Article

Using drawings to understand the child's experience of child-centred care on admission to a paediatric high dependency unit

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Abstract

Family- and child-centred care are philosophies of care used within paediatrics where the family and/or the child are central to healthcare delivery. This study explored the lived experience of hospitalized school-aged children admitted to a paediatric high dependency unit in New Zealand to gain insight into child-centred care from a child's perspective. An interpretive thematic approach was used where the child was asked to draw a picture of 'a person in the hospital' that was further explored through interviews. The interviews were recorded and transcribed verbatim with an inductive thematic analysis completed, drawing on the child-centred care framework. Twenty-six school-aged children participated. The pictures included drawings of family, staff, children and themselves. The themes generated from the interviews were *relationships* with themselves, family and staff and psychosocial, emotional and physical *support*. Children described themselves as co-creators of their own healthcare experience, consistent with child-centred care, while drawing on the principles of family-centred care. Further exploration of the concepts of 'participation versus protection' and 'child as becoming versus child as being' will contribute to translation and integration of child-centred care and family-centred care principles into practice, theory, research and policy.

Keywords

Children's participation, family-centred care, nurse–child relationships, nurse–family relationships, paediatric

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Introduction

Family-centred care (FCC) is a philosophy of care where family are central to care delivery, whereas child-centred care (CCC) is when the child is central, forefront and the actor and co-constructor of care delivery within the context of family and community (Coyne et al., 2016; Foster, 2015). Theorists report on a theoretical dichotomy between FCC (Shields, 2015, 2016) and CCC (Coyne et al., 2014, 2016) where gaining the child's and adult's perspective is required to gain a holistic lens of the child's lived experience and needs (Manning et al., 2017; Nilsson et al., 2013; Soderback et al., 2011). An adult's perspective includes the parent, staff or family's perception of what is in the best interests of the child, whereas a child's perspective is the child's perception of what is important (Soderback et al., 2011; Sommer et al., 2010).

A child's best interest is reflected when the child is respected, consulted, provided information and included as an active recipient of healthcare that acknowledges the child's age, maturity, competency and need for parental consent and/or presence (Coyne et al., 2016; Stålberg et al., 2016). The core principles of CCC include the child being seen as a social being and a key agent in family partnerships and collaborations with staff where dignity, respect, honesty, privacy and opportunities to make decisions about their care are promoted (Coyne et al., 2014, 2016; Sommer et al., 2010).

The admission of a child into hospital can install feelings of anxiety, fear and frustration for the child (Chappuis et al., 2011; Manning et al., 2014a) and family (Burns-Nader et al., 2014) with synergy or different perceptions reported between the child and family (Foster et al., 2013; Popp et al., 2013; Stabb et al., 2013). Every child and family bring unique attributes and experiences to a hospital admission that can influence each admission and future health (Dow et al., 2012; Sommer et al., 2010). Knowledge of the adult and child's perspectives, attitudes, needs and satisfaction regarding their hospital stay is an essential factor to incorporate into FCC and CCC to identify and tailor service provision and treatment to maximize a positive healthcare experience including short- and long-term outcomes (Curley et al., 2013; Manning et al., 2014b, 2018).

A therapeutic relationship between adults and the child enabled through communication (Gibson et al., 2010) and participation (Coyne and Harder, 2011) is influenced by the child's developmental and chronological age (Coyne and Gallagher, 2011), illness severity (Coyne et al., 2014), past experiences (Coyne and Gallagher, 2011), treatment (Coyne et al., 2015), coping strategies (Wilson et al., 2010), society (Coyne et al., 2013), hospital environment (Utkan, 2012) and the adult's perception of the child's role in shared decision-making (SDM) (Lambert et al., 2010). The need for adults to protect the child from undue stress and to agree on the child's level of participation in SDM is dependent on the adult's skill in understanding the child's world (Sommer et al., 2010) and is an ethical issue that requires further research (Carter et al., 2014). Randall and Hallowell (2012) suggest that staff need to critically reflect on how adults communicate and place children within a socially and politically constructed childhood to achieve cultural and ethical symmetry (Randall et al., 2013), whereas Coyne and Harder (2011) propose participation from a situational standpoint to allow a balance between protection and SDM.

