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Title page

Descriptive title: The social and physical environmental factors associated with the play of children living with life threatening/limiting conditions: A Q methodology study

Short title: supportive play environment

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Conflicts of interests

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

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Data availability

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

Ethics approval

Children and their carers provided informed, 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.

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ABSTRACT:

Background: Living with a life threatening/limiting condition changes and challenges children's play. The environment is known to support participation in play, yet there is a lack of evidence highlighting its specific factors contributing to children's play. In this study, we investigated the perspectives of children living with life threatening/limiting conditions with regards to the environmental factors that are related to their engagement in play whilst receiving inpatient healthcare.

Methods: Twenty-seven children took part in this study. Participants were aged between 5y and 11y, diagnosed with life threatening/limiting conditions and were receiving care at either a children's hospital or hospice in either Kuwait or the UK. Children were asked to rank-order a Q set according to their perceived importance. The used Q set comprised of social and physical environmental factors. The data were analysed using factor analysis and content analysis.

Findings: Two shared viewpoints were identified which represented children from both countries. For factor1, the children's need for social connectivity guided their answers regarding the environmental factors. For factor2, although children considered being surrounded by others important, their selections of the play conditions directed their play. For both factors, children had relatively little concern for outdoor and the type of play to

engage in, with the exception of arts and crafts play activities which were deemed important.

Conclusions: Play settings are important to support rich, social play experiences and opportunities that match children's play preferences. Children living with life threatening/limiting conditions in Kuwait and the UK have relatively similar play needs.

Keywords: vulnerable children, palliative care, play, environment, Q methodology

INTRODUCTION

Play is an essential determinant of children's health; a strong positive relationship exists between participation in play and children's health and well-being (Gerlach, Browne, & Suto, 2014; Law & King, 2014; Moore & Lynch, 2018). However, play is under-researched for children living with life threatening/limiting conditions, despite the fact that these children are experiencing sustained disruption in their play (Jasem, Darlington, Grisbrooke, Lambrick, & Randall, 2020). Life threatening/limiting conditions are mainly characterised with shortened lifespan, where the likelihood of death is before reaching adulthood (i.e. before their 18th birthday) (McNamara-Goodger & Feudtner, 2012). For some, there might be curative treatment which however may also fail (e.g., organ failures of heart) and for others there is lack of any hope for curative treatment (e.g., severe cerebral palsy) (McNamara-Goodger & Feudtner, 2012; Shaw et al., 2015).

These health conditions are characterised with prognostic uncertainty. Therefore, considering such conditions, play is integral to the parallel planning of care for those children. They can benefit from the process of engagement (i.e. interaction with peers allows children to fully experience their childhood) and from participation (i.e. developing later-life skills) (Lynch & Moore, 2016; Mandich & Rodger, 2006; Sturgess, 2003). The few available studies have indicated that a hospital stay (or hospitalisation) restricts play for children who are living with life threatening/limiting conditions (Angstrom-Brannstrom, Dahlqvist, & Norberg, 2013; Jasem et al., 2020; Lima & Santos, 2015). It has been shown that children are often unable to engage in many of their desired play activities, such as building Lego or colouring and reading, because of hospitalisation (Angstrom-Brannstrom et al., 2013; Gibson, Aldiss, Horstman, Kumpunen, & Richardson, 2010; Lambert, Coad, Hicks, & Glacken, 2014b; Lima & Santos, 2015; Nabors, Liddle, Graves, Kamphaus, & Elkins, 2019). Similarly, children's participation in play may be limited through the reduced availability of play materials more generally, and the need for more age- and gender-appropriate toys (Aldiss, Horstman, O'Leary, Richardson, & Gibson, 2009; Gibson et al., 2010; Kirk & Pritchard, 2012; Lambert, Coad, Hicks, & Glacken, 2014a; Lambert et al., 2014b; Lima & Santos, 2015). It has also been shown that hospitalised children are often denied access to the available play spaces (e.g., playroom and playing outside) (Gibson et al., 2010; Lambert

et al., 2014b; Mufti, Towell, & Cartwright, 2015; Verschoren, Annemans, Van Steenwinkel, & Heylighen, 2015), and living with life threatening/limiting conditions can inhibit children's opportunities to play with others (Adistie, Lumbantobing, & Maryam, 2019; Angstrom-Brannstrom et al., 2013; Graham, Truman, & Hoigate, 2015; Mufti et al., 2015; Nabors et al., 2019; Witt et al., 2019).

