Moving and handling and managing physiological deterioration of deceased children in hospice cool rooms: practice guidelines for care after death

Abstract

Children's hospices provide a range of services for babies, children and young people who have life-shortening conditions, including care after death in specialist 'cool bedrooms'. Caring for children after death is a challenging area of hospice care, with variation seen within, and between organisations. The study aims to identify current practices and to produce guidelines that promote safe practice in moving and handling and managing physiological deterioration of children after death. An electronic questionnaire was sent to all 54 British children's hospices; 33 responded (=62% of hospices). Variation in the way in which children's hospices delivered care after death was identified, in terms of the length of stay, care provision and equipment used, owing to demands of individual families and the experience and confidence of practitioners. Internal variation in practice can lead to practitioner anxiety, and risk-taking when providing care, particularly in the presence of family members. Practice recommendations have been made that reflect the practical demands of caring for a child's body after death; these have been split into two parts: moving and handling considerations and managing physiological deterioration. These recommendations should be used to support the development of policy and practice, allowing organisations to standardise staff expectations and to support practitioners when caring for children after death.

Keywords: *bereavement; care after death; continuing professional development; evidence-based practice; family centred care; hospice; moving and handling; palliative care; practice development; staff support*

Key points:

- Practice in caring for the bodies of children after death, and supporting bereaved families varies significantly between organisations.
- Caring for children after death can be emotionally challenging for practitioners, particularly those with less experience.
- Practitioners involved in caring for children after death should be enabled to move and handle a deceased body, anticipate and manage physiological deterioration and be able to support bereaved families.
- A family-centred approach to care should continue to be adopted when caring for a child after death
- Organisations should develop evidence-based practice guidelines and a programme of education to underpin practice, supported with practice supervision.

Introduction

Children's hospices in the UK provide a range of services for babies, children and young people ('children') who have a life-limiting or life-threatening condition. Care can start from the point of diagnosis or recognition, and extend throughout the child's life, and include short breaks, symptom management and end-of-life care. Care after death in specialist '*cool bedrooms'* as well as emotional and well-being support for bereaved families are important elements of hospice care (Chambers 2019). This paper focuses on caring for the bodies of children in cool bedrooms, particularly moving and handling and managing physiological deterioration of children after death.

Background

Martin House Children's Hospice, a regional children's hospice in the north of England, undertook a review of moving and handling practices when caring for deceased children to inform the development of a care after death policy. Martin House staff were surveyed to identify practitioner challenges within the hospice. A national survey of hospices was conducted to enable the benchmarking of care provision. These have been published separately (Tatterton et al. (2021a) (2021b). The majority of children's hospices who responded to the survey requested that findings were shared through publication, which this paper addresses.

Cool bedrooms have been an integral part of children's hospices since the first children's hospice, Helen House, which opened in 1982. The majority of the UK's 54 children's hospices, as well as similar facilities around the world, offer care after death, where the bodies of children can be cooled, allowing them to stay for an extended period after death (Forrester 2008). The technology used to cool bodies had developed in recent years to include cooling blankets, allowing greater flexibility in the place of care. Despite this, hospices remain the most common location for care after death (Hackett and Beresford 2021).

The emotional challenge of caring for people after death is widely recognised in the literature (Peterson, Johnson et al. 2010, Zheng, Lee et al. 2018, Barnett, Moore et al. 2019). In a related paper (Tatterton et al., 2021a) we identified that a lack of policy and practice convention added to the challenge of caring for deceased children, particularly around anticipating,

recognising and managing physiological deterioration and how to move and handle children after death to enable transfers, practical cares and memory making activities.

Aim

The aims of this study were to:

- identify moving and handling practices when caring for deceased children in hospices around the UK, and
- produce guidelines that promote safe practice in both moving and handling and managing physiological deterioration of deceased children.

Method

An electronic survey was developed to explore the approaches taken by children's hospices in caring for the bodies of deceased children in hospice buildings around the UK. The survey was derived from the questionnaire used to explore practices within Martin House (Tatterton et al., 2021b) by the research team which included a funeral director (DB), moving and handling trainers (AH, NL, JG), staff nurses (LK, JL) and consultant nurse (MT) who are all proficient in handling the bodies of children after death. GoogleForms was used as a platform for data collection, comprising 10 questions. The survey was piloted with four children's hospices around the UK; the feedback informed the final version of the survey.

