

'Cold bedrooms' and other cooling facilities in UK children's hospices, how they are used and why they are offered: A mixed methods study

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Abstract

Background: The death of a child is acutely distressing. Evidence on the benefits and value to parents of spending time with their dead child have now been integrated into routine practice and is regarded as a bereavement support intervention. UK children's hospices have a tradition of using 'cooling facilities' (cold bedrooms, cooled blanket/mattress) to extend this period of time by slowing deterioration of the body.

Aims: To describe: (1) type and use of cooling facilities in UK children's hospices, policies and practices regarding their use, and any changes over time. (2) Director of care's views on the purpose of cooling facilities and the rationale for hospice-specific practices.

Methods: An explanatory mixed-methods design consisting two phases: a cross-sectional survey of directors of care of UK children's hospices ($n = 52$) followed by semi-structured telephone interviews with a sub-sample of respondents. Survey data were analysed using descriptive statistics and interview data using directed content analysis.

Results: 41/52 hospices completed the survey and 13 directors of care were interviewed. All hospices had cooling facilities. Some offered use of portable cooling facilities at home, though take-up appears low. Hospices differed in approaches to managing care and duration of use. Views on whether parents should observe deterioration informed the latter. Directors of care believed they provide families with time to say 'goodbye' and process their loss. Challenges for staff were reported.

Keywords

Cold bedrooms, cooling facilities, cooling blanket, cold cot, bereavement, grief, paediatric palliative care

What is already known about the topic?

- Previous studies indicate that parents value the opportunity to spend time with their child after they have died.
- Children's hospices in the UK have 'cooling facilities' (e.g. cold bedroom, cold blanket/cot) which extends the period of time before the child is transferred to a funeral directors. This sort of provision is less common in other countries.
- Anecdotal evidence suggests hospices vary in the cooling facilities offered and practices regarding their use.

What this paper adds

- Types of cooling facilities provided by UK children's hospices varied, including whether they could be used in families' homes.
- Significant variations in practice – such as duration of use, use of care plans in the post-death period, and families eligible to use cooling facilities – were observed.
- Directors of Care characterised the time parents used cooling facilities as a period of transition, and believed their use eased the early days of grief.

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Implications for practice, theory or policy

- Studies of parents' experiences of using cooling facilities are needed to support evidence-informed practice in cooling facility provision.
- Access to cooling facilities for parents of children not known to children's hospices appears patchy; clinics/hospitals may want to consider establishing cooling facility pathways with local children's hospice(s).
- Children's hospices may need to review their training and staff support systems for those providing after death care for families

Background

The death of a child is a deeply distressing experience and is widely accepted as being a more profound and intense experience compared to other bereavements.^{1–4} Numerous studies report the consequences of the loss of a child including increased the risk for mental health problems, threatens relationships, and affects parents' ability to work.^{1,2,5} Bereaved parents are also higher-risk than other groups for complicated grief.^{3,6}

There is growing evidence that the way parents are supported immediately after their child's death, and into longer-term, impacts outcomes.^{7–12} Within this, evidence on the value^{13,14} and potential benefits to parents of seeing and holding their dead baby or child in the period immediately following death^{1,12,15–18} has meant providing this opportunity has been integrated into routine practice and is now regarded as bereavement support intervention.^{19–22} (We note that cultural traditions and religious beliefs influence whether and how this is offered.^{4,22,23}) Wider literature, and theory, on how 'time with the body' may facilitate acceptance of death and meaning-making support this development.^{14,24–26} However, unless the body is cooled in some way, this period of time is limited to a few hours, at most.^{17,25}

