

'Eat, sleep, internet and talk': an exploratory study of play profile for children living with palliative care needs

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Abstract

Background: Play is central to children's lives. Children living with palliative care needs experience disruption in their play. In this study, we sought to discover the characteristics and patterns of children's play when receiving care in children's hospital wards and hospices in Kuwait and the United Kingdom.

Methods: A qualitative nonparticipatory observation design was used. Thirty-one children were observed, between the ages of 5 and 11 years, all diagnosed with life-limiting or life-threatening conditions and receiving palliative care. The data were analysed using content analysis.

Results: The children's illnesses were negatively impacting their ability to have typical play for their age and development. The children's interactive play was with grown-ups and very rarely with other children. This was associated with isolation precautions, the child's need for assistance and a lack of play resources that match children's physical and cognitive abilities. This gave rise to their engagement in more sedentary, solitary play. The findings of the study did not indicate significant cultural differences between the two countries.

Conclusion: Children living with palliative care needs may be socially isolated due to their illnesses and their play participation can be limited. Understanding the influencing factors that determine these children's play is essential for implementing effective modifications to enhance their play routines.

Keywords: palliative care, play, vulnerable children

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Introduction

Play is central to children's lives and to their acquisition of skills.¹ It serves different purposes for different groups, including their physical, cognitive and psychosocial development.^{2,3} Despite the available evidence suggesting differences in cultural values and attitudes towards play, it is a universal dimension. Play is one of the children's rights, regardless of any health condition(s) that they are living with.^{2,3}

There is strong evidence that children living with palliative care needs often experience loss or impairment that affects their participation in

play.^{4–6} This may be related to physical constraints to equipment use (e.g. technology-dependent children and the limitations placed on their play from using these devices), or as a result of the child's health condition, either directly or as a consequence of necessary precautions (e.g. being in isolation to reduce infection risk).^{4,6–8}

There is limited research into the nature of play in children with palliative care needs and most studies have been limited to children with oncological conditions.⁸ Witt *et al.*⁷ explored the impact of leukaemia on play in children aged 3–13 years and found that children usually participated in

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passive play activities, such as watching TV or movies, using tablets or smartphones, and that such activities constituted primarily solitary play. Similar findings have been shown in a cohort of children undergoing cancer treatment, wherein most were shown to use electronic devices, which can be easily manipulated in their own bed space as a form of entertainment.⁹ It is clear that the child's health condition can significantly negatively impact their ability to engage in active play, leaving the child weakened and with limited physical mobility.¹⁰ However, most often children's play is with adults during their hospitalisation, which demands time and energy from adult caregivers.^{7,11,12} It is plausible that this reliance on adults for play may impact the nature and frequency in which a child can engage in play.

In this observational study, we sought to explore the nature of the everyday play of children living with palliative care needs while receiving inpatient care. The research's objectives were to

1. Discover the characteristics and patterns of children's play in hospital wards and hospices.
2. Explore differences in these children's play across two countries and cultures: Kuwait and the United Kingdom.

Methods

This is an observational study with children living with palliative care needs to explore their play nature. For the purpose of this study, play was referred to as the child's behaviour of engaging in a freely chosen activity that appears to carry a subjective experience of joy and fun.^{13–15}

Study design

An observational qualitative approach¹⁶ was used to explore this under-studied phenomenon regarding the everyday play of children living with palliative care needs, within the inpatient health-care settings. This was part of a larger study exploring features of a supportive play environment for children with palliative care needs.¹⁷

Participants

Children were recruited from four settings: a children's hospice and hospital in Kuwait, and a hospice and hospital in the United Kingdom. The inclusion criteria were children diagnosed with a

life-limiting or life-threatening condition and have palliative care needs, and aged 5–11 years representing middle childhood ages. The clinical team at each setting identified participants who were eligible for the study.

Recruitment and ethical consideration

The sampling was purposive in terms of participants and times of observing.^{18–20} Each child was observed on two different days at different times of the day, morning and afternoon, each for 1 h. This was helpful to sample the phenomenon to cover as many factors as possible that could be related to time of the day.