Specific limitations to children's play can indicate more broadly that the environment which surrounds play may be a major factor in limiting the play participation for these children (Jasem et al., 2020). However, there is lack of evidence to promote our understanding to what factors within the environment these are. In addition, why these children may not be able to access specific play areas, equipment or resources. Of the available studies in this area, none have directly focussed on children with life threatening/limiting conditions in relation to play and in particular, the environment which surrounds play. Furthermore, most of the established evidence is limited in its generalisability worldwide, as the majority has been based on Northern Hemisphere hospital practices, and they have not considered culture as a factor which may influence children's play (Jasem et al., 2020). This is despite the fact that evidence proposed variations across cultures regarding play (Hughes, 2010; Rubin, Fein, & Vandenberg, 1983). Cultural factors that could influence play can include family structural arrangements, cultural beliefs and practices have influence on the expression of play, the determination of play partners, the setting in which play occurs and time allowed for play (Parham, 2008; Roopnarine, 2011; Rubin et al., 1983). Therefore, the aim of this study was to understand the perspectives of children living with life threatening/limiting conditions about the environmental factors that are related to their play. By reviewing the literature (XXXXX), it has been found that the factors which were deemed most pertinent to be explored included social- (e.g., relationships and norms) and physical- (e.g., buildings, spaces and objects) environmental factors. Accordingly, we investigated children's priorities/preferences around these factors and their engagement in play whilst receiving inpatient healthcare.

METHODS

Study design and methods

A mixed-methods approach was adopted in this study using Q methodology. Q methodology is a mixed-methods approach that helps researchers to examine the shared participants' viewpoints regarding a specific issue (McKeown & Thomas, 2013; Watts & Stenner, 2012). When using Q methodology, the studied phenomenon is presented on cards (called a Q set) and the participants are asked to rank-order them along a continuum (the process of sorting is referred to as Q sorting) (Figure 1). Participants are encouraged to give verbal information and comments on their rationale behind the positioning of each item within the Q sort (McKeown & Thomas, 2013; Watts & Stenner, 2012).

In this study, the Q set was developed to include different social and physical environmental factors related to children's play. These were developed through extensive reference to the academic literature, existing questionnaires and conversations with experts in this field. This was started initially with generating an overly large number of items in order to ensure covering the topic widely. These were then reduced to a manageable number of items by the research team. This process was conducted by subsequent examination of the significance and clarity of the items. Similar statements were removed, others were grouped using more general terms to broaden the item coverage and its semantic content (Watts & Stenner, 2012). Twenty-eight items were created and are presented in Table 1. To reflect a cultural difference between Kuwait and the UK, one extra item was used in Kuwait Q set only (see Table 1). All resources were developed in two languages, Arabic and English, and piloted within each community. Images were used to represent the environmental factors on the Q set with short phrases/words written below each picture (Ellingsen, Thorsen, & Storksen, 2014), see Table 1.

This phase was followed by piloting to ensure the creation of a broadly balanced and representative set of items. Four normally developing children, from both Kuwait and the UK (4, 5, 6 and 8 year-old children) participated in this process.

Participants

Purposive sampling was used to recruit participants. The data were collected from children diagnosed with life threatening/limiting conditions according to the spectrum of Children's Palliative Care Needs (Shaw et al., 2015). They should be between the ages of 5 -11 years of age in order to represent middle childhood ages. Children should be receiving inpatient care at one of four settings: a children's hospice or hospital in Kuwait (a Middle Eastern Arab country), or a children's hospice or hospital in the United Kingdom (UK). These two countries were selected as two of different cultures as well as the researchers had ample access to these two societies.