Less well-understood is the practice of cooling the body in order to offer an *extended* period (i.e. a few days) in which parents can freely spend time with their child, either until the funeral or before the body is transferred to a funeral directors. In the UK this is specified in national guidance¹⁹ but, to our knowledge,²⁷ is the only country where this is the case. The origins of this can be traced back 40 years to when the UK's first children's hospice, which opened in 1982, included a 'cold bedroom' facility. This model of provision was subsequently adopted by the 50 or so UK children's hospices set up in since then, the majority of which include inpatient/residential services. The recent emergence of portable, electric-powered 'cooling blankets/mattresses/cots' has, if offered, opened up to families the option to take their child home rather than staying at the hospice. Reasons why PPC provision in other countries may not incorporate such 'cooling facilities' include the fact that, compared to the UK, paediatric palliative care/children's hospice provision may be more nascent and/or does not include bereavement support.^{22,23} The cultural and faith profile of the population is

also likely to be at play.⁴ That said, an initial analysis of data from a survey²⁸ of bereavement support provided by children's hospices in Europe and elsewhere ($n = 16$, representing children's hospices in 11 countries) indicates a small minority provide cooling facilities and, among those that do not, the majority support their introduction.

Despite longstanding use by UK children's hospices, few studies have investigated their provision of cooling facilities. Two studies have investigated parents' experiences, but both only recruited from one hospice and one collected data via a questionnaire.^{17,25} Both report that parents' valued unrestricted access and close proximity to their child, enabling them to spend time with them, adjust to the reality of their death, and slowly separate from them. Importantly, all parents had stayed at the hospice and described the value and importance of access to emotional and practical support (e.g. funeral planning) from staff. Two studies^{29,30} report staff's attitudes and experiences of caring for children using cooling facilities. The first was in a children's hospice, which explored staff's experiences of cold bedrooms,²⁹ the second was based in a hospital in Sweden and explored midwives' experiences of using a cold cot.³⁰ Both explored staff's experiences and reported difficulties managing odour and physical deterioration, and emotional impacts on staff.

Anecdotal evidence from the UK children's hospice sector suggest differences between hospices in the types of cooling facilities being used, practices regarding their use and the support provided to parents, and that practices have changed over time.^{19,31} However, this has not been investigated systematically. The long-standing position of cooling facilities as a core element of UK children's hospices' provision and, potentially, adoption of this provision by other countries provide a clear argument for further research into this element of paediatric palliative care. This paper reports the first of a two stage investigation on cooling facility use in UK children's hospices.^{28,32}

Aims

To describe:

- Type and use of cooling facilities in UK children's hospices, current policies and practices regarding their use, and any changes over time.

- Directors of care's views on the purpose of cooling facilities and the rationale for hospice-specific practices.

Methods

Design

We employed an explanatory mixed-methods design³³ consisting of two phases: a cross-sectional survey of directors of care of all UK children's hospices ($n = 52$), followed by short, semi-structured telephone interviews with a sub-sample of survey respondents. The purpose of the interviews was to generate additional detail on topics covered in the survey responses and explore explanations for practice. It is important to note that we were not seeking staff's views on their experiences of caring for families using cooling facilities. Research ethics committee (REC) approval was obtained (Department of Social Policy and Social Work REC, University of York: SPSW/S/18/9).

Setting and participants

The study concerned cooling facility use by UK children's hospices, defined as: a standalone service (nurse- or doctor-led) which is separate to hospital care and provides palliative care to children with life-limiting conditions and their families, with that care provided either in an inpatient/residential facility and/or in the family's home.

Participants were directors of care of children's hospices, defined as: staff not directly involved in providing care/supporting children and their families, but responsible for the leadership, management, development and transformation of clinical services.

Sampling and recruitment

The survey sample comprised directors of care of all children's hospices in the UK. These were identified via publicly available information online.

The sample for the telephone interviews comprised a sub-group of survey respondents. At the end of the survey, respondents indicated whether they would be interested in participating in a brief, follow-up, semi-structured telephone interview. Twenty-one indicated that they would. All were contacted by JH via email regarding this.

Data collection

A postal survey gathered data on: hospice characteristics, caseload, provision of cooling facilities, usage of cooling facilities, and policies/practices regarding their use. The participant information sheet stated that by completion and returning the survey, consent was implied. Surveys were completed between September 2018 and January 2019.

