Why you should read this article:

- To increase your knowledge of the principles of moving and handling the body of a deceased child
- To enhance your decision-making about the practical aspects of the care of children after death
- To consider the development of policies and training to standardise care after death in children's hospices

Care after death in children's hospices: recommendations for moving and handling, and for managing physiological deterioration

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Abstract

Background Children's hospices provide a range of services for babies, children and young people who have a life-limiting or life-threatening condition, including care after death in specialist 'cool bedrooms'. Care after death is a challenging but important element of hospice care.

Aim The aims of the study were to identify the practices of staff providing care after death in UK children's hospices, notably their moving and handling practices and their management of physiological deterioration, and to produce recommendations that promote safe and consistent practice in moving and handling and in managing physiological deterioration after death in UK children's hospices.

Method An electronic survey was sent to all 54 UK children's hospices. Free-text responses were analysed using deductive content analysis and used to add depth to the quantitative findings.

Findings Out of 54 children's hospices, 33 responded to the survey. There were great variations in the way hospices delivered care after death, notably in length of stay, interventions and equipment. The lack of consistent practice grounded in evidence-based policy and training may mean that some staff experience higher levels of stress and anxiety than others and that some staff take risks when providing care after death, particularly to express empathy towards bereaved families.

Conclusion Recommendations are made about moving and handling a child's body after death and managing its physiological deterioration. Hospices can use these recommendations to develop policy and training, standardise what is expected of staff and support practitioners in adequately caring for children after death.

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Keywords

bereavement, child health, clinical, death, end of life care, families, grief, hospices, manual handling, nursing care, palliative care, patients, professional, professional issues, terminal care

Introduction

Children's hospices in the UK provide a range of services for babies, children and young people – in this article grouped as 'children' – who have a life-limiting or life-threatening condition. Care can start from diagnosis, continue throughout the child's life and include short breaks, symptom management and end of life care. Practical care of the child's body after death in specialist 'cool bedrooms' and support for bereaved families are important elements of the services provided by children's hospices (Chambers 2019). This article is based on a survey that obtained responses from 33 UK children's hospices about practices involving care after death. It describes variations in practice and makes recommendations for moving and handling and for managing physiological deterioration when providing care after death in children's hospices.

In 2019, Martin House Children's Hospice, a regional hospice in the north of England, undertook a review of the moving and handling practices of its staff when caring for deceased children to inform the development of an internal policy on care after death. This was followed by a survey of UK children's hospices to explore hospice practitioners' perspectives on caring for a child's body after death and on supporting bereaved families. Extensive findings have been described and discussed elsewhere (Tatterton et al 2021a, 2021b). Most hospices that responded to the survey called for specific guidance on care after death.

Cool bedrooms have been an integral part of children's hospices since the first children's hospice in the UK, Helen House, opened in 1982. Most of the UK's 54 children's hospices, and similar organisations in other countries, offer care after death that generally involves cooling the body and allowing it to remain at the hospice for a period of time (Forrester 2008). This enables families to spend time with their child's body after death, say goodbye and participate in memory-making activities such as making prints or casts of the hands and feet and taking photographs (Tatterton et al 2021a).

The technology used to cool bodies has developed in recent years to include cooling blankets. Before these were available, specialised air conditioning systems were needed to cool bodies. Cooling blankets allow greater flexibility in the place of care after death. However, when families receive care after death from a children's hospice, hospice cool rooms remain the most common location of care (Hackett and Beresford 2021).

The emotional challenges of caring for people after death are widely recognised in the literature (Peterson et al 2010, Zheng et al 2018, Barnett et al 2019). Tatterton et al (2021a) identified that a lack of specific policy and guidance on care after death compounded the challenges of caring for deceased children in children's hospices, particularly with regard to moving and handling, practical care, memory-making activities and how to manage physiological deterioration.