We excluded children who do not speak Arabic or English, languages that the researcher can understand or those who were judged by their responsible clinician to be medically unstable or do not have the mental capacity to participate at the time of the study.

Data collection

Potential participants were identified by the clinicians within the research field. Willing participants were then contacted by the first researcher to be provided with a full explanation of the research. The response rate in Kuwait was 93.3% while it was 68.4% in the UK.

Each participant was asked to prioritise the Q set according to their perceived importance, from most important '+4' to most unimportant '-4', on a grid arranged along a 9-item continuum (Figure 2). During this activity, the participants' verbal comments were recorded using audio-recorders and utilised in the subsequent data analysis. The participants'

arrangements of the Q set (i.e., the positioning of each item on the grid) were documented by the researcher leading the data collection. We followed the methods outlined by Watts and Stenner (Watts & Stenner, 2012).

Data analysis

Each participant's arrangement of the Q sort was analysed using an exploratory factor analysis technique using Principal Component Analysis via the PQ method software V.2.35 (Schmolck, 2015). This allowed individuals' viewpoints to be statistically grouped forming a 'factor' (e.g., participants who had similar arrangements of the Q set/ similar Q sorts form a groups of participants) (McKeown & Thomas, 2013; Watts & Stenner, 2012). The qualitative data – the participants' recorded verbal comments – were analysed using card content analysis. There qualitative data allowed for understanding the quantitative data and the rationale behind the found level of importance for each of the Q items (Gallagher & Porock, 2010).

Ethics

Ethical approval for this study was obtained from the University of xxx Ethics Committee (no. 27832), Health Research Authority (REC reference: 18/WM/0127) and granted from each hospital and hospice. Prior to any child's participation, they provided written or verbal consent, as they wished, and their legal guardians provided written informed consent.

FINDINGS

Twenty-seven children participated in this study. As detailed in Table 2, the number of participants in both countries were similar. The children's health conditions varied in type and severity, but the most common diagnosis in the sample was related to oncology. The majority of participants were identified as being within the 'yellow' group according to the Spectrum of Children's Palliative Care Needs (see Table 2 further details) (Shaw et al., 2015). Hence, the study sample included children with palliative care needs whose risk of dying is expected before adulthood, but not within the next few months.

Two factors were extracted for each group, in Kuwait and the UK: Factor 1, *the social experience of play*, and Factor 2, *conditions of play*. Due to the high association which was found between the two factors in the two countries (Jasem, 2019), the inferences were interpreted together.

Understanding a factor (i.e., understanding participants' viewpoint descriptions) are based on the location of a Q item on the grid which gives the factor array illustrated in Table 1. For example, item #14 in factor 1 had a factor array score of 0 (neutral) in Kuwait and -4 (most unimportant) in the UK, and so is listed as: #14: 0, -4, respectively.

Factor 1: The social experience of play

Twelve participants were significantly associated with this factor (i.e., children who held the viewpoint [represented by this factor] more strongly than other participants), as presented in Table 3. This comprised six children from each country. All of the children from the UK were female, while three from Kuwait were male. Their average age was 8.5 y. All of the children from Kuwait were Arab and all of those from the UK were White. All but two were recruited from the hospitals.

In this factor, children perceived the social environment to be of high importance. The children enjoyed playing with others and in particular with family (#1: +4, +4) and pets (#8: +3, +4). This was also in line with their responses to other items which were linked with a playmate, regardless of the level of importance placed on that play type, including swimming (#3: +3, +3), joking (#5: +2, 0), active play (#12: +2, +1) and others (#20: +4, +3; #25: +1, +2). A participant commented on the electronic devices (#25: +1, +2) stating: *'taking my cat and playing with her on the PlayStation'* (9-year old boy at Kuwait hospital). Children discussed a variety of play types in the context of being with others, despite many of these being able to be played and enjoyed independently.

