**Title:** 'My Hospital Family': Family perceptions of a Singing Medicine project in a Children's Hospital in England'

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**Abstract**

Arts in Health projects are growing in number in the UK. One such project, Singing Medicine (SM), is offered to children with short and long-term health care needs at a Children's Hospital in England as part of the Hospital's Play Department. In an environment where children can experience loss of control over decisions and restricted play experiences, musical games and activities offer children affordances for choice and agency. They can also benefit parents and wider family members. In contrast to previous quantitative studies that explored the transferrable benefits of music participation for children, this paper reports on a qualitative study involving semi-structured interviews with families of children with long-term health care needs (ages 3 – 14 years old). A new concept of 'The Hospital Family' is introduced from analysis of data. Family members valued relational aspects of the musical games and suggested that benefits lasted beyond the life of the child. These findings are explored in the context of ecological systems theory and Froebelian principles.

**Key words:** Singing; Hospitals; Families; Children; Play; Musical Games

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## Introduction and context

The Singing Medicine project is one of a growing number of Arts in Health projects being delivered in the UK. This presents opportunities for researchers and artists to collaborate in order to explore societal and individual social benefits. In an era in which creative subjects are being squeezed in education, the role and value of the arts in health settings is increasingly acknowledged as will be discussed.

### *Singing Medicine*

Singing Medicine® is an award-winning project delivered weekly to all wards and to in-patient areas at a Children's Hospital by Ex Cathedra vocal tutors. The project aims bring all the benefits of play through singing to children staying in hospital using a repertoire of songs written by the vocal tutors themselves with additional well-known singing games. In an environment where children can feel they have lost control over their lives, singing games offer children opportunities for decision making and expression. The games also support areas of children's learning and can be adapted to meet children's individual needs as required. The Vocal Tutors visit all wards at the Hospital every Friday and all children who wish to participate are included. The singing games are tailored to individual children but the Vocal Tutors also work with groups of children in the Play Room, where children who are well enough come together to join a group session. There is no prescribed timing for the session but they usually last between 10 and 20 minutes depending on the nature of the session, the number of children and the children's interests. Families join in with the sessions and are encouraged to do so by the Vocal Tutors. Health care professionals such as nurses and allied staff such as pastoral staff also join in with the sessions on occasion and often request the tutors to visit specific children who they think might benefit. This is sometimes context specific, for example end of life situations.

### *This study*

The study reported on here focuses on family perceptions of their child's participation in participatory singing games for children with a range of health care needs at a children's hospital.

The study aimed to explore the views and perceptions of parents and wider family members whose children participate in the musical activities and games in the Singing Medicine project.

Research questions included:

1. What are the views and perceptions of family members on the role of musical activities and games during their child's stay in Hospital?
2. How can the application of ecological systems theory and Froebelian Principles help in understanding the meaning of these findings within the multiple integrative contexts in which children live and learn?

Froebelian principles are (Froebel Trust www.froebel.org.uk/):

- The integrity of childhood in its own right.
- The relationship of every child to family, community and to nature, culture and society.
- The uniqueness of every child's capacity and potential.
- The holistic nature of the development of every child.
- The role of play and creativity as central integrating elements in development and learning.
- The right of children to protection from harm or abuse and to the promotion of their overall well-being.

It should be noted that the views of health professionals were also sought during the study, however, this paper will report only on family member perceptions.

*Ecological systems theory*

Systems theorists suggest that children grow and develop in family systems and families are embedded in broader-based social systems. Events within and between systems reverberate and have either or both direct and indirect effects on the behavior and development of children, their parents and the family as a whole. As noted by Bronfenbrenner (1993: 7):

> *Whether parents can perform effectively in their child-rearing roles within the family depends on the role demands, stresses and supports emanating from other settings…Parents' evaluations of their own capacity to function, as well as their view of their children, are related to such external factors as flexibility of job schedules, adequacy of child care arrangements, the presence of friends and neighbours who can help out in large and small emergencies, the quality of health and social services and neighbourhood safety.*

