Play of children with life-threatening/limiting conditions: a scoping review

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Abstract

Objective: Play is essential to children, provides opportunities to promote their health and wellbeing. Children living with life-threatening/limiting conditions experience deprivation in play.

Method: This paper provides a scoping review to identify relevant literature regarding the play of children with life-threatening/limiting conditions and factors influencing their play participation. A search of literature published between 1990–2017 was conducted in health, social care and built environment fields using defined criteria. Identified papers were critically appraised and analyzed.

Findings: Thirteen papers were reviewed. The findings indicate that children's play is influenced by their health conditions and play opportunities, including the limited available appropriate play equipment and the need for more spaces that are easily accessible allowing play and social interaction.

Conclusion: There is a need to maximize the available appropriate play opportunities by understanding and considering the needs of children living with life-threatening/limiting conditions.

Keywords: pediatrics, play and playthings, palliative care, terminal care, hospice care

1 **Introduction**

2 A child's experiences are assembled through play; its essential role in children's lives has
3 long been acknowledged (Isenberg & Quisenberry, 2002; Rigby & Huggins, 2003). Play is a
4 fundamental building block for children's skill acquisition, as it involves different physical,
5 mental and emotional aspects (Parham, 2008). Throughout play, physical development can be
6 achieved because play is closely related to active physical participation (e.g., building gross
7 and fine motor skills and coordination) (Smith, 2010; Wood & Attfield, 2005). A child's
8 participation in play can also provide a safe atmosphere in which to develop social skills
9 (e.g., learning role taking and sharing) and facilitates their emotional development (e.g., self-
10 control, managing conflicting feelings and being sensitive to others) (Gray, 2011; Rubin,
11 Fein, & Vandenberg, 1983). Additionally, cognitive growth, including planning, attention
12 skills and language development, can be linked to play skills as well (Isenberg &
13 Quisenberry, 2002; Rigby & Huggins, 2003).

14 The different functions that play serves have attracted the attention of researchers and
15 professionals from a variety of fields. Although it is a multi-disciplinary concept, all
16 researchers agree that play is a key facilitator of a child's optimal growth across different life
17 domains (Isenberg & Quisenberry, 2002). However, each discipline tries to investigate play
18 from its own perspective and interests. From the perspective of occupational therapy as a
19 profession concerned with individuals' occupations, play is considered to be a child's
20 primary occupation. Occupations include the purposive activities that occupy one's time,
21 bringing meaning and adding value to life (Clark & Lawlor, 2009; Strong et al., 1999). It is
22 noteworthy that a strong, positive relationship exists between participation in occupation,
23 particularly play, and children's well-being (Hocking, 2009; Moore & Lynch, 2017).

It is unfortunate that less attention is paid to the need for play for children living with life-threatening/limiting conditions (LTC/LLC) (Amery, 2016; Boucher, Downing, & Shemilt, 2014).

The number of children diagnosed with LTC/LLC worldwide is estimated to be more than 21 million (Connor, Downing, & Marston, 2017). These children often experience a loss or impairment that affects their participation in play, despite the fact that the role and value of play may be greater for vulnerable children with LTC/LLC (Amery, 2016; Boucher et al., 2014). In addition, there is a level of uncertainty around prognoses, meaning that LTC/LLC children may live into adulthood and require the skills that play can enable them to attain (McNamara-Goodger & Feudtner 2012; Shaw et al., 2015). Play is integral to children's experience of childhood; they benefit from the process of engagement (i.e. interaction with peers allows children to fully experience their childhood) and from the outcome of participation (i.e. developing later-life skills).

Regardless of children's prognoses or medical conditions, they remain children and have the right to act and live as children with the need to play (Boucher et al., 2014; United Nations, 2006). Children need encouragement to continue playing as a way of preserving their childhood and facing their illnesses in a less traumatic way, with the best quality of life possible. However, little is known about the play of children with LTC/LLC. The aim of this literature review is to review empirical studies discussing the play of children with LTC/LLC to explore their play characteristics and possible factors influencing their participation in play. By so doing, we add to the body of literature relating to understanding the play of children living with LTC/LLC. Additionally, this review will help to identify related issues that have a role to play in influencing children's participation in play.

Methods

The review was carried out according to (Aveyard, 2014) guidance and is presented in accordance with the PRISMA method (Moher, Liberati, Tetzlaff, Altman, & Group, 2009) (Figure 1).