Semi-structured interviews with a sub-sample of survey respondents explored reasons why cooling facilities were provided, views regarding impacts on parents, the rationale for hospice-specific practices, and staff support and training needs. A topic guide ensured consistent and comprehensive coverage of topics across interviews. Audio-recorded verbal consent was obtained before the interview commenced. Interviews were audio-recorded and conducted by JH between December 2018 and May 2019.

Data analysis

Survey data were inputted into SPSS and descriptive statistical analyses were conducted. Most questionnaires had missing data, particularly numerical data (e.g. caseload, number of deaths, number of families using cooling facilities). This was expected, children's hospices record their activities in different ways (e.g. caseload vs occupancy rate) and to differing levels of detail. Where relevant, we report sample size per question.

Interview data were analysed using directed content analysis.³⁴ Detailed summaries of telephone interviews (including, where pertinent, verbatim quotes), organised under a broad topic areas pre-determined by the topic guide, were generated. An a priori coding framework was used to index the summaries. Data which could not be categorised, were checked to see if they represented a new code or subcategory of an existing code. Those which did not, were given new codes/sub-codes. Identification of overarching themes by grouping codes was the next step. Descriptive analytical writing was used to record observations and to support comparisons within the dataset.

Results

Sample and sample characteristics

About 41/52 hospices participated in the survey. Of the 21 respondents who expressed interest in taking part in a follow-up telephone interview, eight did not respond to contacts from the research team, 13 interviews were therefore completed. Interviews lasted between 18 and 63 min (mean = 39 min; median = 38 min).

Characteristics of hospices represented in the study are presented in Table 1. Survey respondents were directors of care in hospices providing residential and hospice-at-home facilities. Hospices with residential provision ranged in size from those with less than five bedrooms to eleven or more. The majority of hospices imposed upper age limits of 18 or 25 years. The interview sample represented this range of provision.

Availability and type of cooling facilities

All residential hospices provided cooling facilities on site. The majority (35/37) had one or more dedicated 'cold

Table 1. Characteristics of hospices represented in the survey and follow-up interview sub-sample.

Characteristic	Number of hospices	
	Survey sample (<i>n</i> = 41)	Interview sample (<i>n</i> = 13)
Type of provision		
Residential and hospice-at-home	27	11
Hospice-at-home only	5	1
Residential only	8	1
Number of bedrooms (residential hospices only, <i>n</i> = 35)	(<i>n</i> = 35)	(<i>n</i> = 11)
5 or less	10	5
6–10	21	5
11–19	4	1
Upper age limit (<i>n</i> = 40)		
18 years	14	5
25 years	20	5
26 years or older	6	3
Missing data	1	
Bereavement team/service		
Yes	39	13
No	2	0

bedroom(s)'. However, some (12/32) no longer cooled the rooms (using integrated air-conditioning systems), using instead a cooling blanket/cot. Most (25/35) also reported using cooling blankets/cots and/or portable air-conditioning in regular bedrooms in order to meet demand for cooling facilities. This was also the approach taken by the two without 'cold bedrooms'. Use of portable air-conditioning alone in regular bedrooms was unusual (*n* = 2).

The majority of residential hospices (31/37) also provided portable cooling facilities for use at home. For almost all, these were introduced less than 5 years ago. Three of the four hospice-at-home services also offered cooling blankets/cots for use at home, with the fourth planning to introduce them shortly. The majority of respondents (20/26) reported using cooling facilities from when their hospice opened, or within a couple of years.

Take-up of cooling facilities

Thirteen respondents provided data on the number of children on their caseload who had died in the previous calendar year (2017) (total *n* = 450; deaths not necessarily occurring in the hospice), and the number who had used cooling facilities (total *n* = 200). The proportion of families using cooling facilities varied between services from all families to less than one in five.