The environment or ecological system consists of both the social world and the physical world of the child and exists at a number of levels. Children therefore grow and develop in a social and cultural context influenced by the bi-directional interactions and relationships within and between the environments they inhabit. Their learning and development is therefore socially and culturally constructed through interactions and relationships with others in environments where meanings and languages are shared. Most importantly children develop in the context of relationships within the microcontext of family relationships and other proximal environments where they might spend a lot of time. The social and physical resources within these microcontexts are influential and interactional with the child's own character and genetic inheritance (Bronfenbrenner, 1979; 1993). This model is useful as a tool to consider the activities provided by arts in health projects such as those available to children in a Children's Hospital and the potential influence on their relationships with wider family relations and hospital staff such as nurses.

*Arts in health settings*

In relation to the health benefits of participation in the arts generally, APPGAHW (2017a) and Fancourt (2017) highlight a wide range of possible ways in which the arts can support health and wellbeing of individuals, communities and societies in the context of contemporary models of health discussed above. This includes helping with specific identified conditions as well as promoting wellbeing, healthy behaviours and social engagement. However, children's rights in terms of access to participation, the wider benefits of such projects such affordances for family relationships, children's perception of hospital and hospital experiences, any lasting

effects after participation/illness or indeed the necessary personal characteristics of the individuals who deliver the projects are not discussed in the literature. The APPG (2017a:1) does, however, acknowledge the potential for arts in health to improve children's hospital experiences, especially in relation to the design of creative health environments:

> Participatory arts in children's hospitals provide a pleasurable diversion from the anxiety of treatment and the boredom of long waiting times

Included in the broad definition of arts are singing and musical activities as well as performing arts such dance, drama, juggling and visual art such as painting and drawing (APPG, 2017a; Fancourt, 2017). Associated with the concept of social prescribing (which seeks to address health and wellbeing from a holistic perspective using a range of non-clinical interventions), participatory arts projects are growing in number in the UK (APPGAHW 2017b).

Some examples of the way in which participatory arts projects have been demonstrated to improve children's recovery from illness and management of long-term conditions are discussed below. A project providing somatic dance for children recovering from brain injury on orthopaedic, cardiac and neuromedical wards at Alder Hey Hospital found that patients became less anxious and better able to move after participating in the project. The researchers argue that this points to a role for improvised dance within paediatric health care and pain management (Dowler, 2013). Art therapy has been used in Great Ormond Street Children's Hospital for children with chronic conditions that prevent them from attending school and found to diminish fear and pain help to build coping strategies (The Teapot Trust, nd.). Creative writing has been proven to increase literacy and wellbeing (See Beyond Words, n.d; Spratt, 2012) and arts and creative play to reduce weight - related health problems (Matrix Insights, 2009). The APPG (2017a: 87) are convinced that 'participatory arts and arts therapies enhance social, emotional and behavioural development in young people.' These findings are not surprising as it is well established that music in particular has a number of transferrable benefits for children's overall development across developmental domains (Bugos and DeMarie, 2017; Hallam, 2015; Schlaug 2015; Silvia *et al.* 2016; Osborne, McPherson, Faulkner, Davidson, and Barrett, 2016). For a more

discursive narrative—see Henriksson-Macauley, 2014.) and in particular pro-social skills, particularly when the musical activities are shared rather than solitary; (Williams, 2015). It is also noted that music influences emotions (Barrett, Brown and Welch, 2019; Juslin &Vastfjall, 2008; Sloboda, O'Neill & Ivaldi, 2001). Sloboda (2011) for example found that listening to music helps with emotions by distracting from a distressing situation or helping individuals to think about the situation in a rational way. In addition music plays a role in creating happiness and relaxation.