Review methodology

For the stated purpose of this review, a scoping review was utilized. Very little is known about play as childhood everyday routine for children living with LTC/LLC. Therefore, this scoping review assists in mapping the available literature broadly and comprehensively (Arksey & O'Malley, 2005; Armstrong, Hall, Doyle, & Waters, 2011).

The review was conducted by setting and following a strict protocol to promote the reliability of the findings (Aveyard, 2014; Cronin, Ryan, & Coughlan, 2008). Furthermore, it was undertaken by identifying, critically appraising and synthesizing the relevant studies from a range of professional contexts, including health, palliative care, social services, sociology studies and design- and architecture-related topics, to comprehend the play of children living with LTC/LLC (Cronin et al., 2008; Davis, Drey, & Gould, 2009; Thomas & Harden, 2008).

Data sources and search strategy

To extract the most relevant empirical literature, a comprehensive search was conducted through multiple searches in electronic databases (AMED, CINAHL, PsychINFO, Medline, EMBASE, Web of Science, Scopus, ASSIA and Cochrane Library) (Table 1), grey literature, manual searches of relevant journals (Table 2) and reference lists. The search was limited to papers published between 1990 and October week two 2017. Although it can be considered a long time period, this was selected due to the limited number of available studies. Only literature written in the Arabic or English languages was searched, to limit the possibility of mistranslation from other languages in which the researchers were not fluent.

1 The main search terms (Table 3) “children”, “play”, and “LTC/LLC” were selected from the
2 overall research topic with different keywords and subject headings being used in
3 combination with Boolean operators (AND, OR) and search symbols to ensure that as many
4 relevant studies as possible were considered.

5 *Selection criteria*

6 To be included in the review, the studies must have discussed the play of children with
7 LLC/LTC. The authors needed to be clear in their results regarding the sample group. The
8 included studies had to have mentioned either life-threatening or life-limiting conditions,
9 palliative or end-of-life care, or long-term complex health conditions. The study also needed
10 to have included children aged between 5-11 years. This is because we are interested in
11 understanding daily play in middle childhood ages and their active involvement in selection
12 and preferences; younger children are usually and expected to be directed by caregivers,
13 while older children will be in an adolescent stage and engage in activities under the umbrella
14 of leisure. No restriction was imposed on the place of play (e.g., home or healthcare setting)
15 or the country of publication. Despite acknowledging the potential cultural influence on play,
16 this is an under-researched field, and therefore, studies were included irrespective of country
17 of origin.

18 We excluded non-research literature (anecdotal views or opinions) because they only
19 described the authors’ expectations or anticipated the way things happen rather than their
20 reality. In addition, studies examining the effectiveness of play, such as play with therapeutic
21 intent (e.g., sand play or pretend play) or play as a distraction (e.g., in hospital waiting areas
22 or emergency departments) were excluded. Studies focusing on staff or parents’ satisfaction
23 regarding services/facilities were also excluded. This was due to the aim of reviewing the
24 characteristics of children’s play and their views.

Research outcome

A vast number of papers were yielded (3635, Figure 1), perhaps because of the broad search terms used. However, it was important to review all of the relevant possibilities. To determine the relevance of a paper and decide whether it met the inclusion/exclusion criteria, the abstracts and titles were initially, screened and then the full papers were reviewed.

Study selection

A total of 3,635 studies of potential interest were retrieved by the literature search after removal of duplicates. The records were thereafter screened by title and abstract, resulting in 238 papers, which were fully reviewed using the inclusion and exclusion criteria. Following this, 67 studies were assessed against the inclusion and exclusion criteria. A further number of studies were excluded, mostly because they were either non-empirical research, studied play's therapeutic effectiveness, evaluated therapeutic camping programs on children's conditions, or targeted other age groups, i.e., adolescents. This process resulted in 13 relevant papers being included in this review (Figure 1).

Data appraisal and extraction

Quality was assessed using CASP, a critical appraisal skills program to review the quality of the reviewed papers, and the Joanna Briggs Institute Critical Appraisal Tools (The Joanna Briggs Institute, 2017) for appraising the evidence (Thomas & Harden, 2008). The appraisal guides were selected considering study design; i.e., qualitative guidance was used, and where the study was mixed in design, it was used along with a quantitative guidance. Each of the relevant papers was read and logged into a summary table detailing the key characteristics of the studies (Table 4).

