

Moving and handling children after death: an inductive thematic analysis of the factors that influence decision-making by children's hospice staff**Abstract:**

Hospices for children and adolescents in the United Kingdom provide care to the bodies of deceased children, in specially-designed chilled bedrooms called 'cool rooms'. In an effort to develop resources to support hospice practitioners to provide this specialist area of care, the study aimed to identify the factors that influence decision-making when moving and handling children's bodies after death in a hospice cool bedroom. An internet-based survey was sent to all practitioners employed by one children's hospice. A total of 94.9% of eligible staff responded (n=56). An inductive approach to thematic analysis was undertaken, using a six-phase methodological framework. Three core themes were identified that inform practitioners' perception of appropriateness of moving and handling decisions: care of the body, stages of care, and method of handling. The complexity of decision-making and variation in practice was identified. Practitioners relied on both analytical and initiative decision-making, with more experienced practitioners using an intuitive approach. Evidence-based policy and training influence the perception of appropriateness, and the decisions and behavior of practitioners. The development of a policy and education framework would support practitioners in caring for children's bodies after death, standardizing expectations, and measures of competence in relation to moving and handling tasks.

Keywords:

death; evidence-based practice; family centred care; moving and lifting patients; nursing; palliative care; pediatric; professional education

In 2018 alone, more than 4,600 babies, children and adolescents (children) died in the United Kingdom (UK) between the ages of birth and 18¹. Although not all deaths were the result of a

life limiting or life-threatening condition¹ many of these children will have used, or been eligible to use, the services of children's hospices after their death.² There are more than 86,000 children living with life limiting and life threatening conditions in the UK³ many of which can be supported by the 54 children's hospices around the country. Children's hospices provide a range of care services for children with palliative care needs. All children's hospices are charitable organisations; services non-means tested and provided for free to all families. Children's palliative care is defined as '*an active and total approach to care*'^{4(p.9)} and includes care offered to families of children before, during and after the death of a child. This paper focuses on care provided to deceased children in children's hospices '*cool rooms*'. Cool rooms are specially designed bedrooms within children's hospices that allow the bodies of children to be cared for after death, due to cooling facilities in the room. Parents and family members can visit and spend time with a child's body, which is laid in a bed, rather than in a coffin or trolley, as may be the case when using more traditional services, such as a funeral director or morgue. Whilst in a cool room, parents often hold and touch their child's body, as well as creating memories or artefacts, such as handprints and photography. The care offered by children's hospices are in addition to those of funeral directors.

In the UK, there are no legal restrictions on where a body can lay between death and the funeral. The length of time a body can remain in a hospice varies throughout the UK, from a few hours, right up until the child's funeral which can be three weeks after death. At Martin House, children's bodies can stay for five days after death, before being transferred into the care of a funeral director.

While preparing a care after death policy, focusing on caring for bodies and supporting bereaved families after the death of a child from a palliative condition, it became apparent that there was no contemporary published evidence focusing on this area of children's hospice care.

To inform policy and practice, a survey was designed to explore the experiences of staff involved in the moving and handling of children after death. In addition to exploring moving and handling of children's bodies, we wanted to identify the sources of emotional challenge for practitioners delivering family centred care after the death of child, published separately⁵. The findings, together with those of this study, have led to the production of clinical guidelines relating to the care of children after death.⁶

Decision-making

Decision-making is an essential element of the clinical practice of nurses⁷ and allied health professionals.⁸ It is widely acknowledged that decision-making requires consideration and evaluation of many complex and often competing factors. In nursing, research has predominantly focused on elements of decision-making considered important to nursing practice, including knowledge of the patient, reflection, experience and intuition and context. Similar findings have been reported in research focusing on decision-making by occupational therapists⁹ and physiotherapists.¹⁰

Both analytic and intuitive decision-making processes have been described in published literature. Analytical decision-making describes practitioners who combine cues from patients and families to form a plan or intervention that address patient and family need. Intuitive decision-making, based on practitioner experience, describes decision-making that draws on previous experience in comparable situations. Awareness is developed over time, leading to practitioners feeling in tune with the needs of those in their care, and where practice may appear to be without rationale.¹¹ Literature suggests that the use of intuition is valued by health professionals, although the use of intuition varies. Nurses and occupational therapists with more experience have been found to use more intuition to inform practice,^{9,12} where less experienced practitioners utilise an analytic approach to decision-making.