The way staff communicate and relate to the family and child's transitional needs and the factors that influence these needs are areas that require further research as these interactions, experiences and relationships could influence psychological and health outcomes more than illness severity, length of stay or treatment received (Manning et al., 2017; Tornqvist et al., 2015). There is a plethora of literature on the adult and child's experiences in various hospital settings within an FCC framework (Cunningham and Rosenbaum, 2014; Foster and Whitehead, 2017b; Foster et al.,

2016) with limited literature on the relationship between the adult and child's perceptions of a child's paediatric critical care hospital experience within a CCC framework (Dickinson et al., 2014; Lambert and Glacken, 2011; Nilsson et al., 2013; Shields et al., 2015). The purpose of this study was to explore the child's perception of a hospital admission to a paediatric high dependency unit (PHDU) in New Zealand. A PHDU is a unit that provides an enhanced level of basic and intermediate observation, monitoring and intervention of critical care that can be safely delivered on a normal ward by competent staff (Healthy London Partnership Children and Young People's Critical Care Pathway Group, 2016).

Methodology

Design

An interpretive inductive phenomenological cross-sectional approach, involving drawings and interviews, was used to gain insight into the self-reported lived experience of 26 school-aged children from one PHDU in New Zealand (Gray, 2014).

Setting

The PHDU is an eight-bed unit that provides level one and two paediatric critical care treatment and monitoring of non-invasive ventilation support and multi-organ failure in a tertiary setting to over 700 inpatients in New Zealand every year. The hospital did not have a paediatric intensive care unit (PICU), so if children required level 3 critical care, they were transferred to the adult intensive care unit (ICU).

Sample

Through convenience sampling, 26 school-aged children (5–15 years of age) were recruited consecutively within the PHDU. The findings presented in this article were part of a larger study that used a convergent mixed method design where parents ($n = 104$), staff ($n = 88$) and children ($n = 26$) within the PHDU completed either the needs of parents questionnaire, intrinsic spirituality scale and/or child drawing hospital tool during 2011–2012 (Foster and Whitehead, 2017a, 2017c). Children needed to have a basic command of the English language and have given informed voluntary assent/consent with signed parental consent. A pilot study involving seven school-aged children within the PHDU was undertaken prior to this study, no changes were required.

Data collection

The researcher introduced herself to the parents and child 24 hours following admission into the unit. Once recruited into the study, data collection took place within 72 hours to allow memories to remain fresh for the child. At a time that was convenient to the child, family and staff, the child was given eight coloured crayons and one A4 sheet of white paper and asked to draw a picture of 'a person in the hospital' (Clatworthy et al., 1999a,1999b). The drawings were not scored for a level of anxiety as it was the self-reported meaning and connection to CCC concepts evident within the drawings and interviews that were of interest (Carter and Ford, 2013). Once the drawing was complete, the researcher asked the child seven open-ended questions formulated from the literature (Carroll, 1999; Colville et al., 2008; Playfor et al., 2000) (Table 1). All interviews were recorded

Table 1. Interview guide.

1. Please tell me about your drawing.
2. What was good about being in the PHDU?
3. What was bad about being in the PHDU?
4. What do you remember most while you were in the PHDU?
5. What or who helped you feel good while you were in the PHDU?
6. Are there things you could recommend to have in the PHDU?
7. Is there anything else you would like to add?

PHDU: paediatric high dependency unit.

and demographic data collected (age, ethnicity, gender, admission type and length of stay). To ensure authenticity, the interview was played back to the child and parent prior to transcription.

Ethical considerations

Hospital and university ethics approval (URA/08/05/033) was granted where the principles of informed consent, respect, beneficence, integrity, confidentiality and justice were upheld.

Data analysis

The descriptions of the drawings and open-ended questions were collected at the same time and analysed iteratively through inductive thematic content analysis by three separate researchers to ensure rigor. Researcher reflexivity was disclosed by each researcher at the beginning of the study to limit potential bias. Concepts on the phenomena of CCC were underlined (findings), coded (in vivo coding) and grouped into smaller or larger categories and themes based on similarity of meaning (Thomas, 2006). The researchers moved between the transcribed data until no new themes or categories were evident and compared these findings with the content evident in the drawings until a consensus was reached.