Children and their carers provided informed written assent and consent, respectively, to take part in this study. Ethical approval was granted by the ethics committee at the University of Southampton (No. 27832), Health Research Authority (REC reference: 18/WM/0127) and each research site.

Data collection

Data collection was undertaken by one researcher (ZJ). Data were systematically gathered using a prior-planned guidance, observational schedule that included recording the areas of observations, children's play behaviours, play tools, their interactions with others during play, and any culture-play-related factors. These data were also triangulated with the use of photographs (where applicable) and *via* informal discussions with participants to elucidate unclear dimensions raised during the observation. Photos were taken that were used for the purpose of this study only, and where appropriate consent to use photographs in reporting the study was secured.

The researcher followed the child and observed without interruption. The researcher took the role of a 'marginal participant' where the role was largely passive to gather data as they were naturally occurring.¹⁶ The researcher did respond only when the child asked, but without leading them. Thus, some children had their parents, siblings or visitors.

The researcher utilised several techniques to manage the asymmetrical power with the children and minimise the social distance that might affect the quality of the data. This included showing interest in the child's play and valuing the child's world, explaining the research in a comprehensive fashion appropriate for each child's level

Table 1. Characteristics of the participants.

Characteristics		Kuwait hospital	Kuwait hospice	UK hospital	UK hospice
Sample size, <i>n</i> (%) ^a		10 (32.2)	3 (9.6)	10 (32.2)	8 (25.8)
Gender, <i>n</i> (%)	Male	3 (30)	1 (33.3)	3 (30)	4 (50)
	Female	7 (70)	2 (66.7)	7 (70)	4 (50)
Age ^b , mean (SD)		6.9 (2.07)	6.6 (2.8)	7.9 (1.9)	8.7 (2.05)
Ethnicity, <i>n</i> (%)	Arab	8 (80)	3 (100)	–	–
	Asian/Chinese	1 (10)	–	1 (10)	1 (12.5)
	White British	–	–	9 (90)	6 (75)
	Black/African	1 (10)	–	–	1 (12.5)
Diagnosis, <i>n</i> (%)	Neurology	1 (10)	1 (33.3)	1 (10)	5 (62.5)
	Oncology	3 (30)	1 (33.3)	2 (20)	1 (12.5)
	Haematology	4 (40)	–	2 (20)	–
	Congenital	2 (20)	–	–	2 (25)
	Genitourinary	–	1 (33.3)	1 (10)	–
	Cardiology	–	–	2 (20)	–
	Metabolic	–	–	2 (20)	–
	Spectrum of palliative care need, ^c <i>n</i> (%)	Yellow	8 (80)	2 (66.7)	8 (80)
	Amber	2 (20)	1 (33.3)	2 (20)	2 (25)
Total hours of observation		20	6	20	16

^aThe percentage is calculated for the total sample size.
^bMean and standard deviation are used to present the descriptive data.
^cAccording to the Spectrum of Children's Palliative Care Needs:²⁵ *yellow*: children expected to die before adulthood (18 years old) and *amber*: children where death is expected in a few months to years.

of understanding, creating specially designed children's information sheets that were based on their age and obtaining their approval to participate alongside their legal guardian's consent.

Analysis

The data were analysed using content analysis qualitatively and inductively.^{21,22} Phases of content analysis were followed as set out by the Elo and Kyngäs²¹ framework. NVivo12 was used to manage the data. The data were coded and categorised. Random samples of observation notes and photos were independently assessed against the coding framework by the research team (ASD

and DR) and then discussed with the data collector (ZJ) to ensure consistency and achieve inter-coder agreement.^{23,24}

Findings

Data were collected from 31 children and equated to 62h of observation. Table 1 provides the participants' demographic information.

Three categories relating to children's play were identified (Table 2), namely, (1) influence of the conditions on children's play, (2) children's play patterns and (3) children's interaction during play, each of which is presented in turn.

Table 2. Identified categories.