These children appreciated being with anyone who may have been interested in playing with them (#2: 0, +1; #4: -1, -2) and gave little attention to having playmates of a similar age or gender (#6: -4, -3; #7: -3, -4), as demonstrated by placing these items as the most unimportant on the grid.

Given that these children preferred not to play on their own, they gave less perceived importance to having a private play space (#17: -2, -3) and were less concerned about the accessibility of the settings (#16: -1, 0; #19: -2, -1). An 8-year old girl at Kuwait's hospital commented: *'mummy is with me,'* thereby placing less attention on her level of independence. When considering the playroom (#18: -1, -2), a space which can allow social interaction, one of the children explained from her viewpoint that: *'It's boring... because you have to play on your own'* (11-year old girl in the UK hospital). Outdoor areas were rated of neutral importance also (#11: 0, +1; #10: +1, 0;).

Factor 2: Conditions of play

Eight children were significantly associated with this factor (Table 3). Their average age was 8.1 y. They were all recruited from the hospitals. Five of them were from Kuwait, and five were female.

The children who significantly loaded on this factor prioritised the conditions of their play in terms of some of the play equipment, spaces and playmate. They were very selective in their play choices regarding both the social and the physical items; accordingly, their selections of the play conditions guided their play.

Despite family being highly ranked (#1: +4, +4) they would have preferred, if given the option, to have had a playmate of a similar age and gender (#6: -1, 0; #7: 0, +1), when compared to factor 1. They did not consider the availability of pets (#8: -1, -3) to be essential for their play. These children would choose to play with age- (#13: +1, +2) and gender-appropriate toys (#14: +2, +2), if available. One of the children clearly stated that he would play with *'only boys' toys* (7-year old boy in the UK hospital). These children were found to prioritise being indoors; consequently, they did not care much about issues related to outdoors (#9: -1, -4; #10: -2, -1; #3: -3, -4). A similar positive response in linking the environmental context with their play participation was found for arts and crafts play (#20: +2, +3) and the playroom (#18: +4, +4). When one of the children was asked about the importance of the playroom (#18: +4, +4) he answered: *'because I love drawing'* (7-year old boy at Kuwait's hospital). Furthermore, swimming and water play (#3: -3, -4) were deemed extremely unimportant, with an 11-year old girl in Kuwait hospital responding by laughing when she was asked about water play, replying: *'I'm at the hospital, why do I need to swim?'*

Differences found in the data

After presenting the two factors, it is important to re-emphasise that in both factors, family (#1) and arts and crafts activities (#20) were always highly ranked, whereas, neutral importance was commonly placed on most of the play activities (see Table 1: #21; #23; #24; #25; #26).

The majority of items between the two factors were similar in each country. Of the differences, the level of importance placed on independence was higher in the UK sample than in Kuwait (#16; #19), whereas in Kuwait, playing Lego (#27) and engaging in dressing up (#15) were typically higher than in the UK. For the two factors of children in Kuwait, the availability of a paid caregiver (#28) was extremely unimportant to children's play. It is of note that it was not possible to compare the differences between the settings as only three participants were recruited from the hospices (see Table 2).

DISCUSSION

This study is the first to investigate the perspectives of children living with life threatening/limiting conditions regarding the social and physical environmental factors associated with their play. Our study found that being with others was essential for the children in this research to enjoy playing, regardless of what the type of play was. The children would play with whoever was willing despite acknowledging their own preferences. Children had relatively little concern for having outdoor play areas and, with the exception for arts and crafts play which was consistently highly ranked, for the type of play activities to engage in. Our findings indicate that the play needs for the included participants are very similar across the two cultures, despite the proposed acknowledgment of variations in children's play across cultures/communities (Hughes, 2010; Rubin et al., 1983).

