Music therapy in the hospital-at-home: A practice for children in palliative care

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Abstract
This pilot research study investigated music therapy in a hospital-at-home setting for children in palliative care, focusing on parental and nurses experiences of music therapy. Nine families included in the study were interviewed after receiving a maximum of five individual music therapy sessions at home with a Music Therapist. In addition, a focus group interview with allied health professionals involved in the patients’ care was conducted investigating the multidisciplinary team’s experiences with music therapy. Results revealed that the families drew attention to the feeling of being isolated—yet connected due to music therapy. All the families reported the importance of the relationship to the Music Therapist, while emphasizing flexibility and joint music-making. Music therapy within hospital-at-home treatment was reported as a meaningful and much appreciated form of therapy, while the multidisciplinary teamwork was highly valued by both the health personnel and the families. The results showed the need for a highly skilled Music Therapist to support the families’ complex and dynamic needs within a hospital-at-home setting. The results demonstrated the need for, and the possibilities of, a dynamic music therapy programme adapting not only to the patients’ individual needs but additionally providing family-centred care that considered shifting locations.

Keywords
children; families; hospital-at-home; multidisciplinary; music therapy; paediatric palliative care

Introduction
Paediatric palliative care is a way of thinking about and constructing the care and level of services for children and their families when they are faced with a life-threatening and/or life-shortening illness. The overall philosophy is to enhance the quality of life in all phases of the illness by providing physical, emotional and psychosocial comfort (Blichfeldt-Ærø and Leinebø, 2017; Lindenfelser, 2013; World Health Organization [WHO], 2018).

Life-threatening conditions are illnesses where medical treatment may result in a cure but may fail. Life-shortening conditions are illnesses where there is no cure, and the child is likely not to live longer than early adulthood (McNamara-Goodger and Feudtner, 2012). Palliative care itself and the definition of when to introduce the term palliative care are widely discussed in the literature. As a result, palliative care might sometimes occur late in the course of illness, where the patient and family actually might have benefitted from this approach at an earlier stage (Bergstraesser, 2013).

The Norwegian Ministry of Health and Care Services has published ‘National Guidelines for Paediatric Palliative Care’ (Helsedirektoratet, 2017). These guidelines emphasize multidisciplinary approaches and practical strategies, with a specific focus on how and when to implement appropriate services to support patients and families. Music therapy is highlighted in these guidelines as an important agent to reduce anxiety and stress; however, it is not stated how this might be carried out (Helsedirektoratet, 2017).

‘Hospital-at-home’ is an adjunct service of the hospital, offering advanced medical treatment in the patient’s home setting when the patient’s condition allows for it. Such an organizational arrangement means that patients spend less time located at the hospital, while still being inpatients. This service provision aims to enhance the quality of life for patients and their families.

The present pilot research study presents a novel music therapy programme in Norway. There are several examples of Home based music therapy programme (Liu et al 2015; Schmid and Ostermann 2010). However, this study is slightly...
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Bradt defines paediatric medical music therapy as ‘[...] the use of music and the therapeutic relationship to promote healthy coping and safeguard the child’s psychosocial well-being during inpatient and outpatient medical treatment’ (Bradt, 2013: 3). Music therapy in paediatric care offers a wide range of interventions for meeting the child’s biopsychosocial needs. More specifically, music therapy aims to support symptom management and to regulate the body’s physiological parameters through the use of individually tailored music therapy interventions (Clark et al., 2014; Tuquet and Leung 2014). The Music Therapist builds a therapeutic relationship for psychosocial support throughout the various phases of the child’s illness. The music therapy relationship (Trondalen, 2016) then offers opportunities for playful and supportive interactions with family members and medical staff, while using the hospital environment as an arena to highlight the child’s resources, which may offer the hospital setting alternative meaning (Bradt, 2013; Leinebø and Aasgaard, 2017).

When working in a paediatric hospital, Music Therapists meet children with a diversity of diagnoses across various age groups. Some patients have complex treatment protocols, and many have diagnoses that fall under the umbrella of palliative care; a potentially life-threatening and/or life-limiting illness. Families react and cope differently when approaching and living with a potentially life-threatening diagnosis, that is, additional existential dimensions, which often involve major stressors for the family. Adversities such as loss, physical and psychological stress might be associated with negative implications for mental health and well-being. Living with childhood cancer, for example, involves a multitude of stressors and challenges that might put the child and family’s resilience to the test (Dun, 2013). However, there is also a possibility of building resilience through difficult experiences under the right circumstances with appropriate support (Herrman et al., 2011; Seery, 2011).

In palliative paediatric care, music therapy affords many possibilities to support the child and family to discover resources. It adapts to meet the changing needs over time, while also offering new arenas and opportunities for communication and interaction. Music may also allow for structure, stability, memory making and legacy work (for example, a recorded song, or the family’s use of music after the Music Therapist has left), and finally, holds the flexibility to include all family members regardless of age, musical training, or interest in music (Abad and Edwards, 2004; Lindenfelser et al., 2012; Shoemark et al., 2018).