Category	Subcategory
Influence of the condition	Isolation
	Assistance
Play patterns	Play with electronic devices
	Accessibility to play resources
Interaction during play	Limited play interaction with other children
	Frequent playmate
	Play with healthcare team

Influence of the condition

Isolation. The children's palliative care needs arising from their health conditions were negatively associated with their play in several ways. Some of the children were in isolation and thus unable to share other areas (e.g. the playroom) or to share play equipment. For example, a 7-year-old boy at Kuwait's hospital who was in isolation was in his individual patient room; he frequently repeated his need to leave the room: 'I'm feeling bored, I want to get out of the room ... I want to go to the playroom'. His mother suggested bringing him toys from the playroom, but he replied, saying, 'But I want to go out'.

Assistance. Children's health conditions left them weakened. The children had difficulties using small objects, in particular in their constructive play (i.e. creation, making and building), such as fitting Lego bricks, getting glue or simply opening the lid of a colouring pen. A 9-year-old girl within the UK hospital was left feeling frustrated from having to frequently ask for a help; she said disappointedly, 'Cannot open pens'.

People who provided the assistance vary according to the settings and to each family. For some, it was nurse, play specialist, physiotherapist, volunteers or family members. For some children, adults were observed doing the play for those who appeared to have poorer cognitive and language skills in regard to their ages. They were either moving the child passively to interact with toys or playing in front of the child. In one instance, a carer was seen passively moving the hand of 5-year-old girl at a hospice to move a brush (see Figure 1).

Play patterns

Play with electronic devices. Figure 2 presents the types of play that children participated in across the four settings. Playing with electronic devices was the most observed type of play that children engaged in. Children considered it as part of their everyday activities when they were asked about their routine: 'I only play with the phone. If the phone was not charged, I will sleep' (7-year-old boy in the Kuwait hospital) and 'Eat, sleep, internet and talk' (7-year-old girl in the UK hospital). Children used electronic devices to watch YouTube, to play games and to take photos. It is worth highlighting that the availability of an Internet connection was required for most of their play. The Internet therefore, at times, facilitated play (albeit online) with others. When not playing with electronic devices, children played with others (almost always with grown-ups), including pretend, constructive, and explorative play.

The Kuwait hospice was the only setting in which none of the children played with electronic devices because it was normal practice for the staff (e.g. play therapist and music therapist) to develop and implement a preplanned organised schedule of activities for the whole day. Some of the activities were decorating a photo frame and outdoor play.

Accessibility to play resources. The different settings had different areas where children could play, and an extensive array of play equipment (Figure 3). Some settings have accessible outdoor area or a playroom. In addition, at the hospices, they had specialised equipments that were adapted to children's special needs (Figure 4). However, the limited accessibility of these available resources (e.g. restrictions within the setting such as a trained staff member should be available for the area to be used by the child or lack of capability to use independently) was perhaps the greatest influencing factor on children's play. This was very clear in regard to the active play (see Figure 2), which was one of the least play types.

It was notable that that majority of children's time was spent playing on electronic devices, except for children in Kuwait's hospice, both in Kuwait and the United Kingdom, and that this was particularly evident when they were observed in their room on their beds, but also when in the playroom. Children were used to having these electronic devices accessible and reachable as they could use it whenever.

Interaction during play

Limited play interaction with other children. Limited play interaction between children was observed. This was largely in shared areas, in the four settings. When children did interact, it was for very short group activities where the children’s play was in parallel; children played alongside other children nearby, but with very limited or no interaction. Table 3 is a summary of the common features with regard to children’s social interaction during play in each setting.

Frequent playmate. Other children’s cooperative play (i.e. child plays and interacts with others) was with grown-ups (e.g. their parents, play specialists and volunteers) when these adults were willing and available. For a number of participants in both countries, the parents replied passively to their children’s play during the beginning of the observation: ‘I will tell you from now, she (the child) will just be in her bed playing with her iPad’ (a mother of a 6-year-old girl at the Kuwait hospital). However, this was not the case during the 2 h of observation. This child herself asked the



Figure 1. Child engaging in colouring with high level of physical assistance.

researcher if she could play with her, she suggested different types of play (e.g. hand clapping games, pretend school play and colouring) and