Drawings

Drawings have been used in the past as a way to engage children in research, measure anxiety and build therapeutic relationships with adults (Ångström-Brännström and Norberg, 2014; Clatworthy et al., 1999a; Dolidze et al., 2013; Manning et al., 2017). While the child was drawing the picture, the researcher stayed with the child to ensure it was the child's drawing and used this opportunity to build a relationship in which the child's description of their drawing and responses to the interview guide flowed smoothly as a continuation of this engagement. Interpretation of the drawings was undertaken in synergy with the child's description of the drawing to limit the likelihood of false inferences (Carter and Ford, 2013; Dolidze et al., 2013, Driessnack, 2005; Gross et al., 2006). The drawings, descriptions of the drawings and transcribed interviews comprised the data.

Results

Most of the drawings were completed within 30 minutes with the interviews lasting up to one hour. Twenty-six school-aged children consented to participate and eight children declined. The

Table 2. School-aged children's demographics.

Child's number	Gender (female/male)	Age (years)	Diagnosis (acute/planned)	Ethnicity	Number of findings (interviews)
1	Male	8	Ileus, acute	European	11
2	Female	7	Pancreatitis, acute	European	37
3	Female	8	Appendix, acute	Maori	18
4	Female	14	Ileus, acute	European	34
5	Male	5	Laminectomy, planned	European	16
6	Male	7	Multi-trauma, acute	European	16
7	Female	5	Brain tumour, planned	European	1
8	Female	6	Kidney tumour, planned	European	6
9	Female	12	Syndrome, acute	Chinese	31
10	Female	9	High BP, acute	European	22
11	Female	11	Asthma, acute	European	59
12	Female	11	Endocrine, planned	European	60
13	Female	8	Multi-trauma, acute	European	20
14	Male	5	Asthma, acute	European	11
15	Female	9	Asthma, acute	African	15
16	Female	7	Asthma, acute	Fijian	20
17	Male	8	Influenza, acute	European	35
18	Male	15	Anaphylaxis, acute	European	34
19	Male	5	Asthma, acute	European	19
20	Male	12	Diabetes, acute	European	24
21	Feale	8	Tonsillectomy, acute	European	22
22	Male	12	Asthma, acute	European	15
23	Female	6	Asthma, acute	European	44
24	Male	12	Encephalitis, acute	European	44
25	Female	6	Multi-trauma, acute	European	74
26	Male	10	Multi-trauma, acute	European	31

majority of admissions were younger children (69%) of European ethnicity (84%) whom had an acute admission (84%) with a short stay (96%), who had transferred into the unit from the emergency department (41%) or adult ICU (12%) with pre-existing co-morbidities (62%; Table 2).

Drawings

Most of the children drew themselves ($n = 18$), family members ($n = 18$), staff ($n = 8$), children ($n = 4$) or objects associated with religion ($n = 2$). A total of 86 items were counted in the pictures including machines/monitors ($n = 24$), beds ($n = 17$), chairs ($n = 15$), artefacts ($n = 12$), medicine ($n = 9$) and play activities ($n = 9$). Despite children being instructed to draw 'a person in the hospital', 24 children stated their picture included themselves, family, staff or another child as these people were important to them.

Themes

All of the children spoke freely about their families, pets, schools, likes, dislikes, hobbies, aspirations, fears and recommendations in response to the interview guide. Inductive thematic

Table 3. Children's hospital experiences.