Arts in health projects can also provide emotional relief in end of life situations. APPG (2017a: 12). The participatory arts and arts therapies can offer physical, psychological, spiritual and social support to people facing death. They can assuage the pain and anxiety of terminal illness and assist people in coming to terms with dying. They can help people to find meaning in the story of their lives and develop hopeful narratives. They can give voice to those who no longer feel able to speak and restore a sense of control to those who feel powerless. Every year, 12,500 parents in the UK experience the loss of a child (Lambert, 2015). However, there appear to be fewer arts in health projects currently that specifically support parents in this situation, with the majority reported on in the APPG in inquiry (2017a) focussing on end of life situations for older people. One project that aimed to support bereaved mothers was 'Surviving the Loss of Your World' established by two bereaved mothers in North London in 2007. Over 12 weeks in autumn 2014, six members of the group came together with an artist to explore different creative processes – including drawing, embossing, screen printing, sewing and audio recording. The aim was to capture experiences and the essence and memories of lost children. The project evaluation found that the artistic processes were 'rather similar to grief itself, slow, and allowing us to talk, bond, weep, laugh as we progressed our ideas and produced something that reflected our children' (https://slowgroup.co.uk/). This emphasises the importance of relationships in end of life situations. This is especially important for nursing staff as their role in end of life situations in 'providing compassionate and sensitive end of life care with the support of the wider multi-disciplinary team' is an important aspect of nursing (Royal College of Nursing, n.d.). At such times nurses must take account of the

emotional needs of the family as well as the health care needs and pain management needs of the child.

*Children's rights*

In terms of children's rights to engage in creative activities and make choices, the United Conventions on the Rights of the Child stipulate in Article 31 that every child has the right to relax, play and take part in a wide range of cultural and artistic activities and Article 12 states that every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously. This right applies at all times, for example during immigration proceedings, housing decisions or the child's day-to-day home life. These rights are arguably consistent with Froeblian principles, ecological systems theory and the APPG findings on the benefits of participatory arts engagement as described above. They might also be difficult to fulfil and observe in restricted environments where acute care, survival and recovery are necessarily prioritised, such as Children's Hospital emphasising the structural inequalities in the social determinants of health (APPG, 2017a).

## Methods

The research approach adopted a qualitative interpretive design in order to elicit thick descriptions and rich stories of children's lives through parent reports. Semi-structured interviews were undertaken with parents and other family members of children who are currently visiting their child during their stay at the Hospital. The aim was to select a maximal variation sample of children / families aged birth to eight from diverse social and cultural heritages and with a diverse range of healthcare experiences to participate. Inclusion criteria: having a child with a health care need attending the Children's Hospital and being able to and willing to participate in an interview to share experiences. Exclusion criteria: not having a child with a health care need attending the Children's Hospital / not wishing to participate in an interview. In practice, opportunity sampling was adopted as it proved difficult to identify parents and other family members who agreed to participate and had sufficient time to participate in an interview on visiting their child in Hospital. Because of this only children with long-term health care needs are included in the

sample (no parents of children with short-term health care needs volunteered to participate).

All participants were reminded of their right to withdraw and to anonymity and confidentiality prior to the interview commencing. Interviews lasted between 15 minutes and 40 minutes and took place at the Hospital. Interviews followed a semi-structured interview schedule that provided the opportunity for participants' own reflections on their experiences and knowledge. Interviews were digitally recorded, anonymised by use of a code and transferred to a specific OneDrive account. Only the researcher had access to this account through an individual login. Information sheets and consent forms were approved by both research ethics committees (see below Ethics section). Consent was specifically sought for any potentially identifying data such as ethnicity or other personal data.

Data were analysed to answer the research questions at the first level allowing common and discrepant themes to emerge subsequently. Research questions identified *a priori* themes and thereafter emerging themes were identified. Qualitative content analysis provided the opportunity to organise, condense and categorise data through a process of interpretation of and inference from participants' original expressions. This was an inductive process rather than being theory guided and deductive. A process of reducing and clustering to form initial codes or sub-categories that described followed. The unit of textual analysis was an extract from a transcription with factual connection to an idea and issue. After initial codes had been identified in data of two or three transcripts, codes were compared with each other according to similarities and differences to determine which data 'look alike' and 'feel alike' as suggested by Lincoln and Guba (19853: 47). The data analysis was informed by processes of thematic analysis – a foundational analytical method designed to identify, represent and report thematic patterns that occur within the data (Braun and Clarke 2006).