The benefits of experience-based decision-making is widely reported in contemporary research, ¹³⁻¹⁵ indicating that experienced nurses make better decisions, when compared to less experienced practitioners. ¹⁶ The use of intuition and clinical experience alone are not sufficient as a basis for decision-making nor to develop confidence or competence. Experience, combined with education and development is important for developing the competence of nursing staff. This is supported by Nibbelink and Brewer,¹⁶ who recognise the importance of combining clinical experience and evidence for improved care delivery.

Caring for children who have died

Caring for a patient who has died is commonly recognised as one of the most challenging and demanding aspects of nursing, ¹⁷ even in a hospice environment. ¹⁸ This is perhaps more significant in children's hospice care, as despite the number of children who use hospices having life-limiting or life-threatening conditions, death is not an everyday occurrence. To provide some context, as a regional children's hospice caring for a population of approximately five million people, over the last five years the hospice has cared for an average of 24.5 deceased children in cool rooms per year.

Literature suggests that caring for those who are dying and supporting their families is emotionally and physically challenging, but often a rewarding and positive experience ¹⁷ Death is one of the most common stresses of nursing; ¹⁹ nurses have also reported experiencing anxiety, grief, distress, anguish, feelings of helplessness, frustration and expressed a lack of confidence in coping with patient death. Although these studies did not include hospice nurses, anecdotally it is acknowledged that these experiences are echoed in practitioners within the palliative and hospice care workforces ²⁰, and that these experiences can affect decision-making.

Aim

To enable the development of a policy that reflects the realities of practice, this study aimed to identify the factors that influence decision-making by children's hospice practitioners, when moving and handling children's bodies after death in a cool bedroom.

Method

A survey was developed to explore the perspectives of hospice practitioners who provided care to the children after death, around moving and handling practices while the child's body was cared for in the hospice.

Design

The survey was designed following discussions with a group of nursing, allied health professional and care staff who worked at the hospice, including moving and handling trainers, an experienced clinical academic and a funeral director, who were all experienced in providing care after death. Data were collected using a Google Forms questionnaire, comprising 11 questions. Quantitative data on length of service and professional background was sought. Qualitative data were obtained using open questions and free text boxes designed to facilitate practitioner reflection on their practice, encouraging them to consider how their values and previous experiences impact on their approach to care. The survey was piloted with 10 members of staff; comments made informed the final version of the survey.

Sample

To be eligible for participation in this study, individuals needed to be employed by the hospice as permanent or occasional members of staff. Participants had to have provided direct care to at least one deceased child and have supported a minimum of one bereaved family while their child's body was in the hospice.

Ethical considerations

The study was entered into the Integrated Research Approval System (project ID: 292283), 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 by the hospice's research committee, who were aware that it could submit an application to the Research Ethics Service should the proposal raise material ethical issues, however this was not felt to be the case for this study. The study was supported by the hospice research committee and Strategic Leadership Team. The authors all worked for the hospice at the time of completion.

Participants were informed both verbally and in writing that completion of the questionnaire was voluntary, and that they could withdraw at any time without offering reason. Questionnaires were analysed anonymously. Data were stored electronically on an encrypted drive, complying with UK General Data Protection Regulations.²¹ Practitioners were not offered any incentive to participate.

Data analysis

An inductive approach to thematic analysis was undertaken using NVivo (QSR International Pty Ltd. Version 12.6, 2020). A six-phase methodological framework²² was used to assure rigor in coding and thematic development. Responses to individual questions were amalgamated by MT. These were read and re-read independently to ensure familiarity with the data by MT and AH, who made notes on initial impressions and potential connections. Line by line coding was used to develop initial codes, again developed independently, before being discussed and scrutinized by the wider research project team. *A priori* codes were not used.