Survey respondents (*n* = 40) were asked which factors (specified in the survey) they believed affected use of cooling facilities. Religious beliefs (*n* = 16/40), ethnicity

(*n* = 13/40), place of death (*n* = 13/40), and whether or not the death was expected (*n* = 9/40), were regarded by respondents as affecting whether families used the hospices cooling facilities. Very few respondents regarded the child's age (*n* = 3/40) or diagnosis (*n* = 3) to be associated with usage of cooling facilities. Three respondents volunteered additional factors which, in their experience affected usage. These were geographical proximity to the hospice and size of the family home.

Usage at home

Information on use of cooling facilities at home compared to at the hospice is limited, with just two hospices able to provide a breakdown of usage by place of use. One reported more families used cooling facilities at home than at the hospice (21 vs 13) over the previous 12 month reporting cycle. For the other, use at the hospice was much more likely (4 vs 43). Differences between these hospices in size of catchment area may account for this.

Among the directors of care we interviewed, use cooling facilities at home was regarded as unusual. Their accounts suggest hospices may assume parents want to stay at the hospice and that they are not being routinely informed of the option to take their child home. However, all interviewees acknowledged the importance of supporting families to use cooling facilities at home if they wished.

Approaches to care

Interviewees were asked about use of standardised protocols/care plans when cooling facilities were used. Some described working to a cooling facility-specific care plan covering care of the child's body and family which specified tasks/activities (e.g. memory-making, information provision, issues to raise/discuss with family), timing of specific discussions (e.g. funeral planning) and duration of use. Others described a checklist of activities mainly related to care of the body. Finally, some reported their hospice had not formalised their practice in this way. Residential hospices which offered parents the option to use a cooling facility at home reported maintaining contact (via telephone, and varying rates of frequency) with families but, consistently, a much more responsive approach was taken. Here, any protocols around timing of contacts/visits were presented as being solely for the purpose of care of the body.

Duration of use and responding to deterioration

The majority of residential hospices (*n* = 21/36) reported being entirely flexible regarding the number of days cooling facilities could be used. Where limits on duration of use

Table 2. Policy regarding duration of use of cooling facilities: in hospice versus at home.

	Policy re at home duration		Total
	Some flexibility	Entirely flexible	
Policy re in hospice duration			
Some flexibility	6	6	12
Entirely flexible	1	17	18
Total	7	23	30

were imposed ($n = 15/36$), policies varied between hospices in terms of number of days. Most ($n = 11$) reported they restricted use to a maximum of between 5 and 7 days. Two restricted use to 2 or 3 days, and two reported cooling facilities could be used for 10 days or longer. Whilst we did not ask for more information on this, seven survey respondents wrote that the condition of the child's body played a key role in determining actual duration of use.

Most survey respondents ($n = 21/37$) reported that practice regarding duration of use had not changed. Where changes had occurred there was no consistent trend; 10/16 had reduced duration of use (often informed by other hospices taking this step) and 6/16 increased it. Where interviewees were directors of care in hospices where duration of use had been reduced, some resistance to this from families and, sometimes, staff was reported. When asked about their hospice's rationale for their duration of care policy, interviewees expressed diverse opinions on whether it was advisable for parents to see deterioration of their child's body. This influenced both hospice policy on duration of use, and how deterioration was managed in terms of parent awareness and preparation. Some believed seeing changes in their child's body helped parents come to terms with their child's death and said that it 'gave them permission to say goodbye' (participant 4). Hospices adopting this view encouraged staff to talk openly with parents about deterioration and the changes they could expect to see. These hospices were typically entirely flexible about duration of use of cooling facilities. Others held the opposite view, believing that seeing deterioration was unhelpful. In these instances, interviewees described strategies their service adopted to manage this, such as softening or reducing lighting and having a shorter/stricter policy on duration of use. A further group of interviewees believed that some parents do not experience deterioration as distressing/notice it, and that this delayed the process of acceptance of their child's death and a desire to stay at the hospice for a longer period of time. Imposing a maximum duration of use was used to manage this.