Participants

54 children's hospices were invited to partake, invited via email from Martin House, and through the eBulletin by Together for Short Lives, a national charity that champions children's palliative care in the UK.

Research ethics

Ethical approval was sought through the Integrated Research Approval System, however was exempt from Research Ethics Committee review, due to involving staff, recruited as research participants by virtue of their professional role. The study was reviewed and supported by the hospice research committee and Strategic Leadership Team.

Participants were informed that completion of the questionnaire was voluntary, and that they could withdraw at any point without rationale (Evans, Robling et al. 2002). Names of organisations were collected; however, these were removed before the questionnaires were analysed. Data was stored electronically on an encrypted drive, complying with GDPR regulations (Summers 2018). Practitioners were not offered any incentive to participate.

Data analysis

Results were collated using Excel. Free text responses were analysing using deductive content analysis, as described by (Elo and Kyngäs 2008). These were used to add depth to the quantitative findings.

Findings

33 organisations responded to the survey, representing 62 percent of British children's hospices. Variations in practice were identified across all aspects of care after death, including the length of time that a child's body can remain in the hospice, location of the cool bedroom in relation to where the child died, care provided and the equipment used to support care, as shown in table 1.

How long can children's bodies remain in the hospice after death?	
Until funeral	2
7 days	13
5 days	17
3 days	1
Does the child stay in the same bedroom or are they moved to a different room after death?	
Same	6
Different	27
Other	0
How are they moved to a different room?	
On bed	30
Carried by family	27
Carried by staff	2
How many times is the child's body checked over a 24-hour period?	
Once per shift	11
2-3	8
3	13
4	1

Table 1: *responses from organisations regarding practices in caring for the bodies of children after death*

Caring for the deceased child's body

Variation was seen in the number of times that a child's body was checked over a 24-hour period and what organisations included in the care performed by staff (table 2). Hospices generally recommended minimal handling, where '*hands off*' visual checks were performed, assessing for '*any visible fluid leaking, sudden unexpected deterioration in appearance including odour.'* Other hospices take a more comprehensive approach, including the rolling of bodies and the checking of cooling equipment. Organisations highlighted the challenge of

knowing exactly what and how to check for deterioration, their drive to meet the needs of the child's family, and the emotional impact of balancing these on hospice staff.

> *'The adrenaline of dealing with a child and their family following death may make what is normally routine tasks seem more intense. For some staff, especially less experienced, the unknown may make things more anxious i.e., what's it like to move a dead body, what will it do?'*

Variation within teams was noted by some hospices, acknowledging the lack of clear guidance to underpin policy and practice. 21 hospices made direct calls for care after death guidelines.

> *'Practice varies with different staff. We don't insist on moving the child although we know that some staff do, to check for leakage. We ask that staff look for general deterioration to help us prepare families if the child needs to be moved to the funeral director/chapel of rest before we would normally do so. We've said for years that a policy would be great so guidance on what to include would be really helpful.'*

24 organisations said they offer no specific training on caring for children after death. For most, understanding was gained at the bedside, by working with experienced members of staff. Variance in care is widely reported in many aspects of children's hospice care, but in relation to care after death, organisations were concerned about the appropriateness of the flexibility offered and how it fits with '*recommended practice*'.