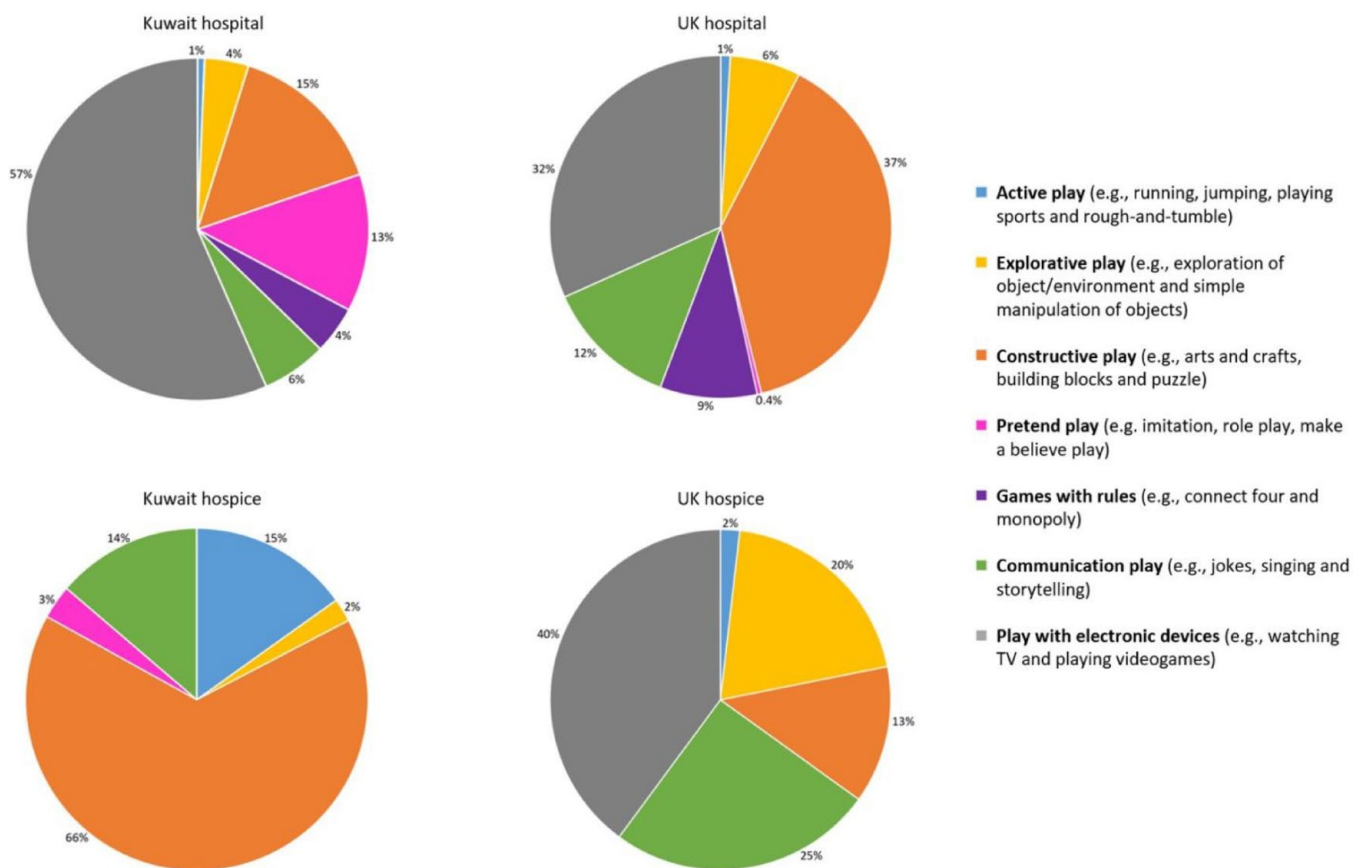


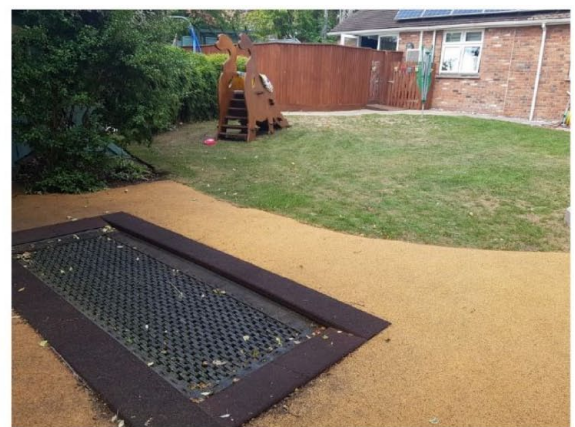
Figure 2. Types of play that children participated in across the four settings.