Aim

The aims of the study were to:

- Identify the practices of staff providing care after death in UK children's hospices, notably their moving and handling practices and their management of physiological deterioration.
- Produce recommendations that promote safe and consistent practice in moving and handling and in managing physiological deterioration after death in UK children's hospices.

Method

Survey

An electronic survey was developed by the research team to explore care after death practices by staff in children's hospices in the UK. The survey was adapted from the questionnaire that had been used to explore staff's practices at Martin House (Tatterton et al 2021b). The research team included a funeral director (DB), moving and handling trainers (AH, NL, JG), staff nurses (LK, JL) and a nurse consultant (MT), all of whom are proficient in the moving and handling of the bodies of deceased children. The survey was piloted with staff from four children's hospices, whose feedback informed the final version. The survey comprised ten questions. More information can be found in Tatterton et al (2021a, 2021b).

Participants

All 54 UK children's hospices were invited to take part in the survey by an email from Martin House and through the e-bulletin of Together for Short Lives, a charity that champions children's palliative care in the UK.

Ethical considerations

Ethical approval was sought through the Integrated Research Application System of the Health Research Authority. The study was found to be exempt from review by a research ethics committee because it involved staff recruited to the study by virtue of their

professional role, as opposed to patients. The study was reviewed and supported by Martin House's research committee and strategic leadership team.

Potential participants were informed that completion of the questionnaire was voluntary and that returning it would signify consent to participate (Evans et al 2002). Practitioners were offered no incentive to participate. Names of organisations were collected but removed before the questionnaires were analysed. Data were stored electronically on an encrypted computer drive, complying with the General Data Protection Regulation (GDPR) (The National Archive 2021).

Data analysis

Quantitative results were collated using a spreadsheet application. Free-text responses were analysed using deductive content analysis, as described by Elo and Kyngäs (2008), and used to add depth to the quantitative findings.

Findings

Of the 54 hospices, 33 responded to the survey, representing 61% of UK children's hospices. The quotes reproduced below are extracted from participants' free-text responses.

Hospices were asked to identify the biggest challenges in care after death. These were:

- Practical issues of moving and handling adult-sized children.
- Managing physiological deterioration.
- Supporting staff with the emotional challenges of addressing the needs of bereaved families.

Practices in care after death

Variations in practice were identified in all aspects of care after death, including the length of time that a child's body could remain at the hospice, the location of the cool bedroom in relation to where the child had died and the number of times a child's body was checked over a 24-hour period (Table 1).

Type and frequency of interventions

Variations in practice were seen in the type and frequency of interventions included in care after death (Table 2).

In terms of checking for deterioration, hospices generally recommended minimal handling and hands-off visual checks to assess for any visible fluid leakage and sudden unexpected deterioration in appearance including odour. Some hospices took a more comprehensive approach that included rolling the child's body so that incontinence pads and less accessible parts of the body such as the back could be checked more thoroughly. Hospices highlighted the challenges of knowing exactly what and how to check for physiological deterioration and of balancing the need to conduct practical interventions against their emotional effects on staff while also addressing the needs of the family. One hospice commented:

'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, for example, what's it like to move a dead body, what will it do?'

The physical assistance offered to families to enable them to touch their deceased child's body varied, ranging from lifting the body and placing it on the parent's lap to no assistance.

Moving and handling equipment

The range of moving and handling equipment varied greatly between hospices (Box 1). Most hospices used profiling beds, which can be adjusted for height and position. Comments suggested that even when certain types of equipment were available their use varied between staff. In 11 (33%) of hospices, small children could be physically lifted and carried by staff without equipment.

Variations in practice and lack of specific guidance

Twenty-four (73%) of the hospices said they offered no specific training to staff on care after death. Most staff would gain knowledge at the bedside working alongside more experienced members of the team. Hospices said that the lack of specific guidance on care of children after death made it difficult to develop policy and training, which created variations in practice between staff. This led to them accepting experience rather than formal training as a basis for practice.

'Experience is key. Good moving and handling techniques should cross over to care of the dead child, but environments may be different.'