> *'We try to be flexible with families, but sometimes it hard to know where to draw the line. This has made us think about the appropriateness of what we do and how we help our staff think about what is and is not best practice.'*

	Always	Often	Some	Occ	Never
CHECKING for deterioration	30	2	1	0	0
MANAGING deterioration	22	10	1	0	0
Washing (whilst in the bedroom)	8	9	9	7	1
Bathing (outside the bedroom)	0	1	9	11	12
Changing pads and dressings	11	0	11	11	0
Changing clothes	8	16	4	0	0
Memory making activities	27	6	0	0	0
Passing to parents for cuddles	10	19	1	0	3
Transferring into coffin	18	10	0	0	5
Other	7	0	0	0	26

Table 2: physical checks performed to a deceased child's body whilst in a hospice cool room

Moving and handling children after death

Organisations were asked to identify their biggest challenges in moving and handling children after death. These were:

- managing physiological deterioration,
- practical issues of moving and handling adult-sized children,
- supporting staff.
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As illustrated in table 3, most hospices used profiling beds in their cool rooms, allowing the bed height and position to be adjusted as required. The range of moving and handling equipment available for staff to use varied greatly between organisations. Comments from hospices suggested that even when available, the use of equipment varied amongst staff, with little consistency in its use. Organisations acknowledged that a lack of specific guidance made it difficult to develop policy and training, which led to variation in practice between staff. This led to organisations accepting custom and experience as a basis for practice, rather than training:

'Experience is key and some hospices see more deaths than others. Good moving and handling techniques should cross over to care of the dead child, but environments may be different.'

What kind of bed do you use in your cool room?	
Profiling, height-adjustable bed	31
Non-height-adjustable bed	2
What equipment is used?	
Mobile hoist	9
Ceiling track hoist	1
Slide sheets	24
PAT slide	29
Bed sheets	22
None	0
Small child may be carried	11

Table 3: moving and handling equipment used when caring for children after death

Hospices noted how the completion of the survey had made them reflect on their practice, discussing the lack of available guidance, and calling for national guidelines.

'this has really made us think about our practice. We're glad you are hoping to produce guidelines. We would like to know what others are doing and to know if what we are doing is right.'

Discussion

There was great variation in the way in which children's hospices delivered care after death, specifically, the length of stay, care provision and equipment used (Tatterton et al. 2021b). Most approaches were congruent with legal requirements (HM Government 1974, HM Government 1992, Health and Safety Executive 1998, Health and Safety Executive 1998, Health and Safety Executive 2002) and professional guidelines (Smith 2011), Chambers

(2019), although concerns were raised by some that the approach to care was not always consistent. Organisations reported variance owing to demands of individual families and the experience and confidence of practitioners. This correlates with the findings of (Piers, Azoulay et al. 2011) and Tatterton et al., (2021a), suggesting that practice and decision-making is influenced by factors including the level of experience, professional background of the practitioner, and training they have received. Variation was also seen in the way organisations supported staff to deliver care to children after death and to support bereaved families through training, education and ongoing clinical supervision, required to enable practitioners to reflect on, and share their practice openly (Irwin, Bliss et al. 2018, Cerratti, Tomietto et al. 2020).

Practices discussed by hospices were generally safe and congruent with existing professional guidelines (Chambers (2019), Hospice UK (2020)), however examples of care that contradicts best practice, such as the use of bedsheets to move a body up or down a bed were shared. Organisations shared concerns that although they were assured that their practice was safe, it was varied and sometimes unequitable, often left to individual practitioners, with practice based on anecdote and previous experience, without the availability of a specific policy or guidelines on which to base practice, despite such being widely and freely available (Chambers 2019). Organisations reported an association of risk-taking behaviours and practitioner desire to portray or express sorrow and flexibility for bereaved families, keen to demonstrate family centred care (Dennis, Baxter et al. 2017). This correlates with the findings of Tatterton et al. (2021a) (2021b) and (Pike 2004): 204, who recognised '*the stress of the situation means that they are more likely to take risks*, emphasising that practitioner emotion must not prevent safe practice.

Organisations generally accepted the importance of enabling families to touch their deceased child, supporting families to do so with varying degrees of physical support, ranging from lifting a body and placing on a parent's lap, to providing no physical assistance. Organisations reported concern in understanding the parameters of '*normal*' deterioration and supporting staff to recognise when deterioration may indicate that a child's body should be transferred into the care of a funeral director. Calls for guidelines were made about how to allow safe and appropriate handling by family members, without causing damage to, or hastening physiological deterioration of the body.