Figure 3. Available play equipment; almost all sorts were available.



(a)



(b)

Figure 4. Specialised adapted equipments for children using wheelchair: (a) Fare wheel in Kuwait's hospice and (b) wheelchair trampoline in the UK hospice.

the researcher engaged with her in all of her suggestions (Figure 5).

Play with healthcare team. The healthcare team rarely engaged with children's play, particularly those within the hospital setting. An 8-year-old girl pretended to be a thief and covered herself with a blanket when the healthcare team – the 'police' as she imagined – entered her room at the hospital. However, they did not respond to her play because when they entered the room they discussed the child's care with the mother and then left the room without interacting with the child. Very few of the healthcare team interacted with the children, to ask what they were doing. Their

interaction with children at the hospitals was limited to their medical care. Hence, some of the children initially avoided the researcher in this study as they did not expect an adult at the hospital to play with them or even have interest in their play. One of the children (5-year-old boy at the UK hospital) later on explained their avoidance: 'I don't want you to give me injection and feel pain'.

Observed differences

Despite the fact that most of the findings were similar across the four settings, a few differences were noted between Kuwait and the UK, and the hospital and hospice.

Table 3. Common features of children’s social interactions during play in each setting.

Research settings		Kuwait hospital	UK hospital	Kuwait hospice	UK hospice
Child’s social interaction with	Family members ^a	No play interaction	Limited play interaction ^b	Limited play interaction	Were not present
	Other children	No play interaction	Minimal parallel play ^c interaction	Parallel play interaction	
	Staff at the setting	No play interaction	Limited play interaction	Engaged in play	Engaged in almost all children’s play
	Frequent playmate	Usually played on their own	On their own or with play specialist	On their own or with family members	Hospice staff

^aIncludes siblings.

^bThe other person interacted with the child during their play but for very short period, and not during their whole play time.

^cParallel play is a child plays near others who is also playing but there is no interaction between them.

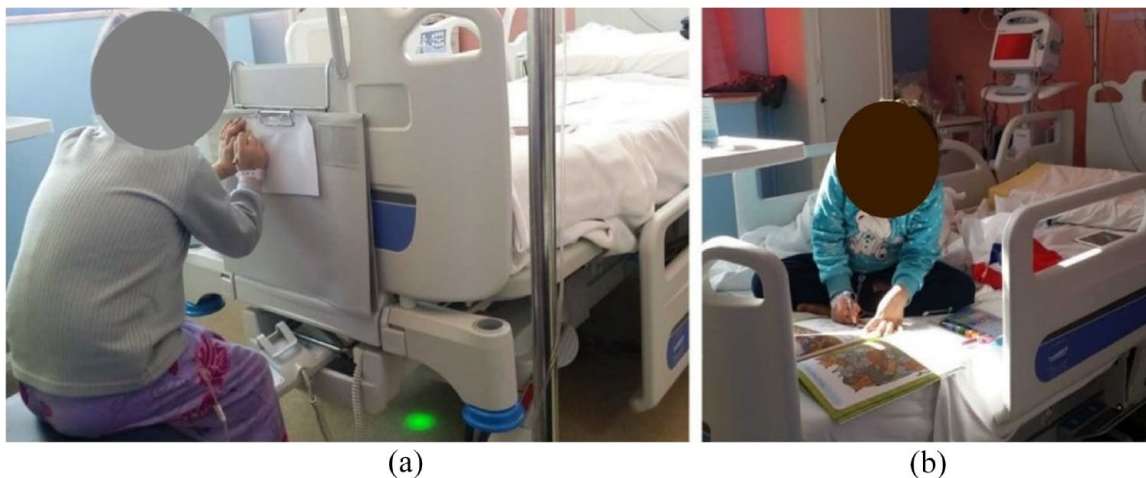


Figure 5. A child playing with the researcher: (a) Playing school pretend and (b) colouring.