Preliminary themes were created by grouping codes, principally due to frequency or patterns. For example, respondents discussed the use of patient hoists, slide sheets and patient transfer boards or PATSLIDE®, which were collated into an initial theme ‘*equipment*’. We ensured that all data derived from the completed surveys was represented in the thematic framework before progressing. Themes were then reviewed and refined to ensure that they made sense and were supported by the data. Finally, we identified the essence of the theme and developed a diagram to illustrate the relationship between themes that explains the factors that influence decision-making around the moving and handling of the bodies of deceased children by children’s hospice staff.

Findings

In total, 59 practitioners were invited to complete the survey; a total of 56 surveys were returned and analysed (94.9% response rate). Participants comprised 58.2% registered nurses, 9.1% occupational therapists or physiotherapists, and 32.7% nursing support workers (unlicensed assistive personnel). Eighty percent of staff worked for the organisation for two or more years. All staff were paid – no volunteers are used in the direct care of children.

Findings have been organised into three core themes: care of the body, stages of care, and method of handling, which all influenced decisions made around the way in which practitioners moved bodies of children after death. These are discussed below, using quotes from practitioners. Although themes are presented individually, there was strong overlap between themes, each impacting on the other (figure 1), as illustrated by this practitioner:

‘Taking account of the dignity required; the emotions of parents and the colleagues you’re working with – holding their pain is an important element of this work. Preparing those around you and being sensitive to their needs which may change in a moment. Its more than practical tasks.’ (Participant 14)

Care of the body

Practitioners conceptualised the child's body as a child. All practitioners talked about '*children*' in the cool rooms, rather than bodies and discussed talking to the child, providing reassurance and explaining procedures, as would be expected when caring for the child before death. Three subthemes were identified: deterioration of the body, dignity and respect, and family centred care.

Deterioration of the body: bodies can remain in the hospice for up to five days after death, before being transferred to a funeral director or mortuary. Practitioners discussed the deterioration of the child's body, specifically colour changes/mottling, stiffening of limbs, abdominal distention and fluid leakage. Some practitioners expressed nervousness in entering the cool room, anxious about how the body may have deteriorated. Practitioners discussed responsibilities in anticipating, recognising and explaining deterioration to family members; some practitioners felt unprepared to do this confidently. Practitioners also discussed fears around hastening deterioration through unnecessary or inapt moving and handling, in terms of both method and frequency.

'I often feel concerned that I will do more harm in moving to check on a child's body than if I don't. It would be good to have some reassurances around possible skin breakdown.' (Participant 23)

Dignity and respect: running throughout the practitioner responses was the abundance of dignity and respect towards the deceased child's body and their parents. Practitioners took this element of their jobs very seriously and were committed to getting it right for families. Staff appeared to accept that moving and handling practices were different after death, in order to demonstrate respect:

'ensuring you maintain respect for the child. Having respect does not necessarily mean moving and handling in the way you would when they were alive.' (Participant 6)

'I remember looking after a toddler in the [cool room]. I probably should have rolled him, but I decided to lift him off the bed and cuddle him while we changed the sheet.' (Participant 19)

Practitioners talked about addressing children's bodies by name, using age-appropriate language and positioning the body in bed as they would have done in life. It appears that this was done for the child, to demonstrate respect and affinity for the child's memory, but also for the bereaved parents, who were considered at all stages of care in the cool room, often delivering care in partnership with the care team.

Family centred care: concordant with all aspects of care delivery in children's hospices, care provided after death was family centred. Practitioners discussed allowing families to lead care at all stages; parents were empowered to carry their child to the cool room and to be involved in washing, dressing and touching their child after death. Family involvement in memory-making activities, such as hand and footprints and photographs was discussed; some practitioners found this aspect of their role rewarding, while others struggled with caring for families at such as early stage of their grief.

'it's important that we allow parents to help if they want to, to give them time to process and say goodbye. It's a really important part of the grieving process.' (Participant 39)

Stages of care

Practitioners talked about caring for bodies in three stages of time: moving the child from their place of death into the cool room, care in the cool room and transferring care to the funeral director.