Respondents were concerned about the variations in practice and how they fitted with best practice in care after death.

'We try to be flexible with families, but sometimes it is 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.'

Hospices said completing the survey had made them reflect on their practice and acknowledge the lack of specific guidance

and the need to share good practice. Twenty-one (64%) of the hospices called for specific guidance on the care of children after death.

'This has really made us think about our practice. We would like to know what others are doing and to know if what we are doing is right.'

'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.'

Discussion

There were great variations in the way the 33 children's hospices delivered care after death, notably in the length of stay, interventions provided and equipment used (Tatterton et al 2021b). Most approaches were congruent with legal requirements (Health and Safety at Work etc. Act 1974, Manual Handling Operations Regulations 1992, Health and Safety Executive 1998a, 1998b, 2002) and with professional guidelines (Smith 2011, Chambers 2019, Wilson et al 2020).

Some hospices expressed concern that the approach to care after death was not always consistent, reporting variations in practice due to the requests of individual families and the level of experience and confidence of staff. This correlates with the findings of Piers et al (2011) and Tatterton et al (2021a), which suggest that practice is influenced by factors including staff's experience, professional background and training. Variations were also seen in how staff were supported, for example through training and/or clinical supervision, to provide care after death and support bereaved families.

In general, care was safe and professional guidelines were adhered to, but there were some examples of care that contradicted best practice, such as the use of bedsheets to move a body up or down a bed (Tatterton et al 2021b). Hospices expressed concern that, although they believed their practice was safe, they were also aware that it varied, was often left to individual practitioners and could potentially be inequitable. They were also aware that their practice was based on informally gained experience and knowledge rather than on formal training and guidance. The existing guidance lacks detail about the practical aspects of care after death, notably in terms of moving and handling and of managing physiological deterioration.

Table 1. Practices in care after death in 33 UK children's hospices

		n	%
How long can a child's body remain at the hospice after death?	Until the funeral	2	6
	For 7 days	13	39
	For 5 days	17	52
	For 3 days	1	3
Does the child stay in the same room or are they moved to a different room after death?	Stays in the same room	6	18
	Is moved to a different room	27	82
How is the child's body moved to a different room?*	On a bed	27	82
	Carried by family	19	58
	Carried by staff	2	6
How many times is the child's body checked over a 24-hour period?	2-3 times	19	58
	3 times	13	39
	4 times	1	3

* Many hospices allow different methods of moving a child's body to a different room and offer some choice to the family. As a consequence the figures in this row add up to more than 33 and the percentages add up to more than 100%

Table 2. Type and frequency of interventions included in care after death in 33 UK children's hospices

	Always	Often	Sometimes	Occasionally	Never
Checking for deterioration	30	2	1	0	0
Managing deterioration	22	10	1	0	0
Washing (in the cool bedroom)	8	9	8	7	1
Bathing (outside the cool bedroom)	0	1	9	11	12
Changing pads and dressings	11	0	11	11	0
Changing clothes	8	16	4	0	5
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

*Including removing feeding tubes and moving the child's body to enable parents to lie with them on the bed

Box 1. Moving and handling equipment used for care after death in 33 UK children's hospices

- Profiling, height-adjustable bed: 31 (94%)
- Patslide transfer board: 29 (88%)
- Slide sheets: 24 (73%)
- Bed sheets: 22 (67%)
- Mobile hoist: 9 (27%)
- Non-height-adjustable bed: 2 (6%)
- Ceiling track hoist: 1 (3%)
- None: 0 (0%)

Implications for practice

- Care after death practices vary significantly between children's hospices in the UK
- Caring for children after death can be emotionally challenging for hospice practitioners, particularly those with little experience
- Practical care for children after death includes moving and handling the body and managing physiological deterioration
- Children's hospices need an evidence-based policy and education framework to underpin care after death

Hospices reported some risk-taking behaviours on the part of staff in relation to moving and handling, such as maintaining prolonged static postures and not using equipment, often due to staff's eagerness to express empathy towards families, demonstrate flexibility and provide family-centred care (Dennis et al 2017). This correlates with the findings of Pike (2004), who wrote that 'the stress of the situation means that [staff] are more likely to take risks'. Tatterton et al (2021a, 2021b) highlighted that staff's emotions must not prevent safe practice.