Data analysis

This review utilizes thematic analysis and synthesis in deriving the main issues addressed in relation to the play of children with LTC/LLC in the empirical literature. This was carried out by initially generating free codes of related areas, followed by developing descriptive themes that assisted in integrating the findings from the studies through a logical flow in relation to continuity and consistency to arrive at the findings (Cronin et al., 2008; Thomas & Harden, 2008).

Findings

A limited number of studies have explored the play of children with LTC/LLC; in fact, only three of them focused on play. Lima and Santos (2015) explored the perspectives of children regarding the influence of play in the care process during hospitalization, and Silva and Cabral (2014) and Graham, Truman, and Hoigate (2015) investigated the impact of children's health conditions on the dimensions of their play. Another six studies that explored children's experience of the care received somewhat addressed play in their findings (Aldiss, Horstman, O'Leary, Richardson, & Gibson, 2009; Gibson, Aldiss, Horstman, Kumpunen, & Richardson, 2010; Kirk & Pritchard, 2012; Mufti, Towell, & Cartwright, 2015; Rabiee, Sloper, & Beresford, 2005; Ångström-Brännström, Dahlqvist, & Norberg, 2013). Some aspects of play were addressed in another four studies that had the main purpose of exploring the supportive hospital environment (V. Lambert, J. Coad, P. Hicks, & M. Glacken, 2014; Veronica Lambert, Jane Coad, Paula Hicks, & Michele Glacken, 2014; Riet, Jitsacorn, Junlapeeya, Dedkhard, & Thursby, 2014; Verschoren, Annemans, Van Steenwinkel, & Heylighen, 2015).

With regard to the thematic analysis and synthesis used, the findings can be classified into three main themes: continuity of play, influence of the conditions on play and play opportunities.

Continuity of play

Children and their parents hope that the children are able to continue in their normal everyday lives, in which play is an integral part (Aldiss et al., 2009; Rabiee et al., 2005; Verschoren et al., 2015). Children enjoy playing (Aldiss et al., 2009; Graham et al., 2015; Ångström-Brännström et al., 2013). It aids in their feeling of normality and adds fun and happiness (Aldiss et al., 2009; Graham et al., 2015; Lima & Santos, 2015). Children can gain comfort at home from play and everyday activities and miss many of these, such as building Lego, playing on the video games, coloring and reading while hospitalized (Gibson et al., 2010; Veronica Lambert et al., 2014; Ångström-Brännström et al., 2013). Having the opportunity to play the games they have at home when hospitalized makes their stay more enjoyable (Aldiss et al., 2009; Gibson et al., 2010; Lima & Santos, 2015). Often, childhood activities are perceived of as "normal" or as doing "normal" childhood things. While children living with a life-threatening/limiting condition may aspire to such "normality", achieving it may be challenging.

Influence of the LTC/LLC on children's play

Lima and Santos (2015) found that children with cancer mainly use electronic devices as a form of entertainment, as they can easily play with them in bed. This can be seen to be a result of the impact of the condition, as illustrated by Gibson et al. (2010) and Silva and Cabral (2014). Their findings indicated that the cancer itself and its treatment restrict a child's active play (e.g., riding a bike) and leave the child weakened and with limited physical abilities (e.g., balancing difficulties or being attached to an infusion) to do things and play physically. Thus, illness and treatment can place limitations on their activities (Aldiss et al., 2009; Graham et al., 2015; Mufti et al., 2015). As a consequence, children may develop more cautious lifestyles and follow the relevant precautions.

Available play opportunities for children with LTC/LLC

The little available data about children's play revealed that play opportunities can be considered a major reason for their participation in play, and this includes play equipment, spaces and playmates.

Play equipment: Despite that fact that toys are a necessary feature of the hospital for children, the children complained about the limited availability of toys, the need for more age- and gender-appropriate activities (Aldiss et al., 2009; Gibson et al., 2010; Kirk & Pritchard, 2012; V. Lambert et al., 2014; Veronica Lambert et al., 2014; Lima & Santos, 2015) and the maintenance and replacement of play equipment (Riet et al., 2014). Play equipment being kept on high shelves or in locked cabinets negatively attracted the children's attention as well (Gibson et al., 2010; Kirk & Pritchard, 2012).

Play spaces: The playroom was one of the most important features of the hospital for most of the children in addition to the toys (Aldiss et al., 2009; Gibson et al., 2010). Being in the hospital can be an unbearable situation, as it can restrict play and take children away from their daily routines (e.g., not being able to build with Lego) (Lima & Santos, 2015; Ångström-Brännström et al., 2013).