Moving from the place of death: children either died in bedrooms in the hospice, where they were transferred into a cool room along the care corridor, or died in hospital or at home, and were taken directly into the cool room via an outside entrance. Practitioners discussed a family-

centred approach to decision-making about the method of transferring from a bedroom to the cool room. Many supported parents in carrying their child to the cool room, or if requested, carried the child's body in their arms. Practitioners suggested they conducted informal risk assessments on an individual basis to decide if carrying the child was safe; this included judgements around the child's weight and length. Where practitioners concluded that a body could not be safely lifted, PAT slides and slide sheets were used to transfer the body onto a trolley, usually used for showering children, before being moved into the cool room.

Care in the cool room: this included lifting the body to allow parents to cuddle their child, checking for deterioration of the body, dressing the body and completing memory making activities such as hand and footprints, casting and photographing. These activities were usually done by two people, often with parents in the room, which practitioners recognised as being important in the grieving process. Practitioners discussed gentle handling, performed as infrequently as possible to prevent deterioration of the body. Many staff were concerned about post-mortem leaking. Compassionate care was evidenced throughout, with practitioners stating the need to be gentle, careful and to make sure the '*child looks comfortable*'. Almost a quarter of practitioners reported to hold static postures for longer, and more than 20% stated that they bend or twist more frequently in the cool room when providing care, compared with caring for children before death, as shown in table 1. This was seen particularly when undertaking memory making activities, such as holding a limb while multiple hand or footprints are taken.

'I aim for minimal disturbance of the child and consider when taking hand and footprints, and the optimum position for that. I usually note how they were positioned prior to moving to try and replicate it afterwards – though I always inform the family and care team, just in case I get something wrong.' (Participant 52)

Transferring care to the funeral director: Bodies usually remain in the hospice for up to five days before being transferred to a funeral director (FD). Practitioners noted that moving the

child from the cool room bed into the care of the FD was usually done by the FD, on occasion with assistance from the Care Team. Infrequently, bodies are placed in coffins before leaving the hospice. Staff noted the challenges of safe moving and handling with this, suggesting that scoop lifts were used, sometimes with a sheet, when bodies were placed in coffins. It appeared that some staff found this emotionally difficult, due to the finality of this act, and the difference in practice between hospice practitioners and FDs, which on occasion, were considered as less gentle and dignified.

Practitioners were interested in understanding more about the physiological changes after death and how these affect moving and handling. Some also suggested that learning about the roles and methods used by funeral directors may enable practice in the hospice:

'it would be interesting to hear from a funeral director about how they move bodies and place them into coffins from my experience [in the hospice], it is not a smooth or as gentle as our other moving and handling activities.' (Participant 9)

Method of handling

Equipment: Staff stated that they did not adjust the height of the bed as often as they would when caring for a living child and did not consider using a hoist as appropriate in most cases.

Feedback suggested that this was predominantly due to not having a hoist in the cool room, although some referred to the availability of mobile hoisting, but also due to desire to ensure the dignity of the body.

Practitioners were asked how much they used moving and handling equipment in the cool room, compared with use with live children. Two thirds of practitioners (66%) suggested that patient transfer boards were used more commonly after death, with 39% using bed or slide sheets more frequently. It appears that hoists were used less frequently, reported by 93% of practitioners. The results are shown in table 2.

Availability: many practitioners stated that they had never considered the use of a hoist in the cool rooms until completing this survey. While some practitioners thought a hoist may be used to support moving and handling in the cool room, most staff felt that even if one was available, they would not use it. The most frequently cited reason for this was to protect the dignity of the deceased child.