Since the research questions guided the study, the first level of qualitative data analysis for interview transcripts, was *a priori*. It allowed content analysis to organise, condense and categorise data. This was followed, at the second level, by an inductive process that allowed initial codes or sub-categories that described participants' experiences to emerge. After initial codes had been identified in the first transcripts, subsequent ones could be compared and contrasted for similarities and differences in

categories. Categories stayed close to the original expressions or records. Some were changed through abstraction and through combining of sub-categories during the analytical process.

*Ethical considerations*

Ethical considerations related to participant informed consent, right to anonymity, right to withdraw at all stages of the research and to power relationships between researchers and participants. Additional concerns relate to participants who may be emotionally and psychologically vulnerable due to their child's long-term health care needs (parents) and/or emotional and physical stress due to providing long-term care (parents and professionals). The researcher was experienced and had worked on numerous projects involving children, families and professionals as participants and took a reflective, responsive stance to the verbal and non-verbal signs and signals that participants utilised to demonstrate their emotional state. The researcher familiarised herself with Hospital safeguarding procedures and a Research Passport was obtained from the Hospital before data collection commenced which offered an additional layer of ethical and safeguarding protection. Ethical approval was given by the Faculty of Health, Education and Life Sciences Academic Ethics Committee and North of Scotland NHS Research Ethics Service as is required of all research conducting on NHS sites.

## Findings

Four parents participated in interviews, four of who had a child who was currently participating in the Singing Medicine sessions whilst the other parent had an adult offspring who had participated as a child. In addition, one older sibling of a child patient participated and one child participated with her mother (and a translator). See Table 1 below for participants' details and characteristics.

**Table 1: Participant details**

| **Participant number/Personal details** | **Details of child** | **Other characteristics** |
|---|---|---|
| 1. Mother of three young children, one of who has a chronic illness. | Male, aged seven years old. Has acute myeloid leukaemia. | The family is Polish and have lived in the UK for 12 years. The child's mother describes him as 'active, plays football and just sparkles his lovely energy, he's a lovely boy'. |

| | | |
|---|---|---|
| **2.** Mother of a child who participated in the Singing Medicine project. | Female who had leukaemia and died after nearly three years of treatment. After diagnosis at the age of five she received two and a half years of treatment. After an initial positive response to treatment, she relapsed nine months later. Following a bone marrow transplant the family say they 'lived' in hospital for nine months before their child died in November 2015. | Her mother said she adored music and dancing. Before being diagnosed she was due to audition for the National Ballet School, but became ill just before the audition. |
| **3.** Young adult aged eighteen who participated in the Singing Medicine project as a child. | The participant was six years old when she diagnosed with leukaemia. | In describing herself, she stated 'I'm very much into music, so I've done grade eight in violin and singing, and I sing in CBSO Youth Chorus in Birmingham and my school chamber choir. I also am a member of the National Youth Training Choir of Great Britain, I do lots of ballet, that's my other big hobby, and I also am a qualified ballet teacher.' |
| **4.** Mother of three young children, one of who has renal failure. | Male aged three years old (he is a twin). Renal failure was diagnosed at seven months of age. He has haemodialysis five days a week in the hospital and he is on a waiting list for both a kidney and liver transplant. | His mother describes him as 'very lively, creative' and says he loves painting, music and singing in a microphone. |
| **5.** Older sister of a child who participates in the Singing Medicine project. | Male aged fourteen who was diagnosed with cancer at the age of ten years old, and attends the teenage cancer treatment ward. | His sister described him as 'previously very active (but now now). Everyone knows him as that bubbly little boy who always smiles at whoever walks in. And he's willing to know people, get to know people. He's more like a people person. However, he has now lost his voice and has become quite withdrawn'. |
| 6. Parent of a child who participates in the singing medicine project interviewed with her daughter and a translator. | Female aged seven years old who has been attending the oncology ward for seven months. | The family moved to England from Albania two years ago and the child has friends in both countries. Her frequent hospital visits have implications for school attendance. She likes school. |