Theme	Category	Subcategory	Exemplar (participant number)
Relationship (360 findings)	Nurses	Actions	The nurses helped me like they encouraged me to take my tablets and stuff . . . (14)
		Characteristics	The nurses were nice, most of them . . . they were happy, yeah . . . she was singing all the time, humming a song, the nurse was telling me she was having a little baby (3)
	Parents	Mum	Mum helped me because she stayed the night, she woke up with me every time (15)
		Dad	Dad's special he sells cars and does lots of things, it's a hard job doing that (16)
	Doctors	Actions	Doctors they're trying to make you better (20) . . . bad because well they're hurting you (4)
		Characteristics	The surgeons because they're funny, nice and friendly and every morning he came in and checked on me (4)
	Family	Family	. . . and my family being here all the time (22), my brother he's naughty all the time, he can't sleep at hospital this is my room and mum's (6)
		Myself	I was getting better and I was helping me get better (26)
Support (359 findings)	Treatment	Procedures	He was ripping that thing off my head that hurt (5) . . . and I was screaming and the breathing thing, the gas bottle, the black mask, very scary . . . (17)
		Symptoms	I was moving the pins in my head . . . EEE . . . EEE . . . and spewing (5)
	Psychological	Visitors	People coming to visit me, it was a good thing (24)
		Coping strategies	Cuddling my teddy bear, his names Ripley (21)
	Activities	Play	Feed the ducks, play in the playroom, borrow some toys, wheelchair rides, go to the café, blow bubbles (19) company with other children (12)
		School	Not going to school, not seeing my friends, not seeing my cat or going to movies or going to the park . . . (9) yeah it would be good to be back at school (5)

analysis of the interviews generated 719 findings, 327 codes, 14 subcategories, 7 main categories and 2 themes; relationships and support (Table 3).

Relationships

The theme relationships contained four categories and included the relationships children described with nurses, doctors, parents and family as was evident in the drawings (Table 3 and Figures 1–4).

The category 'nurses' included the nurse–child relationship and included the nurses' actions and characteristics. Fifteen children described these actions positively when their needs were met as they felt 'supported', 'safe' and 'listened to' and five children negatively when they felt 'excluded, isolated and forgotten', 'scared' or 'growled at' (participants 1, 10, 21, 25 and 26). The children described the nurses' characteristics as being 'kind', 'caring', 'helpful', 'happy', 'smiley', 'cool'

Figure 1. Participant 11.
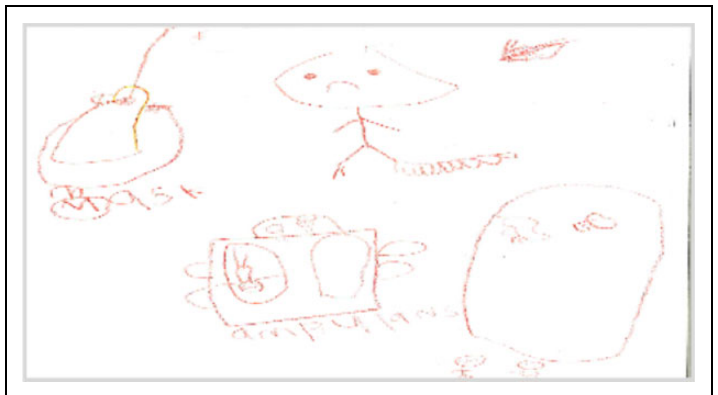

Figure 2. Participant 16.

Figure 3. Participant 14.

Figure 4. Participant 6.

and were remembered by five children when sharing personal information, exchanging gifts and/or felt unique and important (participants 3, 4, 11, 12 and 22).

An 11-year-old child admitted with asthma drew a portrait of the nurse who looked after her. She stated the nurse spent time with her and helped her make decisions. 'Isn't it funny my nurse and I have the same name, it makes me feel special, she is so nice, I really like her . . . '

Feeling special, cared for, listened to, included, loved and valued by staff and/or parents featured in the majority of the children's stories. However, for some children, negative feelings of being excluded, frustrated and angry were evident when the child's right to information, participation, negotiation and consent were not aligned to the child's perspective of their best interests.

The category 'parents' included the parent–child relationship and included mum and dad having 24-hour presence, living in, participating, negotiating, responsibilities, commitments and quality time spent with the child. Twenty-one children stated that to have their mothers and nine children their fathers present in hospital was 'good', 'nice', 'helpful' and 'important' because their parents helped 'change the TV channel', 'looked after them', 'made the pain go away' or installed a sense of 'happiness', 'hope' and 'safety'. One child stated that when her mother was absent the 'pain was really bad but got better when she came back' (participant 15).

A seven-year-old child admitted with asthma relayed how important, special and kind her father was.