'I have never had to use a hoist. I personally find it more dignified and respectful to use the PAT slide, but I suppose there have been times when we have had someone very large in the cold room and a hoist might of helped in that instance.' (Participant 1)

Appropriateness: practitioners appeared to prefer using the least amount of equipment possible, favouring manual techniques, such as using a PAT slide rather than a hoist:

'I do not feel confident that [using a hoist] would be a suitable method for moving and handling due to the condition of a child after death. Using a PAT slide would disturb the body less' (Participant 54)

'I would choose a slide sheet – this is a kinder and more dignified method of moving a deceased child' (Participant 29)

There was general acceptance however that hoists may be useful for lifting older children and young people, with some practitioners reflecting on previous experiences. Other staff suggested that the use of hoists for bodies of children who used them in life would provide families with a sense of normality:

'using a hoist for a larger child or young adult may be safe for staff and maintain some normality for their family. Although timing is crucial regarding rigor mortis etc.' (Participant 16)

Frequency of moving and handling: at all stages of care, staff reported the need to keep moving and handling of children to a minimum. Routinely, children are 'checked' daily to assess for post-mortem changes to their appearance and to observe for any leakage. Staff appeared to be conflicted by the need to check the condition of the body and their desire to limit moving and

handling. Practitioners talked about '*minimal movement and disturbance*', and the need for a body to '*remain in the same position as much as possible to avoid leakage and damage*' (Participant 14)

Discussion

This study highlights the complexity of decision-making around moving and handling of children after death, while being cared for in a children's hospice. This paper focuses on the perspectives of nurses, allied health professionals and care support staff, who deliver care to children immediately after death, and their families, for up to five days. Three factors were identified that impact on the decision-making of staff: care of the body, stage of care, and method of handling. It appears that all three factors were considered by practitioners, used to inform their perception of appropriateness of moving and handling decisions.

A number of sources of stress were identified by practitioners, particularly the deterioration of the body and the need to be able to provide emotional and bereavement support to families immediately after the death of their child. The emotional impact of working in children's hospices, and children's palliative care more widely is well documented.²³ Similar findings have been reported by practitioners working in critical and complex care, both in the UK²⁴ and internationally.^{25,26} The findings that relate to family centred care have been published separately.⁵

Perception of appropriateness

It appears that what practitioners perceive as appropriate is influenced by a number of factors, including their level of experience, professional background and training provided. This correlated with the findings of Jensen et al.,¹² who suggest that practitioners regard care as appropriate when it correlates with their personal and professional beliefs and knowledge.

Practitioners with more experience of caring for children in cool rooms appeared more comfortable in not using equipment and in offering flexible post-mortem care to the body, based on intuition, reflecting their perceived needs of the bereaved family. These findings correlate with the work of Guerrero,²⁷ discussing the art and science of nursing decision-making and clinical judgement, concluding that new nurses can find decision-making around judgements and reasoning difficult due to unconsolidated experience of autonomy, proficiency and skill, and the tendency of more experienced nurses to use intuition as a basis for decision-making.¹¹ The paper supports the concept of providing staff with an evidence base on which to base practice, supported with education, professional collaboration which includes nursing leadership. This point is illustrated neatly by Vega^{28(p.63)} “*Although all nurses should exhibit the qualities that are essential to the art of nursing, nursing interventions should be practical decisions based on evidence-based research*”. The findings of this study support the need to provide practitioners with an evidence base to inform practice, delivered through education and policy.

Practitioner development through education

Jensen et al.¹² note that practitioners who are required to provide care they consider inappropriate are at increased risk of burnout due to moral distress. While what is perceived as ‘appropriate’ will always include personal emotions attitudes experience and beliefs,²⁹⁻³¹ there is evidence to suggest that changes to what practitioners consider appropriate can be influenced through policy change and the provision of evidence-based education. It is therefore important that a shared understanding of appropriateness is engendered, through the provision of education and policy, leading to a sustained change to working practice.

In addition to policy and research to underpin practice, mentorship and peer support are important elements in enabling the development of practitioners. Marcoux, Dickson and

Clarkson³² highlight the importance of mentorship and staff orientation, recommending the development of evidence-based guides for new staff and their mentors. This is supported by Irwin, Bliss and Poole,³³ who found effective mentorship has a positive influence on the confidence and competence of practitioners. Cerratti et al.³⁴ highlight the importance of offering structured support to practitioners to allow the sharing of feelings, creating openness and dialogue.