Although playrooms with a wide range of activities were usually available in healthcare facilities in all of the studies, the specific open hours of these rooms were a cause for concern among the children (Aldiss et al., 2009; Gibson et al., 2010; V. Lambert et al., 2014; Veronica Lambert et al., 2014; Lima & Santos, 2015; Verschoren et al., 2015). These rooms are usually closed after working hours and at weekends.

The use of the play areas can also be limited due to their inaccessibility, children's physical impairments, their need to follow precautions or their medical intervention or isolation (Gibson et al., 2010; V. Lambert et al., 2014; Veronica Lambert et al., 2014; Mufti et al., 2015). Children expressed a desire for more interesting spaces (e.g., fitness rooms, swimming

pools and cinemas) (Aldiss et al., 2009; Veronica Lambert et al., 2014; Verschoren et al., 2015). Additionally, the bathroom was referred to as a place where enjoyable play takes place. In particular, bathing was the most common play time, and the availability of bath-specific play toys was view positively (Graham et al., 2015; Veronica Lambert et al., 2014).

The importance of having shared places to interact with other children was emphasized by the children. It has been mentioned the corridors and waiting areas as places where children could often engage in pleasant social interaction with others (Verschoren et al., 2015). It has also been suggested to have playrooms integrated with the whole hospital or located in the center of the facility (V. Lambert et al., 2014; Veronica Lambert et al., 2014) in addition to having more relational spaces such as gardens (V. Lambert et al., 2014; Riet et al., 2014; Verschoren et al., 2015).

Playmates: Children mostly enjoyed talking about friendships (Gibson et al., 2010; Kirk & Pritchard, 2012; Rabiee et al., 2005). Kirk and Pritchard (2012) found that the majority of them liked school because there are more opportunities for play due to the presence of more children. This is in accord with the observations of Riet et al. (2014), who found that the garden at the hospital expanded the children's experience of social interaction as a place to play. Notably, the presence of siblings allowed the opportunity for play and laughter (Ångström-Brännström et al., 2013).

The social environment's impact on children's play is not restricted to the presence of playmates but also includes the cultural norms and support systems within the community. Mufti et al. (2015) demonstrate that children recognize their communities' discrimination and its influence on losing friends. Being labeled an unwell child in some communities means that other children will avoid making contact with that child. This negatively influences the

child's self-image by viewing themselves as disabled, particularly their limited ability to move during play, which leads to isolation.

Children's limited capabilities disrupt their play with grown-ups as well. Despite the fact that children enjoy playing with parents, nurses and play specialists (Gibson et al., 2010; Graham et al., 2015), the time and energy required from them to facilitate the child's play places a burden on them, resulting in limited opportunities.

Discussion

Children living with terminal conditions deserve optimal care to the last day of their lives, filled with opportunities for meaningful experiences with the best quality of life possible (Boucher et al., 2014). The LTC/LLC may prevent children from fully experiencing their childhood. Facilitating their access to a childhood that is, as far as possible, equitable to that of their peers in their communities (we might say "normal") is a duty of healthcare professionals (Randall, 2016).

Though a limited number of empirical studies have focused on this area, the thirteen studies that have been reviewed that met the stated eligibility criteria identified a number of concerns regarding the play of children living with LTC/LLC. Those findings were presented in three key concepts: 1) the influence of health conditions on challenging and challenging children's play, 2) the significance of continuity of participation in usual play and activities, and 3) the availability of social and physical factors in shaping children's play during their hospitalization.

These few available studies highlighted the significance of children continuing their everyday lives as "normal". Play is an integral part of this continuity by aiding normality, and adding fun and happiness during hospitalization. Both the children and their caregivers

1 acknowledged this essential role of play. This is in line with Ito et al. (2015) who found that
2 ongoing access to normal activities and relationships are components contributing to good
3 death. Therefore, it is important to assist children in maintaining their pre-existing roles.
4 However, their conditions and challenges change the type of play. This underlines the need to
5 understand the types of and reasons for play that children are able/unable to participate in due
6 to their health conditions. Most of the activities that were mentioned as being affected by
7 hospitalization seem to be easily adapted to hospital settings (e.g. Lego and reading).
8 However, more exploration is needed to discover the factors challenging their participation in
9 their preferred activities.

