in order to manage and control the care given and offered to their child. For some it meant a change in perception, attitudes and coping abilities, and for others it was about choice and independence. Ultimately the decision to live life as it was now required parents to accept the restrictions on their lives, make each day the best it could be and embrace a different future.

> That feeling of things being stolen has kind of, gone, in the fact that we know we are where we are, what we saw as normal life, that had suddenly been ripped out from under us, our future had been stolen and that is how it felt. Our future is different now (Parent 28, HA).

Associating the hospice with a sense of living meant that parents perceived their experience at the hospice as positive, and in this way, they recaptured a little of the quality of life that some of them perceived they had lost for themselves and their child.

The need to belong has been described as a powerful motivator for humans and fundamental for health and well-being.[35 36] The sense of belonging that parents experienced at the hospice resulted from being in the '*same boat*' as others, as their child was with other children with LLC and therefore parents perceived an affiliation with other parents. Likewise, belongingness at the hospice was also perceived possible when the parents felt their child was safe and secure and being cared for by staff who were competent and knowledgeable and who were familiar with their child and paid detailed attention to their child's needs and routines.[22]

Table 3 The five dimensions of place bonding as applied to the hospice

	Five dimensions of place bonding identified by Hammitt et al[4 8]	Five dimensions of place bonding applied to the hospice
Place familiarity	The process by which people develop their cognitive knowledge of a place.[8]	Finding a place that parents felt secure and safe to be able to leave their child.
Place identity	The way in which feelings, attitudes, memories, values and behaviours are formed regarding specific physical settings.[38]	The positive and negative connotations associated with the identity of the hospice and the influence that this had on a parent's self-identity.
Place belongingness	The affiliation and connectivity with a place which resulted in the formation of communal bonds.[37]	The characteristics described by parents as fundamental to achieving a sense of belongingness.
Place association (dependence)	The potential of a place to satisfy a person's needs and goals compared with other environments that might satisfy the same needs.[39]	The reliance that parents had with the hospice.
Place rootedness	The sense of feeling so secure and comfortable and completely at home in a location that there is no desire to seek an alternative.[1 2]	The sense that parents had finally found a place where they belonged and where they truly felt at 'home'.

Repeated use and positive hospice experiences led to a sense of rootedness for the parents.[1 2] This was defined by feeling safe, having strong affective bonds, feeling comfortable and at home within the hospice. The paradox was that a place the parents initially dreaded and did not want to enter and where their child's LLC enabled entry, became a normal part of their world, a place of belonging, where parents became part of the 'hospice family' and which they missed when they were not there. The sense of bonding experienced meant that for some of them there was a sense of disappointment when their respite break was over. Despite wanting to find a place to belong and needing respite, parents who had no experience of the hospice remained rooted in the safety of their own home, unwilling to venture across the hospice threshold and unable—at the point they were at in their journey—to envision it as a place where they could put down roots.

DISCUSSION
Informed by the five-dimensional model of place bonding described by Hammitt et al,[4 8] the results of this study offer a new perspective of parents' journeys to seeking and accepting hospice care for their children (table 3). Place *familiarity* meant parents found somewhere where they experienced a similar sense of safety and security that they experienced at home. In the hospice, parents formed relationships with staff who knew their child, were familiar with their routines and competent in caring for their child. This in turn led the parents to a stronger sense of *belongingness*[37] and a feeling that they were not alone and were with people with whom they could share similar experiences. With place *identity*,[38] the hospice offered parents time to be themselves, to grab a glimpse of what they perceived as 'normal' family life, to take a step sideways from some of their caring responsibilities in an environment *associated*[39] with meeting the needs of their child with the LLC. While there was a side of the hospice that parents dreaded, the side they did their upmost to avoid thinking about, the strong sense of bonding offered some reassurances that when the time came

for their child's end-of-life care, that bonding would help them through. Finally, the concept of *rootedness* portrayed the sense that parents in their search had finally found a place where they belonged and where they truly felt at 'home'.

LIMITATIONS
Despite considerable efforts to recruit parents, especially those who were not HUs, the response rate was lower than initially expected. In phase 2, recruitment was solely dependent on community nurses who may not have prioritised recruitment.

CONCLUSIONS
The theory of place bonding offers a new perspective of parents' journeys to seeking and accepting hospice care for their children. Finding a place where parents experienced a sense of bonding potentially made the decision to accept help and support in caring for their child with a LLC more manageable. The hospice was more than just a location, it was more than just a respite service; the hospice possessed meaning, identity and was a place to which parents formed attachments. The theory of place bonding offers children's hospices a new perspective through which to view how parents access, accept and build relationships at the hospice. Evidence from this study suggests that incorporating the five dimensions of place bonding and the characteristics described into the approaches of care offered at children's hospices may offer parents some reassurances that their child will be cared for in a manner that they provide at home.

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