Development of an evidence base

A recurrent challenge of those working within the children's palliative care sector is the lack of an existing evidence base. While the volume and quality of research in this area has increased in recent years, there remains significant areas of practice that are not supported or informed by research findings. The care of children after death is one example where a suitable evidence base is lacking, and care based on anecdote and good intentions.

In order to address this, and produce evidence to inform policy and practice, a national survey has been developed, focusing on moving and handling children after death in children's hospices, building on the work of Pike³⁵.

Strengths and limitations

Using a rigorous approach, this study addresses the paucity of research around decision-making of hospice practitioners, focusing particularly on care provision after the death of a child. More specifically, how their perception of appropriateness is affected by the emotional demands of their work and level of experience in this specialist area of palliative care. To reduce subjective bias³⁶, the research team was multi professional and included an independent funeral director, broadening the perspectives and discussion of the study.

The findings of this study strengthen existing literature that supports the notion of research in forming policy, education and ultimately perceptions of appropriateness³⁷, which has implications beyond palliative care. It is internationally relevant to all fields of nursing and allied health and social care professionals, particularly those practising in specialist clinical areas^{38,39}. Nonetheless it is not without limitations. This study was conducted in a single children's hospice, providing a limited perspective on which to base findings. The use of a questionnaire to collect qualitative data is useful to map consensus⁴⁰, however the approach may have impacted on the disclosure of participants by limiting their responses, or the research team misinterpreting those responses provided⁴¹.

Implications for practice

This study has suggested a number of strategies that may be useful in supporting practitioners to make care related decisions. The complexity of decision-making and variation in practice has been highlighted throughout this paper, demonstrating the importance of training and education to support practitioners in caring for the bodies of deceased children in children's hospices. There is a clear need to develop guidelines around moving and handling children specifically after death, which take into account caring for the body and how to manage physiological deterioration after death.

More generally, this research demonstrates how practitioners' decision-making is influenced by their own experience and that of their colleagues, as well as their confidence and competence in a particular skill, and how research policy and education can support the perception of appropriateness of practitioners.

Implications for policy

The findings of this study suggests that evidence-based policy and training influence the perception of appropriateness, decisions and behaviour of practitioners in relation to moving and handling tasks. The development of a policy and education framework would support practitioners in caring for children's bodies after death, standardising expectations and measures of competence.

Implications for research

The study highlighted the influential position of experienced practitioners within the care team, and the variance in decision-making methodology. Further research is needed to evaluate the quality of decisions, and how the perception of experience or inexperience compares to levels of competence and appropriateness.

Conclusion

Caring for the bodies of children after death is both physically and emotionally challenging. Decisions around appropriateness of moving and handling take into consideration the task, length of time since death and the physiological deterioration of the body. In addition to considering the needs of the body, practitioners seek to provide care that recognises the importance of family and demonstrates continuing respect for the child, through the provision of family centred care and bereavement support. The lack of current guidelines means that practitioners rely on colleagues and their own perception of appropriateness using analytical and intuitive decision-making strategies when considering moving and handling the bodies of deceased children. The development of an evidence-based policy and education framework would support practitioners in caring for children's bodies after death, standardising expectations and measures of competence used by the hospice workforce. In turn, this would reduce the experience of anxiety, anguish and expressed a lack of confidence around decision-making that relates to moving and handling the bodies of children after death.

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	Move the child on your own, more than when you would when they were alive? n (%)	Adjust the bed to a safe working height? n (%)	Bend or twist more than you would when they were alive? n (%)	Hold a static posture for longer? n (%)	Use the same number of staff as you would when the child was alive? n (%)	Use appropriate equipment? n (%)
Always	1 (1.8)	35 (62.5)	0 (0)	0 (0)	19 (33.9)	19 (33.9)
More often	1 (1.8)	1 (1.8)	11 (19.6)	13 (23.2)	8 (14.3)	1 (1.8)
About the same	24 (42.9)	11 (19.6)	28 (50.0)	22 (39.3)	24 (42.9)	16 (28.6)
Less often	16 (28.6)	7 (12.5)	11 (19.6)	15 (26.8)	5 (8.9)	18 (32.1)
Never	14 (25.0)	2 (3.6)	6 (10.7)	6 (10.7)	0 (0)	2 (3.6)