Findings from interviews will be reported under the thematic headings of:

- People in purple shirts
- Music and emotions
- Being part of a hospital family and normalising hospital experiences

- Distraction therapy
- Life after illness and death and lasting effects

*People in purple shirts*

A strong theme that emerged from analysis of data and mentioned by all parents was the significance of the personalities and characteristics of the vocal tutors involved in the project. The Singing Medicine vocal tutors were specifically referred to in very descriptive ways, for example:

'They are fun and enjoyable', 'They are gentle', 'They are inclusive', '[They are] ...People with smiley faces', '[They are] ...People in purple shirts'. The theme is exemplified by the following comment:

> So two people in purple shirts appeared with smiley faces, they introduced themselves and they invited us from our bay to the playroom for a Singing Medicine session. And from the first moment we entered the room there were chairs in a circle, a number of children were sitting on them and these people in purple started singing and involving children in the singing and playing instruments. It was wonderful and a lovely session. C enjoyed it so, so much that he kept asking for them every single day. (Participant 1)

This suggests that the children and families valued the familiarity introduced into the hospital space from the vocal tutors emphasised by their individual idiosyncratic behaviour reinforcing the important characteristics within microsystems (Bronfenbrenner 1979; 1993).

*Music and emotions*

A number of comments were made by family members in relation to the effect of the musical games on children's emotions and mental well-being and also on their own emotional state:

> Music is a very strange thing, and it kind of gets emotions out from you, and because of C's condition, I became very sensitive. So very often music causes tears in my eyes as a kind of reminder of the past, the songs we used to sing together in the past, so it's kind of an emotional thing as well…even talking about it is very emotional (Participant 1)

> There was less sadness and less complaining about being born or things hurting. It doesn't mean that things stopped hurting, but you had another focus. (Participant 2).

> I think singing lifts you, whether you're aware of it or not. I know it does me, even when I'm really sad. It's very difficult to be grumpy about singing and there's a lot to be grumpy about in hospital. But even if you're going, uh, I can't believe they're singing that song again, you can't be grumpy about it. They're all catchy, they all get to you … you can hear people enjoying themselves. You can't help but be happy about it. Even the grumpy teenage boys were happy and laughing at T singing and trying to teach them harmonies. (Participant 2).

> Well, I mean, obviously the most children, it makes them feel happier, makes them feel like they're enjoying themselves, having fun. And then in terms of making choices, within lots of the songs they get to choose what they're singing about or what songs they would like to do next and what instruments they would like to play and things like that….because as an ill child you certainly feel very out of control; with lots of people doing things to you. Particularly, like, I was six when I was diagnosed and at that age you are starting to gain your independence and it definitely felt like it had been taken away from me a bit. So I think Singing Medicine can definitely help with the emotional wellbeing (Participant 3).

> Happiness. It takes them into a zone where they… The rhythm kind of changes their mood, doesn't it? It's about how they were and how they are that day, and music just changes them instantly into a better person. They're happier that day. (Participant 5)

> I like singing and have lots fun (child)… She feels more positive when she takes part in it (mother) (Participant 6)

These comments reveal the effects of children experiencing long-term health conditions in terms of sadness, pain, loss/reduction of autonomy, negative emotional responses, and loss of control, which can be at least partially ameliorated through participatory singing games.

*Being part of a hospital family and normalising hospital experiences*

There was a suggestion from some participants that the vocal tutors adopt a new role in children's lives and become part of the child's 'hospital family' which helps to 'normalise' the child's hospital experience:

> The child is always surrounded by a number of people and depending on where we are, who we spend time with, we build relations with people, like even being in the hospital, it's not a great place to be, is it? We would prefer to be on holiday or back at home or in the park, not in the hospital. But we try to make life as normal as possible in situations which are not chosen by us anyway. When we came to the hospital, seeing all the equipment, and nurses and running doctors, beeping machines. But you try to make life as normal as possible and you try to make links with people you feel special ways that go through between you and this person, and I think we've built this relation with the Singing Medicine people. They became very nice uncles and aunties for C. Yes, it became part of his hospital life, as well his as mine too. (Participant 1).