Finally, returning to data from the survey, where hospices also offered cooling facility use at home, any limits imposed on duration of use in the hospice were not, typically, implemented (Table 2).

Access to cooling facilities by families not previously known to hospices

Twenty-four survey respondents (all with residential facilities) accepted referrals for use of their cooling facilities by families previously unknown to them. All accepted such referrals from community and acute NHS services, and the majority (22/24) also accepted referrals from GPs and the police. However, our data (from 21/24 hospices only) suggests this represents a small minority of those using cooling facilities. Thus in 2017, 14/21 survey respondents reporting receiving such a referral, with the total number of referrals being 30. Number of referrals per hospice ranged between one and eight.

Interviewees believed low referral rates were due to a lack of awareness among hospitals and GPs of this provision. Those working in hospices which did not accept this type of referral said this was due to a belief that such families were more likely to have a previously healthy child who had died unexpectedly. They believed these families required a different approach to bereavement support and that their staff were not adequately trained to provide this.

Challenges for staff

Most interviewees reported care staff were expected take on supporting families using cooling facilities, and care of the body, within their role. However, all reported accommodating staff's wishes to be relieved of such duties due to personal circumstances (e.g. bereavement, pregnancy, or a child similar age to their own).

Whilst interviewees typically described end-of-life and after-death care as 'the pinnacle' (participant 4) of the care provided by children's hospices, they acknowledged it raised specific issues, or concerns, for staff. The issue most frequently described was that of deterioration. Managing deterioration (e.g. leakage, odour, disintegration) was described as very challenging and, in the words of one interviewee, 'outside of a nursing remit and blurred boundaries between their role and that of a funeral director' (participant 2). Interviewees also noted the emotional impact on staff. They believed this was accentuated by the fact that staff often knew the child well having cared for them over a number of years. They also described staff wanting to avoid memories of a deteriorated body 'super-seding' their memories of the child when they were alive.

Other challenges for staff reported by interviewees were finding the right way to communicate with and connect to newly bereaved families, with high levels of concern about 'saying the wrong thing' (participant 11). Conversations about deterioration and managing family's expectations around duration of use were identified as difficult. Interviewees also noted that inexperienced staff's unease could affect their ability to interact naturally with parents. This group were also identified as finding parents'

distress particularly hard to witness. Finally, interviewees noted that supporting families previously unknown to the hospice could be challenging. This challenge of providing emotional support when the time frame in which to get to know the family and build rapport was much shorter usual was highlighted.

Perceived benefits of cooling facilities

Interviewees believed the fundamental thing offered by cooling facilities, and most valued by parents, was the child's body did not have to immediately be transferred to a funeral director or remain in a hospital mortuary. They typically described the early days of bereavement as a period of transition and believed cooling facilities eased this period by offering families time to process their child's death and say 'goodbye' (participant 13) to their child. Critical to this was their proximity, and free access, to the deceased child to sit with, speak to, touch, hold or lie with. Interviewees noted that, for some parents, opportunities to do this when their child was alive had been negligible, or severely restricted, due to intravenous medical technologies, or in cases where a baby had not lived long. An additional identified benefit for parents experiencing a perinatal or neonatal death was the cooling facilities provided 'time for them to be a parent' (participant 22) of their child, for example: they were able to take them for a walk in the hospice grounds, bathe, and dress them. Finally, interviewees highlighted the importance of the hospice as a *place* which provided privacy and with *skilled staff* available to provide practical, informational and emotional support.