Table 1: moving and handling actions in the cool room, compared with caring for a child before death

	PAT slides n (%)	Slide sheets n (%)	Bed sheets n (%)	Trolley n (%)	Hoist n (%)
Always	5 (8.9)	3 (5.4)	7 (12.5)	3 (5.4)	2 (3.6)
More often	31 (55.6)	5 (8.9)	14 (25.8)	15 (26.8)	0
About the same	9 (16.1)	16 (28.6)	25 (44.6)	17 (30.4)	20 (35.7)
Less often	7 (12.5)	20 (35.7)	3 (5.4)	12 (21.4)	3 (5.4)
Never	4 (7.1)	12 (21.4)	7 (12.5)	9 (16.1)	31 (55.6)

Table 2: the use of equipment in the cool room, compared to caring for a child before death

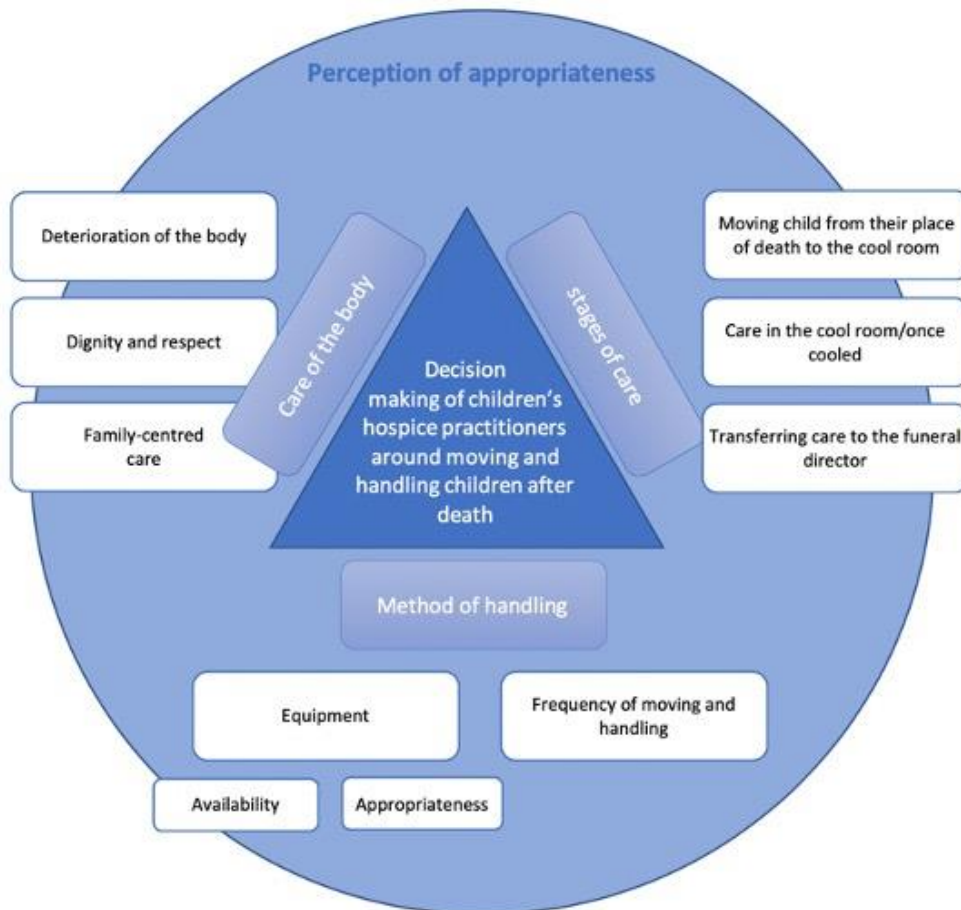


Figure 1: the relationship between the themes