Method and material

The music therapy approach

The context for this pilot study is the hospital-at-home setting at Oslo University hospital in the capital of Norway. Music therapy is a well-integrated part of the multidisciplinary team at Oslo university hospital, offering individual music therapy as well as music therapy groups to all paediatric patients, ranging from newborn to adolescents. The music therapy team consists of five Music Therapists who are employed by the hospital. Referrals come from eight paediatric wards with a wide range of diagnoses.

Some of the wards at the hospital are linked to the hospital-at-home model, where local patients are able to receive care either as an inpatient in the hospital or at home, depending on what model best suits their medical needs. Prior to this pilot, there had been no Music Therapist linked to the hospital-at-home setting. However, some families had previously been referred to the music therapy programme during their inpatient hospital admission and had an existing rapport with the assigned Music Therapist. For other families, the music therapy pilot study was their initial experience of a music therapy programme.

The music therapy work at the hospital is informed by biopsychosocial theory (Engel 1977) and the clinicians have a family- and a resource-oriented approach. Patients receiving palliative treatment are highly prioritized for music therapy due to their complex needs. The music therapy sessions in the hospital-at-home are based on the same therapeutic methods used within the hospital (Blichfeldt-Ærø and Leinebø, 2017). This also includes hygiene precautions as per standard hospital procedures. The Music Therapists make session notes according to standard practice at the hospital.

For this study, expressive and receptive methods including songwriting, instrument training, improvisation, verbal processing, music listening, relaxation and imagery were utilized to achieve individualized therapeutic goals (Mortvedt, 2015). The child’s home and family situation were always taken into consideration (Hodkinson et al., 2014; Nall and Everitt, 2005; Yang 2016). Each session had a length of approximately 45 minutes.
The first music therapy session always consisted of assessing physical and medical conditions and establishing a relationship with the patient and the family. Together with the multidisciplinary team, the Music Therapist and the family then defined specific treatment goals for the music therapy process. The subsequent sessions were based on the patients' needs while using expressive and/or receptive musical techniques and goals were constantly evaluated in cooperation with the team.

The Music Therapist usually brought instruments to the house, such as mini-maracas, metallophones, frame drums, speakers and an ocean drum. Due to hygiene precautions, some children played their own instruments or used those left by the Music Therapist for the duration of the sessions.

Especially in the sessions with the youngest patients, it was sometimes necessary to bring an item such as a toy or animal figure to catch and maintain attention. For example, one wooden storage box turned out to be a 'magical tool', as it created a joint focus and a defined therapeutic environment for the sessions. The patients would knock on the box or sing to make it open.

Familiar and preferred songs were offered to elicit optimum engagement from patients and their families in sessions. Music was age-appropriate and culturally relevant to the families, and the patients' preferences were encouraged (Forrest, 2014). Most of the sessions used live music played by the Music Therapist using a repertoire consisting of traditional Norwegian children's songs and other popular songs on demand. Some children wanted, for example, to sing a popular song about an unlucky man who ended up in the hospital, but who got better. Some of the patients wanted to sing this song every session.

Variations of music therapy improvisation (Wigram, 2004) were used, as the patients and their families were encouraged to make music together with the Music Therapist. As appropriate, siblings, parents, grandparents, carers and extended family members were encouraged to participate in the sessions, using guitar, drums, songs, or dancing. Improvisation was especially attractive to adolescent patients. Recorded music facilitated dancing, for example, 'Despacito' by Justin Bieber and 'Happy' by Pharell Williams. Making playlists was also an important part of sessions for some of the older children, combined with a guided relaxation to music and verbal processing.

The research pilot study

Design. The main goal of the pilot study was to investigate the families' (i.e. parents and caregivers, and the children) and allied health professionals' experiences of music therapy as a service to patients, who were admitted to the hospital-at-home. The research questions were the following: (1) How do families of children admitted to the hospital-at-home perceive music therapy in the home context? and (2) What do allied health professionals think music therapy can contribute to palliative care for patients admitted to the hospital-at-home?

From these questions, the research pilot study design was selected to be qualitative and explorative (Robson, 2002 [1993]). The procedure of analyses was conducted in line with Malterud's (2011, [1996]) systematic text condensation (inspired by Giorgi 1985).

The pilot emerged from requests from families and staff who wanted music therapy to be available at the home hospital, just as it is available when shifting between other wards located at the hospital.

The nature of the study was small and qualitative with the aim to study and document the experiences of the shift in this physical location for the music therapy programme. Ethics was performed due to ethical guidelines, regulations and approvals. The study was proposed to the Regional Committees for Medical and Health Research Ethics and evaluated to be sufficiently approved by the Department of Ethics at the University Hospital. All participants gave informed consent.

Nevertheless, we would like to emphasize that there is a need to pay special attention to not be invasive or intrusive as some may perceive the Music Therapist as ‘yet another’ professional, who visits the home (Horne-Thompson, 2003).