10 Another factors influencing children's participation in play revealed by the literature review
11 was the limited availability of play materials and the need for more age- and gender-
12 appropriate toys. However, this has not been elaborated on in the reviewed literature with
13 clear examples and descriptions. V. Lambert et al. (2014), for instance, gave very vague
14 examples regarding gender-appropriate play, claiming that girls play different games than
15 boys on computers. They added that the available toys are for only younger children. This
16 draws attention to a huge gap in our understanding of children's actual needs and their exact
17 meaning. Some of the researchers studied children from birth until late adolescence (Rabiee
18 et al., 2005) and did not segregate the perspectives of the different age groups or
19 acknowledge the type of reporter. The play needs of children to vary considerably in terms of
20 preferences and developmental play needs (Corsaro, 2015).

21 Play spaces, on the other hand, as perceived by children, were not limited to playrooms but
22 were wherever they could enjoy themselves and have fun. The concept of the built
23 environment's (i.e., physical environment's) influence, indoors or outdoors, was not a
24 consideration of the studies of this particular population. This illustrates the necessity to
25 further investigate the impact of the built environment on play. Some children experienced

difficulties using the play areas, but it was not clear if the areas had been designed in a way that children with various abilities could enjoy and use and what could be the factors limiting the use of these indoor or outdoor spaces. Consequently, many emphasized that children's restrictions/limitations in using the play areas affected their social play. This is evidence of the direct influence that the conditions for play indirectly influence children's playmate relationships.

Strengths and limitations of the review

Due to the nature of the studied concept, most of the studies considered were qualitative in design, except for two that used a mixed-methods approach. Despite this, the studies can help us develop our understanding of the phenomena and the purpose of exploring this field (Daly et al., 2007).

This review used a systematic approach to collect the papers, although it is not considered a systematic review. Due to its lack of predefined, precise research questions, resulting from the limited research in this area. Thus, it is at risk of confirmation bias (Green, Johnson, & Adams, 2006) and lacks extensive data syntheses (Armstrong et al., 2011). Furthermore, including journal articles only written in the English and Arabic languages might have in excluded other relevant studies.

Interestingly, the majority of the studies included children's voices. Despite children generally being under-represented in research. Children are often excluded, with studies including seeking the proxy views of carers instead, which is likely due to ethical issues, ignorance and a belief that children are less cognitively able to communicate (Scott, 2008). This review only included studies with children, or carers representing their children, as participants who were between the ages 5 and 11 years. A number of the reviewed studies included adolescents in addition to parents of children (Graham et al., 2015; Kirk &

Pritchard, 2012), nurses (Riet et al., 2014) and relatives of children, e.g., parents, siblings, grandparents and aunts (Silva & Cabral, 2014) who may not always be able to represent the full picture of children's actual needs or views. Although their inclusion may give a diversity of views, it is important to clearly segregate the different participants' views in the findings (i.e., children's views, carer's views and or healthcare professional views).

A quality assessment of the studies revealed that the majority were rated as either being of good or average quality, which can suggest a reasonable quality overall. Almost all of the studies set a clear aim and used an appropriate design and method to answer the research question, although more detail regarding the methods and modes of analysis are expected, including information about the participants and the presentation of the findings. These shortcomings contributed to the average score. Thus, the process of reaching particular findings was not always clear, especially the reflexivity and the examination of the researcher's role was not transparent in most of the studies. Despite this, a number of important implications that may help to inform future practice and research arising from this review's findings.

The findings that emerged from this review should be considered with caution, especially given that half of the studies were limited to patients with cancer. Children experiencing physical limitations were not well covered by this review; either they were excluded or their inclusion was not made clear in the studies reviewed. This underlines the crucial gap regarding children with more complex conditions. It worth noting that real difficulties exist in identifying individuals with LTC/LLC, which is probably due to the difficulty of the prognosis that defines this population (Fraser et al., 2012; McNamara-Goodger & Feudtner 2012).

Moreover, because most of the studies do not directly focus on play, there is a paucity of literature exploring the challenges to these children's play and the opportunities available to them. This may indicate a predominance of the medical approach and the future-oriented perspectives of adults, in addition to the lack of awareness of the major role of play in both being and becoming. As a consequence, immediate attention is required from professionals, to find alternative ways to enhance children's participation in play and enable the best possible quality of life, whether that life is short or extends into adulthood.