> You know mum's at home with the others, dad comes in here and looks after me. Dad's special he sells cars and does lots of things, it's a hard job doing that, he gets tired, he's really busy but he's always smiling, can you see his smile and the bags under his eyes . . .

The category 'doctors' included the doctor–child relationship and included the doctors' actions and characteristics. Seven children described the doctors' actions positively when they felt 'safe', 'respected', 'listened to' and 'included in conversations' about their care, whereas two children who had long complicated hospital admissions with extensive multidisciplinary involvement remembered these relationships as 'frustrating' (participants 23 and 25). The doctors' characteristics were described by six children positively and related to doctors being 'funny', 'happy',

Figure 5. Participant 2.

'caring', 'nice' and 'super cool', and four children remembered this relationship as 'unique' (participants 4, 11, 22, and 24).

The category 'family' included the family–child relationship inclusive of aunties, uncles, cousins and siblings that 13 children described as 'important'. Eighteen children remembered forming a deeper relationship with themselves that included 'personal growth', 'resiliency', 'independence', 'confidence' and 'strength' within the context of family, whereas a few children were unable to recall events.

A five-year-old child admitted with asthma highlighted how 'scared' and 'frightened' he was because of his fear of the 'steamy medicine' and 'masks' but this time was different, he relayed that he knew it was going to be 'OK' because it always had been OK in the past.

A six-year-old child admitted as a multi-trauma drew himself with a red sun in the background. He stated the nurses and staff were 'kind' and 'caring' but that he just 'can't remember things'.

Self-awareness, mindfulness, personal growth, independence, strength and new perspectives were more evident in the stories of older children who had a chronic illness and/or a long hospital stay.

Support

The theme support contained three categories and related to the various ways children remembered being physically, psychologically and emotionally supported as was evident in the drawings (Table 3 and Figures 5 and 6).

Treatment related to the medical and nursing treatment the children remembered and included procedures and symptoms. Twelve children remembered these procedures as 'freaky', 'horrible', 'upsetting' and 'painful', yet eight of these same children also stated 'it was necessary' and 'important' as it 'helped them get better' (participants 4, 5, 14, 17, 20, 24, 25 and 26). Physical symptoms were described by 11 children as 'shivering', 'spewing', 'scary' and 'annoying' and by four older children with chronic illnesses as 'OK' because 'it was just part of it' (participants 12, 18, 20 and 22).

Figure 6. Participant 19.

A seven-year-old child admitted with acute pancreatitis drew a picture of herself receiving medical support with her mum and doctor standing beside the bed. 'That's me in the bed getting my medicines through my arm and there's my mum and the doctor, yep I'm feeling better now'.

Psychological support included coping strategies and visitors described by eight children as 'sleeping', 'watching movies', 'singing', 'crying', 'screaming', 'cuddling soft toys', 'eating' and 'playing with the many gifts' they received (participants 3, 5, 7, 11, 15, 18, 22 and 26). Gifts included 'books', 'soft toys', 'sweets', 'stationary', 'games' and 'flowers' that were described as 'helpful', 'fun' and 'special'.

Activities included the activities children remembered engaging in with adults and other children in hospital and the activities the child wanted to resume. Activities in the hospital included bubble blowing, crafts, movies, hospital clowns, Radio Lollipops and re-enactment of clinical procedures with other children. Fifteen children described these activities as 'fun', 'helpful', 'great', 'relaxing' and 'important' and a further nine children 'felt sad', 'neglected', 'angry' and 'unfairly treated' when they couldn't participate due to illness severity or isolation precautions. School included descriptions of normal activities 20 children described as 'important' and included 'cooking', 'eating', 'watching TV', 'going out', 'relaxing', 'reading', 'playing sports', 'walking the dog', 'catching up with friends', 'doing stuff' and 'returning to school'.

A five-year-old boy admitted with asthma highlighted the importance of 'getting home' to resume normal activities with his dad. 'That's me and dad playing sword fighting in the shed, can't you see, that's me and that's dad . . . '

Children in the hospital focused on the present as in 'getting better' while moving on into the future by looking forward to resuming activities that held meaning to them relative to their world.