Hospices generally recognised the importance of enabling families to touch their deceased child's body, but the physical assistance offered to them was variable. Hospices called for guidance on how to enable families to handle their child's body without risking damaging it or hastening deterioration. They also reported challenges in understanding what constitutes 'normal' physiological deterioration and in supporting staff to recognise when deterioration may indicate that they need to involve a funeral director.

Strengths and limitations

This study provides new insight into care after death practices in UK children's hospices, particularly moving and handling and managing physiological deterioration. The recommendations were developed collaboratively by hospice practitioners, moving and handling trainers and a funeral director, taking into account the context of hospice care, existing guidance and the legal framework.

There are several limitations. Although 63% of UK children's hospices responded to the survey, variations in location and population served may mean that the findings are not representative. The people who completed the survey were predominantly service managers, not practitioners directly involved in delivering care after death.

There is no one-size-fits-all approach to care after death in children's hospices because of the differences in the way hospices arrange and provide care. The authors hope that their recommendations have been made with sufficient explanation, transparency and precaution to enable each hospice to discern how to apply them.

Recommendations for practice

The recommendations for practice in this article are based on Smith (2011) and have been adapted to the practical demands of care after death in children's hospices (Chambers 2019, Wilson et al 2020) and to the UK legal framework (Health and Safety Executive 2002). They should be considered in the context of individual hospices and the services they offer.

The recommendations are divided into two parts:

- Moving and handling children after death.
- Anticipating, recognising and managing physiological deterioration.

Moving and handling children after death

After a child's death, hospice practitioners should be encouraged to apply the same moving and handling principles they use when caring for a child before death. Optimal moving and handling can be achieved by providing staff with appropriate training, opportunities to gain experience in moving and handling approaches and techniques, supervision and equipment.

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

- Avoid:
  - Moving and handling should be avoided as far as reasonably feasible, although it is not possible to avoid it altogether.
  - Hospices should consider caring for the deceased child in the room in which they have died to avoid transfer between beds and/or rooms. When this is not possible or appropriate the child should be moved to the cool bedroom on the bed in which they have died.
  - When bathing is required but is challenging because of the size and physical condition of the body, the body should remain on the bed and be washed in the cool bedroom rather than being moved to a bathroom.
  - Depending on the body's condition, families should be encouraged to avoid frequent cuddles and/or changes of clothes if these would be likely to hasten deterioration.
  - Transfers into a coffin which present moving and handling challenges should not involve hospice practitioners but should be left to funeral directors.
- Assess – When moving and handling cannot be avoided a robust risk assessment should be undertaken based on the body's condition and level of deterioration. A risk assessment plan should reflect the services offered at the hospice and does not need to be written individually for each child. Risk assessment plans developed before death should not be routinely applied, since they will address different needs. Table 3 shows an example of a routine risk assessment plan ready to be completed.

» Reduce – The risk assessment plan should be followed to reduce the risk of damage and/or deterioration as much as reasonably feasible.
» Review – The completed risk assessment should be reviewed as required, taking into account any physiological changes of the body.

A height-adjustable bed with castors which can be moved to allow access from either side is essential for optimal moving and handling (Smith 2011). It does not need to be a profiling bed, although this can assist with positioning the body to enable care and manage deterioration.

The use of a hoist to move a child's body after death varies and is contentious (Tatterton et al 2021b), practitioners often being left to decide whether or not it is appropriate. The researchers neither recommend nor discourage the use of hoists but suggest that hospices adopt a consistent position on their use supported by clear standard operating procedures, appropriate policy and training, and robust risk assessment.