Implications for Occupational Therapy Practice

The findings of this review have the following implications for occupational therapy practice

- The nature of LTC/LLC and the effects on children's abilities and functioning negatively influence children's participation in their childhood occupation which is play.
- Children's continuous participation in their routines, particularly their preferred play modes and items, while hospitalized is important to their wellbeing.
- Different cultural, social and physical environmental factors shape children's play.
- Promoting children's participation in play can be achieved through targeting and recognizing the strength of the environmental influence, facilitating the environmental enablers and limiting the barriers.

Conclusion

It is a child's right to play and experience childhood. However, children living with health problems usually experience play deprivation. In this paper, studies on the play of children living with LTC/LLC were reviewed. Overall, the selected studies demonstrated that play is influenced by the health condition and limited play opportunities of children, including

appropriate play tools and the need for more areas for play to facilitate social interactions. Continuity in play is believed to have a positive impact. Several environmental factors were highlighted in this review as barriers to children's play, including the need for more age- and gender-appropriate play. In addition to children's concerns about having easy-to-use and easy-to-access play areas.

Generally, the topic of play for children with LTC/LLC is under-represented in the literature. The reviewed studies provide valuable information in terms of the limitations of the literature in this area. There is a need for good-quality studies to explore children's everyday routines, including play, particularly children living with non-oncological complex conditions. Obtaining more insights about their play characteristics and spaces. Awareness of the barriers that a child frequently encounters during play and discovering the enablers of play can support the design of environments for children's different capabilities. Suitable modifications should be proposed and good environmental factors that support play for children living with life threatening/limiting illness should be encouraged, allowing them to achieve a better life experience, to live their childhood, and/or to prepare for a good death.

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Figure caption

Figure 1 PRISMA flowchart of study retrieval and selection process

1 Table 1 The accessed electronic databases

DATABASE	**THE SCOPE/ RATIONAL FOR CHOOSING**	**APPLIED LIMITS**
EMBASE	EMBASE (1980-2017) covers human medicine and related biomedical research	Language: Arabic and English Date: 1990 to October week 2 2017
CINAHL	Cumulative Index of Nursing and Allied Health Literature Plus. It covers journals related to nursing and health related publications.	
Medline	Medical Literature On-Line which is a service of the National Library of Medicine and additional life science journals	
PsycINFO	Psychology Information that covers international literature in psychology and related fields	
AMED	Allied and Complementary Medicine Database contains records for articles relevant to alternative treatments including complementary medicine, occupational therapy, hospice care and palliative care.	

Web of Science	Provides peer-reviewed scholarly journal articles in the sciences, social sciences, arts and humanities	
ASSIA	Applied Social Sciences Index and Abstracts which covers research in the field of social science	
Scopus	Scopus provides output of research in the fields of social sciences, and arts and humanities	
Cochrane Library	Systematic reviews of literature on medicine, nursing and allied health professions	

1

1 Table 2 Manual searches have been done in the following journals

- Journal of Social Work in End-of-Life & Palliative Care
- International Journal of Palliative Nursing
- Palliative medicine
- American Journal of Hospice & Palliative Medicine
- End of Life Journal
- BMJ Supportive and Palliative Care
- Journal of Child Health Care
- European Journal of Palliative Care
- Health Environments Research and Design journal
- Journal of Healthcare Interior Design
- Design Studies
- Architectural Engineering and Design Management

2

Table 3 : Search terms used

Children		Play		LTC/LLC	
OR		OR		OR	
child* pediatric* paediatric* "Pediatrics" "Chronically Ill Children"	AND	play* game* toy* recreation* entertainment* disrtact* "Play and Playthings" "Play Therapy" "Childhood Play Behavior" "Childrens Recreational Games" "Recreation"	AND	"life limit*" "life-limit*" "life short*" "life-short*" "life threat*" "life-threat*" "chronic ill*" "chronic condition*" "chronic diseas*" "chronic diagnos*" "terminal ill*" "terminal condition*"	"terminal diagnos*" "terminal diseas*" "sever disabilit*" "Terminally Ill Patients" "Terminal Cancer" "Chronic Illness" hospice* "palliative care*" "end of life" "end-of-life" "terminal care"