Discussion

In this study, children were actors and co-constructors of their world within the PHDU. All of the children, albeit to varied degrees, were actively involved in the process of acquiring knowledge, rediscovering themselves, negotiating care, sharing feelings and/or creating a scene that was right

for them. Children relied on their relationships with adults, family, children and themselves for this process to evolve that helped construct meaning to their lived experience. There was synergy between what children drew and what they stated their experience was. Overall, the results have highlighted that the children wanted to get better in a hospital that fostered CCC within an FCC context with children being able to have some control over the negotiation and direction of their care.

The new, existing and deeper relationships formed between the child and adults were a recurrent theme evident in this study that illustrates the principles of CCC within an FCC and community context as being critical points described by children. The literature states that the inter-connectedness of personal, familial, societal and ethical variables are factors that can enable or constrain a child's ability to maintain one's identity in hospital that in turn influences the child's and adult's role, experiences and health outcomes (Bluebond-Langner et al., 2010; Rasmussen et al., 2017).

The characteristics that emerged from the interviews and drawings valued by children within these relationships were safety, respect, consultation, honesty, dignity, privacy and participation as key agents in family partnerships and collaboration with adults in synergy with family consent, guidance, involvement and presence. Similarly, hospitalized children have reported satisfaction in care when explanations, information, parental presence, participation, caring staff, recreational activities, visits from family and the meaning children found in comforting themselves and family members were present during their hospital stay (Ångström-Brännström and Norberg, 2014; Coyne et al., 2014, 2015; Coyne and Kirwan, 2012; Manning et al., 2017).

Of interest, all the children in this study included 'a person in the hospital' that had a positive meaning attached to their hospital experience as either being the kind staff member, special parent or family present at the bedside. Sixteen pictures included more than one person and 15 pictures included ways that support was received. The themes' relationships and support were synergistically connected as support was gained through sustaining and/or building new relationships with adults and children.

Chappuis et al. (2011) reported that 83–90% of children in Sweden had positive hospital experiences with parental presence being the most influential factor ($p = .04$) in contrast to age, gender or length of stay. Manning et al. (2017) reported that children in a PICU in the United Kingdom had positive accounts of resiliency, where rich descriptions of disrupted lives and stories, exposure to death and dying, dealing with different social worlds and identities and getting on with life were linked to that child's biographical and social world. Similarly, children in this study reported to a lesser degree concepts of confusion, resuming normal activities, personal growth and moving on. Demography has been reported in the literature as an influential factor to a child's and adult's behaviour, experiences and health outcomes (Burns-Nader et al., 2014; Coyne et al., 2014; Zwaanswijk et al., 2011).

Negative experiences described by some children in this study who had long complicated admissions were similar to reports on SDM in Ireland and the United Kingdom when children switched between wanting adults to be the major decision makers, buffers, information databases and advocates (Gibson et al., 2010) yet also valued being included in minor SDM on information, preferences and treatment (Coyne et al., 2014, 2015; Livesley and Long, 2013). This supports the concept that children are transitioning through different social worlds and identities and rely on adults as authority figures (Bluebond-Langner et al., 2010; Manning et al., 2017) to meet their ever changing state and needs at any given point (Lambert et al., 2010). Similarly, children in other studies have felt overlooked (Jensen et al., 2012), excluded (Gibson et al., 2010), rejected (Salmela

et al., 2010b), frustrated and ignored (Coyne and Gallagher, 2011), burdened (Coyne and Gallagher, 2011; Lambert et al., 2010), marooned and invisible (Livesley and Long, 2013), confused (Coyne and Kirwan, 2012), stigmatized (Manning et al., 2017), alone and bored (Wilson et al., 2010) with adults constraining SDM (Coyne and Gallagher, 2011; Gibson et al., 2010).

The children whom had numerous procedures, ICU input and long hospital stays wanted adults to take control of their care yet also stated they felt frustrated when they were not included in SDM. Whether protecting children from SDM was the adult's way to meet the best interests of the child is unknown in this study as parents' perceptions of this phenomena were not explored but what is known is that some children felt excluded, frustrated and angry when they were not fully consulted.