Recommendations for practice

The following recommendations are based on (Smith 2011), adapted to reflect the practical demands of caring for a child's body after death, the context and convention in children's hospices (Chambers (2019), Hospice UK (2020)), and the current UK legal framework (Health and Safety Executive 2002). The recommendations for practice have been split into two parts: moving and handling considerations, and physiological deterioration.

Moving and handling children after death

Practitioners should be encouraged to use the same principles of good moving and handling that are used when caring for a child before death. This means that skills are practiced, and staff are experienced in the approaches and techniques used. When delivering training, the emotional challenges of caring for children after death should be acknowledged.

The avoid, assess, reduce, review principles of moving and handling (Health and Safety Executive 2002) should be followed, as outlined below:

Avoid

Moving and handling should be avoided as far as reasonably practicable, although it is accepted that it is not possible to remove handling altogether. Hospices should consider caring for the deceased child in the room in which they have died, to avoid bed-bed transfers and moving beds between rooms. Where this is not possible or appropriate, children should be transported to the cool room on the bed in which they died, remaining on the same bed whilst resident in the hospice. Where bathing is required, the body should remain on the bed, rather than being placed in a bath if bathing would be difficult due to the size and physical condition of the child's body.

Depending on the condition of the child's body and any physiological deterioration, families should be encouraged to avoid frequent changes of clothes or cuddles, where it is felt that such actives are hastening deterioration.

Transfers into coffins which pose moving and handling difficulties should be left to funeral directors, exclusive of hospice staff.

Assess

Where avoidance is not possible, we recommend a robust assessment of potential hazards. Individualised, child-specific moving and handing assessments are not required after death, nor should plans written before death be routinely applied, as these reflect different needs. We suggest a routine care plan and risk assessment, which should reflect the specifics of the hospice and services offered. The recommended content is shown in figure1 below.

Task	Equipment required	Number of staff	Method
Transfer into the cool room			
Washing			
Checking for physiological deterioration			
Changing clothes or pads			
Memory making activities			
Enabling family touch			

Figure 1: recommended content of moving and handing after death risk assessment

Reduce

The completed risk assessment should be followed to reduce risk of injury to the lowest reasonably practicable level. This can be achieved though the provision of consistent training and supervision of staff, and by provision and use of appropriate equipment.

Review

The completed risk assessment should be reviewed as required, taking into account the physiological changes to the body and how this can affect handling.

Moving and handling equipment

We recommend that hospices have the equipment in figure 2 available to assist moving and handling of deceased bodies. A height-adjustable bed with castors, with access around both sides is essential to enable good moving and handling practices (Smith 2011). The bed does not need to be profiling, although this can be useful in assisting with positioning to enable cares and to manage deterioration.

Height-adjustable bed Slide sheets PAT slide with straps for any lateral transfers

Figure 2: suggested cool room equipment for moving and handling

The use of a hoist with children after death remains contentious. We do not recommend or discourage using hoists to move bodies but suggest that individual hospices take a standardised position on hoist use within their organisation, which is supported by clear standard operating procedures, underpinned with appropriate policy and supported by robust training and risk assessment.

Where care after death is offered in cold bedrooms, clothing should be available for staff who may be in the cold room for some time to prevent increasing the risk of musculoskeletal injury. This should be long sleeved and not restrict movement.

Anticipating, recognising and managing physiological deterioration

The emotional and physical challenges of physiological deterioration after death are frequently discussed by hospice practitioners. In addition to the recommendations below, it is advised that organisations establish relationships with a funeral director who can provide general advice to the hospice before a funeral director is chosen by the family. Practice decisions should always be based on the condition of the child's body and needs of the family. Practitioners must be able to explain practices and care decisions to families, to help them prepare for, and understand care provided after death.

We recommend that to slow deterioration, cooling is started as soon as possible after death, to between around 3 – 5°c. As a minimum, bodies should be checked once a day, and their condition recorded. Usually a visual assessment is sufficient, where the exposed skin, including face, hands and abdomen are checked without rolling or undressing, as this can mark the child and disturb fluids and gases, resulting in a smell or fluid leakage. A more comprehensive check may be indicated for children who are still being cuddled/moved after death, due to the increased risk of deterioration. Where deterioration is observed, the frequency of checks should be increased, and a funeral director informed of any concerns.