Box 2 lists the equipment hospices should have available to assist in moving and handling a child after death. Non-restrictive long-sleeved clothing should be available for hospice practitioners, who may be in the cool bedroom for some time, to avoid increasing the risk of musculoskeletal injury.

Anticipating, recognising and managing physiological deterioration

Physiological deterioration after death is to be expected and will be influenced by the child's condition and treatment before death, their age, the length of time the body remains at the hospice and the location of care after death. Physiological deterioration can be slowed by implementing the measures listed in Box 3.

Children's bodies should be positioned on their back with their arms and legs straight if possible and a single pillow can be used under the head. Fixed deformities, such as severe scoliosis or hip and knee flection caused by cerebral palsy, should not be corrected and it may be appropriate in such instances to position the body on its side and use additional pillows for support. If the family's religious, cultural or spiritual beliefs entail practical aspects – for example, how the child's head should be positioned – these should be acknowledged and accommodated (Chambers 2019).

Bodies should be checked and their condition recorded at least once a day. A visual assessment is usually sufficient, whereby exposed skin – such as the face and hands – and the skin of the abdomen are checked without rolling or undressing the body, to avoid marking the skin through contact blanching (Payne-James and Byard 2015) and/or disturbing fluids and gases. A more comprehensive assessment – involving rolling and undressing the child's body to check incontinence pads and skin that would not be visible otherwise – may be indicated for deceased children who are still being cuddled and/or moved due to the increased risk of physiological deterioration. When deterioration is observed the frequency of checks should be increased and concerns should be discussed with a funeral director. Box 4 lists the equipment hospices should

Table 3. Example of routine risk assessment plan for moving and handling a child after death

Intervention	Equipment required	Number of staff required	Method
Transferring to the cool bedroom			
Washing or bathing			
Checking for physiological deterioration			
Changing clothes or incontinence pads			
Memory-making activities			
Enabling family to touch the body			

Box 2. Recommended cool bedroom equipment for moving and handling a child after death

» Height-adjustable bed with castors
» Slide sheets
» Patslide transfer board with straps for lateral transfers

Box 3. Recommended measures to slow the physiological deterioration of a child's body after death

» Start cooling the body to between 3°C and 5°C using air conditioning or a cooling blanket and/or mattress as soon as possible after death
» Keep the body out of direct sunlight
» Apply an emollient, such as petroleum jelly, to the lips and to the corner of the eyes towards the nose
» When no visitors are present, cover the eyes, mouth and nose with a dry disposable wipe

Box 4. Recommended cool bedroom equipment to assist in managing physiological deterioration

» Absorbent dressings
» Bin bags
» Black or dark towels
» Cotton wool
» Fragrance diffuser and/or air freshener
» Disposable incontinence sheets
» Dry disposable wipes
» Emollients such as petroleum jelly
» Gloves and aprons
» Incontinence pads and/or nappies
» Paper towels
» Scissors
» Tape measure

have available to assist in managing physiological deterioration.

Hospice practitioners should be able to recognise the signs of physiological deterioration and decide whether they need to involve a funeral director. It is important that they can differentiate between:

- Signs of deterioration that they can manage themselves, although liaising with a funeral director is advisable. These signs of deterioration and their management are described in Table 4.
- Signs of deterioration that indicate the need to involve a funeral director. These signs of deterioration are listed in Box 5. In some cases the child's body can remain at the hospice. In others it is no longer beneficial therapeutically to the family for their child's body to remain at the hospice and the body needs to be transferred to the care of a funeral director.

Ultimately decisions are the prerogative of the hospice concerned.