Previous studies have shown children's general need for companionship when hospitalised (Angstrom-Brannstrom et al., 2013; Nabors & Liddle, 2017; Witt et al., 2019) and a few studies have demonstrated this need with specific reference to children's play (Adistie et al., 2019; Wilson, Megel, Enenbach, & Carlson, 2010). The findings of our study have shown that children with life threatening/limiting conditions greatly value physical play resources (e.g., availability of play space and equipment) when they are related to an increased opportunity for playing with others. For example, the association between the playroom and social play is likely because children can find more people willing to share play in the playroom (Lambert et al., 2014a; Wilson et al., 2010). When the children in this study were unable to interact with others in the playroom, they found that situation to be 'boring' as demonstrated in the findings. However, the current practice in supporting play in palliative care is usually based on providing physical space and equipment for the children to use (Weinberger, Butler, McGee, Schumacher, & Brown, 2017), and therefore, designing the services has to take into consideration facilitating social connectivity which meets children's need for social interaction and enjoyment of play.

Being with others was a play need however the choices of the playmate depended on two aspects: 1) children's preferences and 2) people's availability and their willingness to share play. It had been illustrated in the interpreted factors that two different perspectives for the children emerged from the Q methodology, but these were similar in the two countries. One of the factors placed low importance on a playmate's age and gender, whereas the other group believed they were of neutral importance. The same perspective applied to play with pets. This is contrary to the general consensus in the literature which suggests a tendency in middle childhood to have the same age and gender playmates (Hughes, 2010; Robnett & Susskind, 2010) and which views pets as an important factor for all children (Foster & Whitehead, 2019; Nabors et al., 2019). Differences between the factors regarding these items' perceived importance (i.e., playmate age, gender and pets) cannot be suggested as culturally-bonded or age-related. This is because each factor represents participation from both countries. Rather, differences can be suggested to represent: a) personal preferences, b) already established relationships, and c) the ways in which children were parented and nurtured (Lam, McHale, & Crouter, 2014; Robnett & Susskind, 2010). The situation of the children, for instance receiving care in an inpatient setting, may also lead them to select what is available to them regardless of their individual preferences.

One of the unanticipated observations in this study was the low importance given to play with electronic devices, particularly when considering the large body of evidence that suggests children spend long hours engaging in such play types (Jasem, 2019; Lima & Santos, 2015; Witt et al., 2019). This can be explained by the children's prioritisation of the social play experience. Arcury, Suerken, Ip, Moore, and Quandt (2017) have found that children's media use time decreases in direct relation to an increased number of people sharing the room. Deeming play with electronic devices as less important means simply that they are only less important when compared to other items in the Q set which may provide richer, social experiences. Additionally, when the children were required to prioritise aspects

related to their play using the Q methodology, their selections were based on their perceptions of what the meaning of play is to them. It has been reported by James et al. (James, Jenks, & Prout, 1998) that the meaning of play for the children is different from adults' definitions of play. Accordingly, it is important to understand the meaning that children carry for what play is and their reasons for playing before reaching a conclusion with regards to their play. The social aspects of screen time was not measured in this study, which might be required to understand children's conception of screen time and of the social experiences children may access via using the electronic devices.

Arts and crafts play was prioritised as the highest by the participants in this study. While the children may often chose such play to engage in, studies have highlighted that most of the play activities which are prepared by adults within healthcare settings are arts and crafts activities (Jasem, 2019; Nabors & Liddle, 2017). This outcome could therefore have been subconsciously influenced by what children 'normally' participated in as the play specialists, who facilitated most of the children's play, usually used this type of play with children. This preference by the play specialists could be because of their belief in the usefulness of arts and crafts to provide distraction and to allow the children to express their feelings (Adistie et al., 2019; Foster & Whitehead, 2019; Nabors et al., 2018; Nabors & Liddle, 2017). Similarly, children have highlighted their engagement in crafts and fun activities with a play specialist as a means of distraction for them (Nabors & Liddle, 2017).