Discussion

Main findings

This paper reports the first study of cooling facilities provision and practice among UK children's hospices. We found that all but one hospice offered cooling facilities, with the remaining service planning to incorporate them into their provision. There was strong consensus among the directors of care we interviewed on the value and benefit of offering the use of a cooling facility to bereaved families. Not all hospices gave families the choice to use cooling facilities at home, and, where offered, there is evidence that take up of this option is very low. It is not clear if this is due to parental preferences or the way hospices present this option. There was also evidence that hospices perceive their role to be more hands-off when families choose to use cooling facilities at home. In terms of duration of use, opinions on whether or not it was beneficial, or helpful, for parents to observe deterioration was the key driver of hospice policy. Variability in the extent to which care of the child's body and parental support were guided by an in-house protocol was also observed. We did

not however, gather data on the rationale for these different approaches. Nonetheless, there do appear to be some commonalities, particularly an emphasis on offering activities, which support memento-making. Finally, although most hospices accepted referrals of bereaved families not previously known to them, there is evidence that many are not told about the potential opportunity to use cooling facilities by hospital or other staff.

What this study adds

Significant variations in practice regarding duration of use, management of deterioration, acceptance of referrals of families not previously known to the hospice, and provision of cooling facilities for use at home are testament to the way this aspect of UK children's provision is grounded in cumulative experience and personal opinion, as opposed to research evidence. Importantly, with respect to all these issues, we found evidence of concern or uncertainty among those interviewed. These variations in practice and concerns cannot be fully addressed until further research evidence becomes available. The fact that these variations in practice may have implications on parents' experiences and outcomes means such research should be prioritised. Modern theorisations of grief and bereavement describe grief as an active process, comprising a series of tasks³⁵: acceptance of the reality of loss, processing the pain of grief, adjusting to a world without the deceased, and creating a different but enduring connection, or relationship, with the person lost (often supported by physical mementos). Our interviews with directors of care, which align with existing studies of parents' experiences of using hospice cooling facilities,^{17,25} offer an additional perspective on the ways cooling facilities provided by children's hospices may support the very early emotional and cognitive work associated with the grieving process. Within this, directors of care believed the hospice setting (as a private and separate space), and the skilled and holistic support provided by staff, played a key role. This, potentially, raises questions about the use of portable cooling facilities at home; to date there has been no research into this.

In line with previous studies,^{29,30,36} we identified potential challenges to staff. Specifically, care of a deteriorating body,^{29,30} and supporting families to use cooling facilities who were not previously known to the hospice emerged as key concerns. The latter was regarded as particularly salient when the nature of death (i.e. the unexpected death of a previously healthy child, or very occasionally suicide) is different to that typical of a children's hospice. Whilst directors of care consistently identified less experienced staff as likely to find this aspect of their role as particularly challenged, they acknowledged the potential emotional impact on all staff. Our findings highlight the importance of comprehensive support and training to staff (including, for

example, managing deterioration, the impacts of the nature of the death on grief, working with unfamiliar families). Hospices may need to review existing training/support strategies in light of this finding: something other studies have also called for.^{37–39} Any developments in training and support strategies would strongly benefit from being informed by further research with care staff.

Strengths and limitations

The response rate to the survey was good (79%) but data was typically incomplete due to differences in recording practices between children's hospices and level of detail of routine data collection. This has limited the evidence generated and the extent to which findings can be generalised. Whilst half of survey respondents expressed an interest in taking part in a follow-up interview, securing these interviews proved difficult during the study timeline due to staff availability/capacity resulting in thirteen interviews being achieved. Given this, we have to be cautious about conclusions drawn from interview data. Finally, the study only interviewed directors of care, not the staff directly involved with care/support of families.

Conclusion

Cooling facilities are a core element of UK children's hospice provision. The views of directors of care that cooling facilities may support early grieving processes align with existing studies and grief theories. However, cooling facility take-up, access and practices vary between hospices. Further research is required to further understand the ways cooling facilities may affect early grieving processes (including differences of experience), and how hospices' cooling facility-related practices and care may impact on this. The second stage of this research, a multi-site qualitative investigation of bereaved parents' experiences of using cooling facilities, addresses these evidence gaps.

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Author contributions

B.B. proposed the idea for the study and contributed to the design. J.H. carried out the data collection. J.H. and B.B. conducted data analysis. J.H. wrote the first draft of the manuscript and all authors contributed to the writing of the final version.

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