Differences between countries. More children in Kuwait were observed engaging in pretend play than in the United Kingdom (Figure 2). In addition, considering the patients’ rooms in Kuwait, the researcher rarely found play equipment in the patients’ rooms apart from electronic devices. In comparison, all the children had their teddies with them in the United Kingdom and a few had other things such as Lego and art stuff; however, they were rarely observed playing with these, unless they were with others.

Despite the fact that play specialists were available at both the Kuwait and UK hospital, in Kuwait they were more suggestive that the children play and in the designated ‘playroom’ only;

they were more encouraging towards the children but engaged less when compared with the United Kingdom.

Differences between settings. More communication/language play and engaging in games with rules were observed in hospices compared with the two hospitals (Figure 2). Children played more with others in hospices than in the hospitals. The majority of the activities in Kuwait hospices were parallel constructive play, in which children took the lead (e.g. decorating frames, painting and drawing) (see Figure 6). Conversely, within the UK hospice, most group activities involved singing, or explorative and constructive play, in which adults were playing for the children.



Figure 6. Activity room in Kuwait's hospice.

Furthermore, at both hospitals most of the children's play was observed in patients' rooms or playrooms. In the hospices, children also play on the floor and outdoor, although these areas did not have easy access for the child to independently use the available resources. Regarding playing with the healthcare team, more interaction was observed with children in the hospices. A mother of a 5-year-old girl at the hospice stated that her daughter did not know that the doctor in the hospice was a doctor because of the enjoyable way they interacted with her.

Discussion

This study is the first to explore everyday play of children living with palliative care needs in children's hospices and hospitals in Kuwait and the United Kingdom. The findings of this study revealed that the children's conditions can be negatively impacting their ability to have typical play for their age and development. The children in this study were found in need for an assistant from a grown-up to play due to the consequences of the conditions. The available play resources were often challenging to use and the settings were designed and organised supporting specific types of play. As a consequence, children frequently engaged in sedentary play and rarely played with other children.

The findings of this study are consistent with the current body of evidence demonstrating that living with palliative care needs limits children's

play experience.⁸ It seems that life-limiting/life-threatening conditions are socially isolating health conditions.⁶ In the hospitals, in particular, the use of single patient rooms was one of the factors seemingly associated with very limited interaction between the children. Several studies have indicated that single patient rooms decrease sociability and increase a sense of isolation.^{26,27} This sense of isolation in some cases is required because of the infection control on children; however, it results in (1) the reduction of contact with their peers,⁷ (2) an inability to participate in hospital play activities²⁸ and (3) an inability to use the playroom.¹¹

The play activities which the children engaged in during the observations are in line with current literature, as most of them were sedentary in nature and took place in indoor settings. The children predominantly played with electronic devices.^{7,9,29} This finding is in contrast to what was found in Jasem *et al.*⁶ study in which electronic devices were not the children's preferred type of play. This latter study found that this was the case, unless they had someone to play with. Some children were able to join playmates online. It is important to contextualise our findings regarding the use of electronic devices in these children though, as an increase in 'screen time' is not restricted to children with palliative care needs but is becoming a worldwide issue with 'normally-developing' children also.³⁰⁻³² As a consequence, this can be considered the norms with the wide spread of technology. Thus, in a sense, children living with palliative care needs may simply be mirroring their 'healthy' peers in living a childhood within a technological age.

In addition to electronic devices, constructive play (primarily art and crafts) was the second most common type of play observed. It has been suggested that the arrangement of play spaces and the available equipment encourage such types of play.³³ This could propose why the children in our study were rarely engaged in gross motor/active play as not every setting is arranged in a way that supports gross motor play. In addition, it was noticeable that children often used specific items or required adults' assistance to play. Adults taking part in play has been reported as a means to overcome children's limitations.^{7,29,34,35} One of the reasons that could be alluded to this is a mismatch between the children's capabilities and the lack of play tools matching those children's capabilities. This means there is a lack in the right play

challenge available for these children when assistance from adults is a necessary component of their play.