Table 4. Signs of physiological deterioration that can be managed by hospice practitioners

Sign	Management
Dry lips and eyes	An emollient, such as petroleum jelly, can be used to keep the skin hydrated, full and supple
Subtle smell	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 location and exact size, small blisters can be carefully lanced, drained of fluid and dressed with cling film to reduce the possibility of skin slip. If necessary, a funeral director can be consulted
Open mouth	A rolled-up towel or scarf can be placed under the chin to close the mouth while no visitors are present. If this is not sufficient to keep the mouth closed and the open mouth causes distress to visitors, a funeral director should be consulted
Leakage from wounds or skin	Leakage from wounds or skin can be managed using standard absorbent dressings, changed as needed
Leakage from orifices	Low-level leakage from orifices can be managed by positioning, pad changes or occasional gentle suctioning of the mouth and/or nose. Persistent, excessive or distressing leakage from orifices can be managed using absorbent granules. A funeral director may need to be consulted

Box 5. Signs of physiological deterioration that indicate the need to involve a funeral director

Signs of deterioration that indicate the need for assistance from a funeral director, although the child's body can remain at the hospice:

- Sunken eyes
- Open eyes
- Persistent open mouth causing distress to the family
- Persistent leakage from the mouth and nose
- Anything causing distress to staff

Signs of deterioration that indicate the need to transfer the child's body to the care of a funeral director:

- Excessive leakage from the mouth or nose ('purging')
- Offensive smell
- Skin breakdown

Hospice practitioners often highlight practical and physical challenges of managing physiological deterioration after death (Tatterton et al 2021a, 2021b). It is advisable that they establish a relationship with a funeral director who can provide advice before the family chooses a funeral director. Decisions about how to manage physiological deterioration should always be based on the condition of the child's body and the needs of the family. Practitioners should be able to explain practice and decisions to families to assist them to prepare for care after death.

Recommendations for policy and training

The findings of this study highlight the challenges faced by hospice practitioners caring for children after death and suggest that policy and training influence the decisions and behaviours of practitioners in this specialist area of care. Practitioners should be provided with clear practice guidelines, undergo training designed to underpin practice and receive regular clinical supervision.

Hospice practitioners involved in the care of children after death should receive training, including induction and refresher training, that covers moving and handling. This should include moving and handling techniques specific to the services offered by the hospice – for example, placing the child's body in a coffin. New or inexperienced practitioners should work alongside more experienced colleagues, notably because of the emotional effects of caring for children after death (Raymond et al 2017, Meller et al 2019, Lin and Fan 2020). This is discussed further in Tatterton et al (2021a, 2021b).

Training should include an explanation of the physiological changes that occur after death – such as rigor mortis, skin breakdown and leakage of fluids and gases – and may include embalming. It should stress the importance of cooling the body, positioning the body and preserving skin integrity, as well as the relevance of general moving and handling principles, such as adjusting the bed to an optimal working height and avoiding prolonged static postures. Practitioners should be made aware that when the body of a deceased child is moved air may be expelled from the lungs, which may result in sounds coming from the child's mouth.

Training should acknowledge the emotional challenges of caring for children after death. Practitioners should be encouraged to think about how they will meet the practical

demands of care after death and how this may affect them emotionally, in addition to how to support bereaved families. Staff may feel uncomfortable being around the body of a deceased child, witnessing the physiological deterioration of the body and/or witnessing families' grief (Tatterton et al 2021a).

Families who ask to be present when care is provided after death should be supported to do so. However, hospices should be aware that the presence of family members can place additional stress on practitioners and lead them to overcompensate and take risks in relation to moving and handling the child's body in order to express empathy. Standardising practice and supporting it through policy, training and supervision can assist practitioners to express empathy safely, consistently and appropriately.

Conclusion

Caring for children after death is a challenging area of hospice care and there are variations in practice between and in children's hospices in the UK. The lack of consistent practice grounded in evidence-based policy and training may mean that some staff experience higher levels of stress and anxiety than others and that some staff take risks when providing care after death, particularly to express empathy towards bereaved families. Developing an evidence-based policy and education framework can help hospices to standardise what is expected of staff. This, in turn, can reduce anxiety and risk-taking practices and increase practitioners' confidence to make decisions about moving and handling and managing the physiological deterioration of the bodies of children after death.

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