1 Table 4 Summary of the selected studies' characteristics and findings

Reference and study location	Purpose	Design	Sample	Key findings	Main strength and weakness	Quality rating
Rabiee et al. (2005) **UK**	Identify priorities of children with disabilities and their families regarding outcomes of social care and support service	Qualitative semi-structured interviews with parents and children (whenever the child was not able to participate, other informant, who knows the child well,	Purposive sampling of 50 families (26 families who had a child (0-18 years old) with complex health care needs and 24 who had a child (3-18 years old) who does not use	The families and some of the children have the desire for the child to live life as non-disable child: having interest, future and independence. Children mostly enjoyed talking about friendships. The access to leisure opportunities is significantly influenced by child's health and well. However, the available options for social and leisure activities are limited.	Strength: appropriate method used, especially addressing those with limited communication skills Weakness: the final sample is not clear and the	Average

		participated). Visual and non-verbal techniques used with children who does not use speech for communication	speech for communication		results are not well presented	
Aldiss (2009) **UK**	Identify the views and experience of children with cancer about the hospital care	Use of play and puppet as an approach to collect data during the interviews	Purposive sampling of 10 children (4-5 years old) diagnosed with cancer	Children draw the focus on have volume of and accessibility to toys, playroom and activities as the most important features of a hospital. They mentioned very little about the illness and treatment. And missing parents	Strength: clear sample and sampling method Weakness: limited literature review and vague gap	Good

				and friends during hospitalization was also highlighted.		
Gibson et al. (2010) **UK**	Investigate experience and views of children and young people receiving cancer care to present a model of communication and information sharing	Qualitative exploratory study utilizing three participatory-based techniques according to the participant's age group (play and puppet, drawing and writing techniques and interviews)	Purposive sampling of 38 participants diagnosed with cancer (10 young children between 4-5 years, 17 older children between 6-12 years and 11 young people between 13-19 years)	Playrooms and toys are the primarily reason for satisfaction with hospitals among children. However, they were concerned about the limited play opportunities (e.g., toys, areas, playmates) and the influence of their condition on their play. Children's preferences for communication and information regarding their condition are affected by their age.	Strength: the findings clearly state and segregate the perspectives of the three age groups Weakness: limited literature review regarding the studied concepts	Good

Kirk and Pritchard (2011) **UK**	Investigate parents' and young people's perspectives of hospice support	Mixed method approach using postal surveys followed by in-depth qualitative interviews	108 questionnaires (49.8% response rate) from families who have children (2-30 years old) who had used the hospice in the previous two years. Also in-depth interviews with 12 parents (of children aged 6-20 years old)	The participants expressed high levels of satisfaction with the quality of care in the hospice. Parents acknowledged the clinical and family-focused care while the young people enjoyed the opportunity to meet friends. The need for more age-appropriate activities and facilities was highlighted.	Strength: the use of a mixed method and piloting the questionnaires used Weakness: the analysis process was not illustrated precisely	Average

			and 7 young people (9-22 years old) who were purposefully sampled from the postal survey			
Angstrom-Brannstrom (2013) **Sweden**	Describe a child's experience of being cared until death focusing on the comfort and discomfort factors	Fields notes from observations, the child's drawings and his comments on them and interviews with him, his mother	9 years-old boy diagnosed with cancer, his mother and a caring nurse	Comfort of a dying child can be enhanced by having the family close and experiencing normal daily activity (e.g., drawing and playing). Being home facilitate engaging in everyday activities.	Strength: use of triangulation in collecting data which enhanced credibility Weakness: single case study which	Average

		and a caring nurse			limits transferability	
V. Lambert et al. (2014) **Ireland**	Investigate children's perspectives of ideal hospital social spaces	Exploratory design utilizing participatory art based approach using semi-structured interviews and group workshops	Purposive sampling of 55 children (5-8 years old) in 3 randomly selected hospitals with various health conditions and	The need for readily available, freely/independently accessible and integrated leisure activities for creating positive hospital experience and social connectivity.	Strength: despite that interviews where not audio recorded, immediate electronic field notes were typed	Good

		that incorporated drawings and art and crafts	severities including chronic cases and hematological, oncological, metabolic, respiratory conditions		following the interview Weakness: lack of the sample enough details	
Veronica Lambert et al. (2014) **Ireland**	Explore children's perspectives of ideal physical design features of hospital built environment	Exploratory design utilizing participatory art based approach using semi-structured interviews and	Purposive sampling of 55 children (5-8 years old) in 3 randomly selected hospitals with various health	The children valued colorful, creative interior environment. They highlighted the need for easy access to open spaces or garden that allow free movements activities and need for age and gender appropriate play options.	Strength: clear description of the participants and more than half of the sample had previous	Good

		group workshops that incorporated drawings and art and crafts	conditions and severities including chronic cases and hematological, oncological, metabolic, respiratory conditions	Never the less, adaptive facilities/activities for those with restricted movement.	hospitalization experience Weakness: although sample of the participants art work presented in the results, it lacks to direct quotes to guide the reader to the particular findings	