One of the negative consequences of the mentioned disparity between children's abilities and available play resources is the difficulty to know by observation whether the children were enjoying themselves. For children with complex needs and severe cognitive disabilities, often the adults were observed playing for them or at them, occupying the time. It was not always clear whether the child was enjoying the play and there was limited scope for the observer to truly assess and understand the children's passion and the meaning they may have associated with that play. There is lack of evident guidance on how to assess their enjoyment levels or playfulness, although there are available guidance on how to assess these children's negative experiences such as pain, as shown through combative behaviour and biological plausibility.^{36,37}

The healthcare staff, in particular those at the hospitals, rarely engaged in play; even when the child was playing, they were not aware that the child was playing with them as demonstrated in the findings. In Kuwait, the adults, including the parents and play specialists, rarely played with children in comparison with the United Kingdom; they were more likely to be preparing or suggesting play, rather than be playing with the child. Thus, this might be suggested to be an influence of the culture in shaping children's play, in Kuwait. However, within the hospices, more interaction was observed. As a consequence, play activities that are usually carried out with a playmate were more frequently observed at the hospices compared with the hospital (e.g. communication/language play). This can be suggested due to the differences of the care system, while the hospital wards are focused on symptoms and disease management; hospices, on the contrary, consider the patients' quality of life and respite care.

These findings should be considered with caution as it cannot be generalised to represent all children living in Kuwait and the United Kingdom. However, the thick descriptions provided could help in the transferability of its findings in addition to carry on further research. Future studies are needed to find ways to enhance children's participation in play when they live with palliative care needs. Further research is needed to

facilitate effective modifications in children's play routines to allow equal access to different types of play; for instance, active play which was one of the least observed. Active play for these children, in particular, could help to ensure optimal physical and psychological development. Further work is required to develop valid and reliable measures of children's playfulness and enjoyment for children with communication difficulties and cognitive impairment. Programmes of education need to include participation in play for all staff in services and institutions that care for children living with palliative care needs, such that all staff recognise the right of all children to play and can interact with children accordingly as play participants.

Conclusion

Children living with palliative care needs experience disruption to their play. The observational method in this study afforded a flexible and multidimensional approach of gathering data regarding children's everyday play. Despite acknowledging the cultural influence on children's play, this study contributes to the understanding that the participants from both Kuwait and the United Kingdom shared much in common with regard to their daily play within hospitals and hospices. These children are very often socially isolated due to their illnesses and their play interaction with other children is very limited. A required action is to re-think and figure out how to help these children live their childhood by participating in play.

Key messages

1. The health conditions of children with palliative care needs are negatively impacting their ability to have typical play for their age and development.
2. Most of the children's interactive play is with adults and very rarely with other children using the healthcare facility.
3. Children who were in the hospital or hospice care receiving palliative care were frequently engaged mostly in sedentary, solitary play.
4. The available play resources are often challenging for the children to use due to their physical and cognitive impairments.
5. The way settings are designed and organised is highly associated with limiting the types of play children engage in, most

notably, encouraging playing with electronic devices and arts-based play.

Ethics approval and consent to participate

Children and their carers provided informed written assent and consent, respectively, to take part in this study. Ethical approval was granted by the ethics committee at the University of Southampton (No. 27832), Health Research Authority (REC reference: 18/WM/0127) and each research site.

Consent for publication

For the participants' data to be used, consent was obtained to allow data sharing in academic journals.

Author contributions

Zainab A. Jasem: Conceptualisation; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Resources; Software; Visualisation; Writing – original draft; Writing – review & editing.

Anne-Sophie Darlington: Conceptualisation; Formal analysis; Methodology; Project administration; Supervision; Validation; Writing – review & editing.

Danielle Lambrick: Conceptualisation; Methodology; Project administration; Supervision; Writing – review & editing.

Duncan C. Randall: Conceptualisation; Formal analysis; Investigation; Methodology; Project administration; Supervision; Validation; Writing – review & editing.

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Conflict of interest statement

The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Availability of data and material

The data that support the findings of this study are available from the corresponding author, upon reasonable request.

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