We recommend that hospices have the equipment in figure 3 available to assist in the management of physiological deterioration.

Absorbent dressings
Bin bags
Black/dark towels
Cotton wool
Diffuser/air freshener
Disposable incontinence sheet
Dry, disposable wipes
Emollient (such as petroleum jelly)

Gloves and aprons
Incontinence pads/nappies
Paper towels
Scissors
Tape measure

Figure 3: suggested cool room equipment to manage deterioration

Physiological deterioration after death is to be expected, however steps can be taken to slow deterioration, as shown in figure 4. The condition and treatment the child received before death, their age, length of time and the location of care after death will affect their deterioration. Although some deterioration can be managed my hospice practitioner (figure 5), we recommend liaising with a funeral director. We suggest that funeral directors manage the issues highlighted in figure 6, although it is possible for the child's body to remain in the hospice.

We advise that the changes in figure 7 suggest that it is no longer therapeutically beneficial for a child's body to remain in a hospice cool room, although these decisions remain with individual organisations.

- Ensure the body is cooled, using air conditioning or a cooling blanket/mattress, as soon as possible after death
- Apply an emollient, such as petroleum jelly, to the lips and the corner of the eye towards the nose
- Keep the child out of direct sunlight
- Use a dry, disposable wipe to cover the eyes, mouth and nose when the child's family are not present.

Figure 4: measures to slow physiological deterioration

Sign	Management
Dry lips and eyes	Emollients, such as petroleum jelly, can be used to keep the skin hydrated, full and supple
Subtle odour	Scented oils can be used to mask subtle smells. Fragrances or colognes can be discussed with and chosen by families, as appropriate.
Small blisters	Depending on the size and location of the blister, they can be carefully lanced, drained of fluid and dressed with cling film to reduce the possibility of skin slip. Where necessary, a funeral director should be consulted.
Open mouth	A rolled-up towel or scarf can be placed under the chin to close the mouth, whilst free from visitors. Sometimes this is sufficient to keep the mouth closed. Where the mouth will not stay closed, and this is causing distress, a funeral director should be consulted.
Leaking from wounds	Leaking from wounds or skin can be managed using dressing, changed as required. Standard, absorbent dressings can be used.
Leaking from orifices	Low level leakage may be addressed with positioning and occasional gentle suctioning (oral or nasal), or pad changes. For persistent, excessive, or distressing leaking from orifices can be rectified using absorbent granules. You may need to consult a funeral director.

Figure 5: deterioration that may be managed by hospice practitioners

Sunken eyes
Open eyes
Persistent open mouth (if causing family distress)
Persistent leakage from the mouth and nose
Anything causing staff distress

Figure 6: deterioration that requires assistance from a funeral director

Excessive leaking from the mouth or nose (‘*purging*’)
Offensive smell
Skin breakdown

Figure 7: deterioration that suggests transfer to the care of a funeral director

Training

Hospice practitioners who are involved in the care of children after death should receive training that includes moving and handling children after death, included in induction and refresher training. We recommend that new or inexperienced practitioners work alongside more experienced colleagues, due to the possible emotional nature of caring for children after death (Raymond, Lee et al. 2017, Meller, Parker et al. 2019, Lin and Fan 2020), discussed in Tatterton et al. (2021a) (2021b). Training should include specific transfer techniques, depending on the services offered by the hospice, such as placing a child's body in a coffin.

Training should provide practitioner with an awareness of physiological changes that occur after death. This should include rigor mortis, the leakage of fluids and gases and skin breakdown, and may include discussions around embalming. Practitioners should be aware of the importance of cooling and positioning, preserving skin integrity and the relevance of general moving and handling principles such as adjusting the bed to a good working height and avoiding static postures when involved in care at the bedside, such as memory making or enabling touch with families. Practitioners should be made aware that when moved, air can be expelled from the lungs of the body, which can result in noises being heard from the child's mouth.