Riet et al. (2014) **Thailand**	Identify nurses experience regarding the healing environment, garden, to support sick children	Qualitative study using narrative inquiry utilizing 3 focus group interviews	8 nurses (2 head nurses, 3 ward nurses and 3 nurse administrators) working in two children's wards that includes terminally ill patient	The garden as a non-clinical environment supports the sick children as well as their families: happiness, relaxation, distraction, social interaction. It also has positive benefits for children to as a space to play and in a safe environment, where they learn to cope with their prognosis and participate in educational activities during their hospital stay.	Strength: the reflexivity was addressed Weakness: children's stories regarding their experience were studied from nurses' perspectives	Average
Silva and Cabral (2014)	Investigate the impact of cancer on the	Qualitative design in accordance to	22 relatives of seven children (school age)	The illness itself and its treatment act as barriers to children's play, especially affecting their active	Strength: clear analysis process	Good

Brazil	dimensions of children's play	creative and sensitive method using lifeline and speaker map	receiving outpatient cancer treatment	play and leave the child weakened with limited ability for physical mobility. However, the participants' believed that play is significant part of normal childhood which children need to participate in.	Weakness: lack to the sample's details who were not only parents of children, rather other relatives	
Graham et al. (2015) **UK**	Explore parents' perspectives regarding the experience of their children's with severe cerebral palsy	Interpretivist qualitative study using in-depth semi-structured interviews	Convenient sampling of 7 parents of children (aged 17 months to 6 years) with severe cerebral palsy	Parents believed that children's play is an element of their daily routine. On the other hand, it places a burden on them due to the support they must offer to facilitate their children's play. Some parents perceive play and therapy as separate entities, while	Strength: clear description of the analysis process and useful practical implications	Good

	in terms of their everyday play and the therapeutic use of play			others feel guilty when not incorporating therapy into their children's play.	Weakness: the use of convenience sampling with participants who knew the aim of the study	
Lima and Santos (2015) **Brazil**	Understand the children's perspectives about the influence of play in the care process during hospitalization	Descriptive exploratory qualitative study using photographic recording and semi-structured interviews	8 children (aged 6-12 years) who were hospitalized for cancer treatment	Children prefer activities that can be easily performed in their own beds. They mostly use electronic devices as a form of entertainment. But they also engage in watching television, using toys and drawing. The different recreational activities	Strength: thick description of the participations which allows transferability	Good

				highlighted to provide fun, joy distraction and interaction.	Weakness: sampling method is not indicated	
Mufti et al. (2015) **Pakistan**	Explore the lived experience of children with beta-thalassemia major	Qualitative study exploring children's experiences using two stages: stage one utilized a focus group and role play with the findings subsequently used in stage two	Purposive sampling of 12 children (aged 8-12 years) diagnosed with beta-thalassemia major	Personal as well as contextual factors are shaping children's experiences including societal discrimination and self-identity. Children adopted cautious lifestyles due to their condition. As a consequence, they tend not to participate in lots of play activities, especially ones requiring active physical movement. Consequently, this	Strength: good practice to consider the children as participants; including considering the power-relationship, obtaining their assent and also the methods used	Good

		for further exploration through individual interviews		adversely affected their friendships.	Weakness: the research analysis process was not clear in how stage one guided stage two or how the second was analyzed	
Verschoren et al. (2015) **Belgium**	Investigate children's hospital stay experience and how architecture may	Exploratory study, employing observations in a child oncology ward with face-to-face interviews with	4 children (8-14 years old) who were hospitalized in oncology ward, one of their parents and 5 stuff members	The children need the chance to continue partaking in normal everyday life. In order to design a child-friendly hospital, there was not much concern on specific colors or theme, rather there is a need for adapted places for play	Strength: clear use of method and collected from different perspectives	Average

	contribution to improve this experience	children and their parents and focus group interview with hospital staff members	who work with young children on a daily basis (2 psychologist, pedagogical staff member, head nurse and oncologist)	and distraction and sufficient places for social interaction.	Weakness: obtaining ethical approval is not demonstrated	

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