Our studies in two culturally different countries and settings, strongly suggest that for play space what matters to children is having somebody to play with (Jasem, 2019). However, it worth noting that some items were found to be different; however, these were neither essential play needs, nor ranked as highly important /unimportant across the groups in the two countries, which indicated less differences between children needs across the two studied communities. Differences were noted with regards to children's play activities, for example, playing with blocks/Lego, puzzles, imaginative and pretend play was deemed more important in Kuwait, whereas reading and/or listening to stories held greater importance in the UK. Differences may have resulted from the variation in children's play across cultures and also as a product of school curricula reflecting the aspects given most attention (Hughes, 2010; Rubin et al., 1983). Understanding these differences can have a role in providing more suitable play opportunities for children, which respects their priorities and preferences for play, and may ultimately lead to the creation of better, supportive play environments that enhance children's play participation.

This study had some limitations. The study findings were less representative of children in hospices as fewer participants were recruited from the hospices compared to the hospitals. This was because less participants from the hospice met the study's eligibility criteria and in relation to this, the more complicated cases were observed in the hospices and Q methodology is not appropriate to use with these children. Consequently, this resulted in the under-representation of children with complex needs within our study sample. Despite this, the employed research method, the Q methodology, allowed the use of participatory

research with children that can assist in managing the researcher-child relationship; therefore, empowering the children (Mandell, 1991). This was utilised by having the researcher engage with children in joint action of play. To children, the Q methodology looked like a card game. This method represents how the researcher values children's abilities. Accordingly, it allowed the children's voices to be heard, and the data strongly suggest that these children were able to express what is important to them, which adds to the trustworthiness of the findings.

In conclusion, this study is the first to explore the social and physical environmental factors that are associated with the play of children living with life threatening/limiting conditions, across two culturally different countries. The data were generated using Q methodology, collected from children receiving healthcare in hospitals or hospices. The findings of this study demonstrate that regardless of the differences in children's cultural background, age, gender, condition and its severity, children have very similar play needs and play choices. The findings markedly showed that what matters most to children when considering an environment that encourages their play participation is having a play partner. Thus, creating opportunities of being with others, whilst matching the children's needs and preferences will be of great benefit. The physical aspects of the environment are recommended to be used in a way that supports social connectivity. In addition, advancements in technology can be used when children are away from their loved playmate. Future research should build upon these findings by evaluating the effectiveness of such interventions on children's well-being and the positive experience of play despite their illnesses.

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The authors would like to thank the children for their kindness and willingness to participate. Thanks are also due to the settings which hosted this research study.

Key Messages

1. Being with others is essential for the children to enjoy playing, regardless of what the type of play is.
2. The physical aspects of the environment are recommended to be used in a way that supports social connectivity
3. Children had relatively little concern for having outdoor play.
4. Children had relatively little concern for the type of play activities to engage in with the exception for arts and crafts play for the type of play activities to engage in.
5. Despite what the evidence demonstrates about the long hours' children spent on playing with electronic devices, it is not one of their most important play thing as found in this study.

6. Data collected from the participants in this study demonstrated very similar play needs across Kuwait and the UK, despite the proposed acknowledgment of variations in children's play across cultures/communities.



















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Table 1 Q set

Item no	The item	Visual image	Factor 1		Factor 2	
			Kuwait	UK	Kuwait	UK
1	Family	 Family	+4	+4	+4	+4
2	doctor/nurse	 doctor/nurse	0	+1	-2	-2
3	swimming	 swimming	+3	+3	-3	-4
4	clown/musical man	 clown  musical man	-1	-2	-3	+1
5	Joking	 joking	+2	0	0	0
6	like my age	 Like my age	-4	-3	-1	0
7	like me	 Like me	-3	-4	0	+1
8	Pets	 pets	+3	+4	-1	-3
9	weather	 weather	0	-1	-1	-4
10	beach/ sea side	 beach, seaside	+1	0	-2	-1
11	outdoor	 outdoor	0	+1	0	-3
12	active play	 active play	+2	+1	+1	-2
13	toys for my age	 Toys for my age	-4	-1	+1	+2
14	boys/ girls toys	 boys/girls toys	0	-4	+2	+2
15	dress up	 dress up	0	-2	+3	-1
16	easy moving around	 Easy moving around	-1	0	-2	+3
17	private play area	 Private play area	-2	-3	0	-1