Training should acknowledge the emotional and psychological toll of moving and handling after death. Practitioners should be encouraged to take time to plan how they will meet the physical demands of children after death and to consider the emotional impact of this, which may include supporting bereaved families. The emotional challenges of caring for children after death should be acknowledged in training provision, as this can affect the decisions

made by practitioners. The challenges may arise due to staff being uncomfortable around bodies of deceased children, witnessing the physiological deterioration of a child's body, or witnessing the acute grief of the bereaved family (Tatterton et al. 2021a).

Families who request to be present for moving and handling tasks should be supported to do so, however organisations should be aware that their presence can place avoidable stress on practitioners. This can result in practitioners overcompensating and taking risks to express their sadness for the bereaved family. The standardisation of practice, supported by clear policy, education and clinical supervision can reduce practice variance, and help practitioners to respond and express their empathy for bereaved individuals more safely and appropriately.

Recommendations for policy

The findings of this study suggest that evidence-based policy and training influence decisions and behaviour of practitioners caring for children after death and highlights the challenges that this specialist area of care create. Practitioners should be provided with robust practice guidelines and a programme of education that underpins practice and supported with clinical/practice supervision, illustrated in figure 8. The recommendations for practice in this paper should be considered alongside the context of, and services offered by the hospice service.

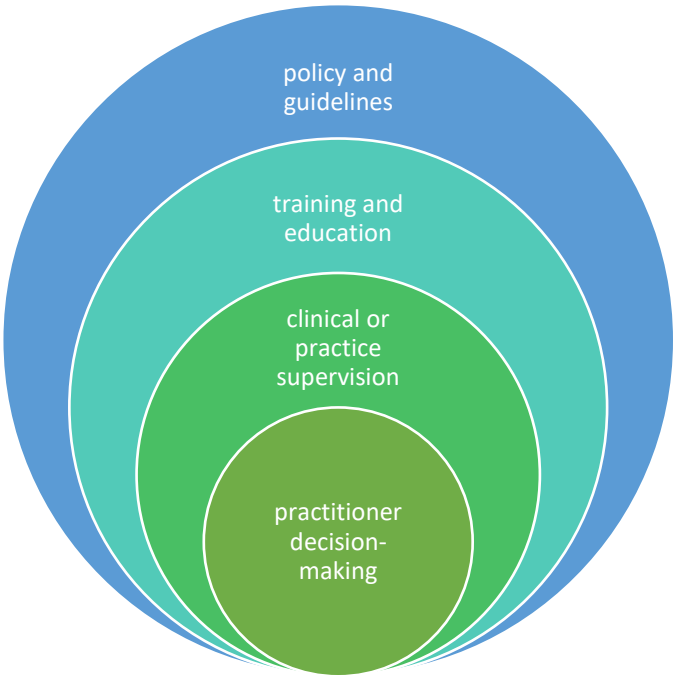

Figure 8: the influence of policy, training and supervision on practice

Strengths and limitations

This study has provided novel insight into contemporary practice of caring for babies, children and young people after death in British children's hospices, particularly on moving and handing and managing physiological deterioration of bodies. The practice guidelines have been developed collaboratively by hospice practitioners, moving and handling trainers and a funeral director, taking into account the context of hospice care and current guidance on moving and handling and *postmortem* practice.

Despite these strengths, there are a number of limitations in this research report that should be considered. Although 63% of children's hospices responded to the survey, the variation in terms of geographies and populations served may mean that the findings are not representative of all hospices. Those completing the survey on behalf of hospices were predominantly service managers, not practitioners delivering care. Finally, a one size fits all

approach cannot be applied across children's hospices, due to the variation in the ways hospices arrange and provide care. We hope that the recommendations made have been done so with sufficient rationale and transparency to enable hospice services to interpret findings and apply to their individual services.

Conclusion

Caring for children after death is a challenging area of hospice care, with variation seen both between, and within organisations. Internal variation in practice can lead to staff experiencing higher levels of stress and anxiety, and taking greater risks when providing care, particularly in the presence of family members. The use of an evidence-based policy and education framework can allow organisations to standardise the expectations and measures of competence of practitioners. This can reduce the experience of anxiety and risk-taking practices and increase practitioner confidence around decision making that relates to moving and handling and managing the physiological deterioration of the bodies of children after death.

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