> I suppose that in a kind of strange environment that was a sense of normality, so I refused to go home until we'd had Singing Medicine. (Participant 3).

These comments exemplify the sense of loss of connectedness to one's own family when experiencing long-term hospital care as well as the enjoyment of building new bonds and connectedness through a new 'hospital family'.

*Distraction therapy*

Participatory art as distraction from pain, anxiety and unpleasantness were mentioned by the APPG (2017a). Parents and family members in this study discussed the role of the singing games in distracting children from painful or boring medical treatment and enabling the child to experience something positive in the midst of unpleasantness. Moreover the experience of participating with their child, affords parents the same experience. This also provides opportunities for parents to have 'happy' memories of their child if the worst happens and the child does not survive their illness:

> I think singing is...it distracts your brain. When I'm singing, and she [my child] used to say the same thing, you have to concentrate on singing and breathing and the words and you can't think about everything else. It takes

over concentration. It needs your focus and you have to concentrate, even if you're not aware of it, on rhythm and breathing and that sort of thing. Although other creative things can distract you mentally, singing tends to be able to distract you physically as well and she needed her painkillers less. I mean, she was on an awful lot of painkillers, she was pressing buttons every five minutes, but singing could distract her for a little bit longer. (Participant 2)

Well it's entertainment; the sessions of haemodialysis are three and a half to four hours. So it's distracting them from what's going on and you've also got the educational and social element, because they do the group with quite similar ages. (Participant 4).

*Life after illness and death and lasting effects*

There was a suggestion that there were long-lasting benefits for both children and family members. Included in this was the motivation to keep promises made to an ill child and enduring memories of pleasant experiences amidst otherwise unpleasant or intrusive medical procedures:

I promised her that when we left the hospital, together, the two of us, I would join a choir, because I've always loved singing and I've run singing groups at churches and things like that. I always promised her I'd join a choir and it was the one thing I've managed to do that I promised her I'd do. (Participant 2)

So yes, I would say that it definitely has a lasting impression and it gives people something else to remember apart from the hospital treatments, even if it is just giggling about it, or whatever, it's...I've heard several of the songs since from children and families. (Participant 2)

I mean, I think from my parents' perspective it was just nice for them to see me enjoying something, because again it was a complete shock for them and they, I'm sure, felt very out of control and concerned about the future. So I think for them it was just nice to see me enjoying something rather than being upset or worried and that's a memory they'll always have. (Participant 3).

These memories of enjoyment and sharing of a pleasant social activity appear to be of significant importance to families in coping with illness and death.

**Discussion and conclusion**

This paper has reported on a qualitative interpretive study drawing on findings from interviews with six family members who have been involved in a musical activities and games at a Children's Hospital in England. In contrast to previous quantitative studies which have focused on the efficacy and wider transferable benefits of participation in arts in health projects, the study reported on here was particularly concerned with children's rights, family relationships and connections.

Data were analysed thematically and themes of: People in purple shirts; Music and emotions; Being part of a hospital family and normalising hospital experiences; Distraction therapy; Life after illness and death and lasting effects identified.

The APPG (2017a; 2017b) and Fancourt (2017) highlight a wide range of benefits from participatory arts in health projects. Many of these benefits focus on skill acquisition or development, mental health or specific health outcomes (for example Dowler 2013; The Teapot Trust, n.d.; Matrix Insights, 2009). The findings discussed in this paper suggest that children, parents and wider family members appreciate the relational aspects of participatory arts projects. The comments related to the identity and characteristics of the vocal tutors acknowledges the importance of routine and familiarity in an otherwise unfamiliar and clinical environment highlighting the role of the social and physical resources in an environment in children's lives (Bronfenbrenner, 1979; 1993). This makes the finding that normalising the hospital experience and the vocal tutors perceived as part of the 'hospital family' unsurprising but novel. Being part of a hospital family emphasises both the potentially negative effect of one's own family being distant and not being within the child's proximal processes during their (potentially long-term) hospital stay, but also the positive effects of developing new bonds and relationships in hostile, unfamiliar environments.