The desire to resume normal childhood activities was reported by all children in this study as important, remembered and helpful. Children in other studies have reported similar concepts of satisfaction in playing with other children (Chappuis et al., 2011), wanting children to play with (Wilson et al., 2010) and by focusing on the present and future as a way to resume normality (Manning et al., 2017). Adolescents in Ireland wanted services to be dynamic and responsive to their needs (Ångström-Brännström and Norberg, 2014), whereas younger children wanted toys, books, television and games (Coyne and Harder, 2011). Eight- to ten-year-old children in Denmark focused on positive memories as did children in Omaha (Jensen et al., 2012; Wilson et al., 2010), whereas children in the United Kingdom focused on hope and positivity as a way to cope with their disrupted lives and social identity (Manning et al., 2017) with four- to nine-year-old children preferring toys and school work (Gibson et al., 2010). Ullan et al. (2012) reported that a play program to reduce children's post-surgical pain in one- to seven-year-old children in Salamunca was successful which is in line with what children have stated is their preferred coping method (Salmela et al., 2010a) and is evident in the three types of play therapy used by child therapists in hospital as normative, medical and therapeutic play (Burns-Nader and Hernandez-Reif, 2016).

Historically drawings have been used as a means to score anxiety and explore the psychological well-being and lived experience of children (Ångström-Brännström and Norberg, 2014; Dolidze et al., 2013; Harder et al., 2015), whereas contemporary research is using participatory and collaborative approaches with art-based techniques as an effective method to gain insight into the child's world (Gray, 2014; Manning et al., 2014b). In this study to gain a true interpretation of the child's world and to decrease the likelihood of false inferences, the child's description and interpretation of the drawings in conjunction with the content of the drawing are what comprised the data (Harder et al., 2011, 2015; Soderback et al., 2011; Utkan, 2012). An acknowledgement that developmental age (Stabb et al., 2013), competence (Salmela et al., 2010a, 2010b), knowledge (Coyne and Kirwan, 2012), preferences (Soderback et al., 2011), relationships with adults (Coyne and Harder, 2011), society and power differentials (Bluebond-Langner et al., 2010; Manning et al., 2017), ethics (Lambert and Glacken, 2011) and the child's ability to participate (Nilsson et al., 2013) are influential variables that need to be considered during research designs and analysis within the context of the phenomena being explored (Gray, 2014).

Implications for practice

These results challenge the position of what approach is in the best interests of the child as children in this study showed synergy between both frameworks by being a co-creator of their own healthcare experience (CCC) and wanting family presence, consent and involvement (FCC). Further research is needed to explore how 'participation versus protection' and 'child as becoming versus child as being' where children are viewed as unique and/or part of a family, competent or

dependent, powerless or empowered where the right, degree and choice to participate is relational and situational (Coyne et al., 2014; Lambert et al., 2010) as directed by the child and adult to allow a balance between protection and SDM (Coyne and Gallagher, 2011; Coyne and Harder, 2011). In addition, inquiry into the influence age, competency, acuity and level of adult involvement with children who have long hospital stays, chronic illnesses, ICU and PICU admissions within an FCC and CCC framework is required (Manning et al., 2014b, 2018; Uniacke et al., 2018). The use of drawings as an adjunct research method is a valid means for children of various ages to express their lived experience and understanding of this in a way that best suits them.

Limitations

Limitations in this study were the cross-sectional design, convenience sampling, small sample size, limited use of data collection methods and lack of information on why the eight children declined to participate. A longitudinal design with the theoretical sampling and the use of adjunct data collection methods (observational, photography and artefacts) with family and/or adult perceptions would add further insight into the child's hospital experience within a PHDU.

Conclusion

This study has illustrated that the physical psychological emotional support and coping strategies described by children appeared to be synergistically interconnected to how therapeutic relationships with staff, parents and themselves were experienced in one New Zealand PHDU. Further research from a global and cultural perspective is required to understand the relationship between children, parents and staff, where communication, demography and health outcomes are explored from a CCC and FCC approach. The use of drawings and interviews in this study have provided rich descriptions, further insight, understanding and knowledge into the school-aged child's hospital experience and factors that influence this lived experience.

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