18	playroom	 playroom	-1	-2	+4	+4
19	getting toys	 Getting toys	-2	-1	-4	0
20	Art	 art	+4	+3	+2	+3
21	singing & dancing	 singing & dancing	0	+1	0	-1
22	cooking	 cooking	-1	+2	-1	-2
23	reading	 reading	+1	+2	+2	0
24	board games	 board games	-2	-1	0	+1
25	videogames	 video / PlayStation Personal tablet (ipad)	+1	+2	+1	0
26	TV	 TV	+1	0	+1	+2
27	Lego	 Lego	+2	0	+3	+1
28*	Paid caregiver	 Paid caregiver	-3	-	-4	-

*item only used in Kuwait's sample

Table 2 Participant characteristics

Characteristics		Kuwait's participants	UK's participants	All participants
Sample size n (%)		14 (51.9%)*	13 (48.1%) ¹	27 (100%)
Gender n (%)	Male	6 (42.9%)	6 (46.2%)	12 (44.4%)
	Female	8 (57.1%)	7 (53.8%)	15 (55.6%)
Age **, mean(SD)		7.71 (1.97)	8.26 (2.06)	8.15 (2.03)
Research setting n (%)	Hospital	12 (85.7%)	12 (92.3%)	24 (88.9%)
	Hospice	2 (14.3%)	1 (7.7%)	3 (11.1%)
Ethnicity n (%)	Arab	12 (85.7%)	-	12 (44%)
	White British	-	12 (92.3%)	12 (44%)
	African/Black	1 (7.1%)	1 (7.7%)	2 (7.4%)
	South-Asian	1 (7.1%)	-	1 (3.7%)
Diagnosis n (%)	Neurology	1 (7.1%)	1 (7.7%)	2 (7.4%)
	Oncology	4 (28.6%)	5 (38.5%)	9 (33.3%)
	Haematology	5 (35.7%)	1 (7.7%)	6 (22.2%)
	Congenital	3 (21.4%)	-	3 (11.1%)
	Genitourinary	1 (7.1%)	3 (23.1%)	4 (14.8%)
	Cardiology	-	1 (7.7%)	1 (3.7%)
	Metabolic	-	2 (15.4%)	2 (7.4%)
Spectrum of palliative care need*** n (%)	Yellow	11 (78.6%)	10 (76.9%)	21 (77.8%)
	Amber	3 (21.4%)	3 (23.1%)	6 (22.2%)

*The percentage is calculated for the total sample size

**Mean and standard deviation are used to present the descriptive data

*** According to the Spectrum of Children's Palliative Care Needs(Shaw et al., 2015); *yellow*: children expected to die before adulthood (18yrs old) and; *amber*: children where death is expected in a few months to years.

Table 3 Factor matrix

Q sort no. (participant's code)	Factor loadings on Factor 1	Factor loadings on Factor 2	Child's age ⁽¹⁾ & gender ⁽²⁾	Country ⁽³⁾ & setting
1.	0.1043	0.6123*	11, F	KW, hospital
2.	0.6397*	0.0965	8, M	KW, hospital
3.	-0.3286	0.0435	8, F	KW, hospital
4.	0.3145	0.7733*	9, F	KW, hospital
5.	0.2224	0.7542*	6, F	KW, hospital
6.	-0.1635	0.4997*	5, F	KW, hospital
7.	0.2555	0.6509*	7, M	KW, hospital
8.	0.3136	0.3495	7, M	KW, hospital
9.	0.6875*	-0.0325	9, M	KW, hospital
10.	0.5318*	0.2357	5, F	KW, hospital
11.	0.5634*	0.0763	8, F	KW, hospital
12.	0.5838*	-0.3787	10, M	KW, hospital
13.	0.0773	0.4424	10, M	KW, hospice
14.	0.7420*	0.1348	5, F	KW, hospice
15.	0.5017*	-0.2450	8, F	UK, hospice
16.	0.6822*	-0.0101	11, F	UK, hospital
17.	-0.1552	0.7696*	7, M	UK, hospital
18.	-0.0315	-0.0440	8, M	UK, hospital
19.	0.4502	0.3468	10, M	UK, hospital
20.	-0.0837	0.8113*	8, M	UK, hospital
21.	0.3941	0.6064*	11, F	UK, hospital
22.	0.4995*	0.2824	9, F	UK, hospital
23.	-0.1088	-0.0551	5, M	UK, hospital
24.	0.5213*	-0.1081	9, F	UK, hospital
25.	0.6701*	-0.0199	11, F	UK, hospital
26.	0.8621*	-0.2252	10, F	UK, hospital
27.	-0.0014	0.2228	5, M	UK, hospital