This latter finding and the lasting effects of the participation in the project for both children and families highlights the way in which participation in an activity in one setting such as a hospital can influence relations within the family home at the mesolevel including parents' experience of their child's death and activities and

ambitions following their child's death as noted by Bronfenbrenner (1979; 1993) and Slowgroup (n.d.).

The powerful contribution to reducing negative emotions through distraction and focused positive experiences and the 'creation of happiness' is evident in the data as noted by Sloboda (2011); Juslin & Vastfjall (2008); O'Neill & Ivalidi (2001). The connection between this theme and feeling part of a 'hospital family' is important in the context of acknowledge relational aspects of the project. Belonging and wellbeing are arguably interactional and bi-directional and children and families sense of wellbeing can be enhanced by this sense of togetherness created through the project.

Returning to Froebelian principles mentioned earlier, the findings suggest that in a hospital environment participatory arts projects promote children's right to participate in activities that are playful and creative and which also offer them affordances for choice making and regaining some control and power over their lives. Such activities also strengthen family connections and bonds (Bronfenbrenner, 1979; 1993). Moreover, they extend the concept of 'family' by introducing the notion of a 'hospital family' potentially reducing family stressors and enhancing family coping capacity. Overall child and family wellbeing are promoted through distraction therapy which enables children to remember pleasant experiences during their hospital visits and parents/other family members to embrace and capture such pleasant experiences for safekeeping and future proofing against any painful experiences of child death.

The ethical concerns of involving busy parents and other family members in research need to be taken into account as well as the complexity and messiness of being sufficiently flexible to account for their availability and emotional state when interviews have been agreed to and planned. Research of this nature cannot be rushed or hurried and extra time must be planned for as contingency within projects.

*Implications for practice*

The findings of this small-scale qualitative study suggest that for children with chronic illness and life limiting conditions, access to and participation in arts projects such as the Singing Medicine musical games provides a number of benefits for children and their wider family members.

It could also be argued that denying children access to such activities limits their possibilities of fulfilling their engagement with Froebelian principles, not to mention entitlement to their rights under the United National Conventions on the Rights of the Child (UNCRC).

This exemplifies inequalities in terms of access to participatory arts and health and wellbeing. Ensuring that children who has lost control over decision making and/or spend prolonged periods of time engaged in painful, intrusive activities have opportunities for play and creativity that allows for self-expression, distracts from pain and helps to connect children to the social and physical world must be a priority.

For nursing staff who must pay close attention to the practicalities and protocols involved in supporting children with long-term health care needs and possible end of life situations there are implications for alleviating pain, providing distraction and supporting a sense of happiness and improved mood. Further to this there are possibilities for supporting families' emotional needs.

There is a further possibility that nursing staff benefit from observing children and families enjoying themselves and from participating in the sessions themselves given the emotional burden that nursing staff carry in their professional lives.

*Limitations of the study*

This study represents in-depth qualitative data and rich descriptions of parents' and other family members' experiences. Trustworthiness was ensured by the use of a well-established and appropriate analytical method for qualitative research and the findings have been shared with family members professionals (member checking) to improve accuracy.

The sample size for interviews was small, only six qualitative interviews were undertaken and none of these were with fathers. This limits the potential for generalisability. However, this was not the aim of qualitative studies and family members' experiences of the Singing Medicine project are subjective and valid in their own right. The study was undertaken in one Hospital/healthcare setting only and for one singing medicine project only. It would be useful to conduct a large-scale

longitudinal study to explore the wider benefits across a range of settings with a higher number of participants.

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