*indicates a defining sort (the significance factor loading calculated at P-value < 0.01)

⁽¹⁾Age calculated in years; ⁽²⁾M for male and F for female; ⁽³⁾KW is for Kuwait and UK for United Kingdom

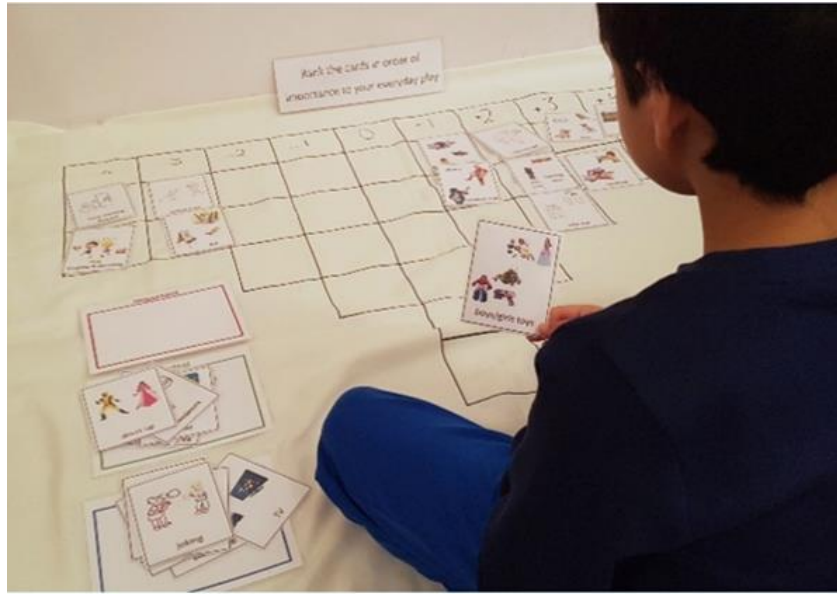


Figure 1 Q methodology

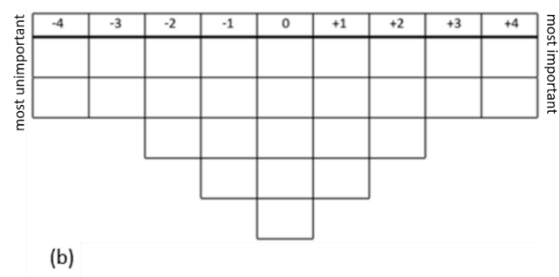
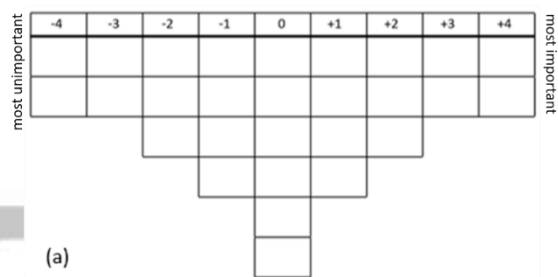


Figure 2 Q matrices: (a) represents children's Q matrix in Kuwait and (b) for the children in the UK