Selection of participants. The information about the study and invitation to participate were distributed through the University Hospital. Inclusion criteria for the study were families (i.e. parents and caregivers and children) of paediatric patients with a palliative diagnosis, that is, life-threatening and potentially life-shortening diseases such as cancer, tumour and severe cardiovascular disease. All the families involved in the study had children between 0 and 16 years. Another inclusion criterion was that parents/guardians of the child/adolescent had to understand Norwegian language, written and spoken. There also needed to be a referral to music therapy from the medical doctor responsible for the patient’s treatment.

A total of 10 families with children receiving palliative treatment were included in the study. The patients were offered music therapy 1 to 2 times per week during the 5 months project period, with a maximum of five sessions. This was due to practicalities and limitations of time and funding. However, five sessions are consistent with a regular music therapy follow-up for families per stay, when they are inpatients at the hospital. Therefore, if a patient was discharged from the hospital-at-home, the music therapy sessions would cease, similar to the usual procedure at other hospital wards.

The allied health professionals included in the study were part of the multidisciplinary team and familiar with music therapy from other hospital wards. The allied health voices that are heard in the study were mostly from nurses working closely with the families. Some of the nurses were also present during some of the music therapy sessions within the hospital-at-home setting.
Data collection. Individual interviews with each participating family were conducted following the semi-structured interview guide (Kvale and Brinkmann, 2015). The questions were focused; however, they also provided an opportunity for families to reflect and elaborate on their experiences with music therapy at home. The interviews with the families took place in their own homes or at the hospital. Due to practicalities and economical aspects, the interviewer was another member of the music therapy team and scheduled a preferred time and place for each family’s convenience. Some of the participating children were present during the interview, some interviews were conducted with one parent and some with two parents. Nine out of the 10 families were interviewed, as one family was unable to attend an interview due to changes in their child’s medical situation.

At times, the interview was interrupted or had to come to an end due to the child’s medical needs. In those situations, a phone call was made by the interviewer shortly afterwards, offering a new time for the interview or the opportunity to add anything over the phone. All interviews were recorded and then transcribed word by word. All families were then provided with a written copy of the whole transcript for approval. For the purpose of this article, the direct quotes used in the present text were translated to English after the analysis.

To investigate the allied health professional’s view on what music therapy may contribute to the hospital-at-home context, a collaborative focus group interview was carried out. All nurses and health professionals involved in the enrolled families’ care were invited to participate. Four nurses were able to attend. An independent researcher in the pilot study, who did not attend the music therapy sessions, performed both the interviews of the families and the collaborative focus group interview with the allied health professionals. The families eventually included the children, if possible. A semi-structured interview guide was provided. Questions included, for example, ‘what was it like for your family to welcome music therapy into the home context?’ and the Nurses were asked to reflect upon the meaning of adding the Music Therapist to the team. In addition, the informants were encouraged to talk with each other, ask questions, share anecdotal stories and further comment on each other’s experiences and viewpoints, in line with a semi-structured and collaborative interview procedure (Kvale and Brinkmann, 2015; Malterud, 2018).

Method of analysis. The data analysis was inspired by phenomenological analysis aiming at developing knowledge about the informants’ experiences and lifeworld within the present context, namely, music therapy in a hospital-at-home setting. Malterud (2011, [1996], inspired by Giorgi, 1985) drew attention to systematic text condensation as a valid technique to develop descriptions within a specific context. The following numbered list presents the steps undertaken for the systematic text condensation:

1. Acquiring a broad sense of the data
   - knowing the material by reading and re-reading
2. Identifying meaning units
   - abstracting the themes to codes
3. Abstracting the content into specific meaning units
   - abstracting the codes to meaning units
4. Condensing the meaning of the above factors

This method of analysis allowed for studying the essences and specific features of the phenomena, while trying to bracket out the personal pre-understanding in the encounter with the data. Reflexivity in the procedure were important prerequisites for the scientific knowledge. Furthermore, the knowledge of the theoretical framework was crucial to a proper and creative interpretation of the empirical material (Malterud, 2011, [1996]).

The interviews were performed by the first author, i.e., independently from the Music Therapist, who did the music therapy at home. The primary analysis then (step1-2) was performed by the first and second author. To further integrate trustworthiness, the primary analysis (step 1-2) served at a point of departure for the discussion of the analysis. Accordingly, step 1-2 were discussed within the whole research group, before steps 3-4 were performed and discussed by the three authors together.

During step 1, each interview was listened to many times to get a broad sense of the data. The transcripts from these interviews were gathered in the same document and treated as one text, using an Excel spreadsheet as a technical aid. During step 2, identifying meaning units, sentences and passages that stood out as important were marked with different colours. The coloured passages were connected and formed themes which later merged into codes. During this step, the data-programme Hyper Research was used, as a technical aid. During the step 3, the different codes made the basis for abstracting the content into specific meaning units. The process of searching for connections across emergent codes included gathering similar codes into one meaning unit before naming it, that is, the procedure of abstraction. The fourth and final step included condensing the meaning from all the above factors. The different steps were kept close to informants’ answers, while being important to keep the anonymity of the informants. Accordingly, no names or places referred to in the interviews were included, neither was specific information which might expose the participants indirectly.

Results

This article will consider the two research questions that ask how music therapy is perceived by both the participating families and other allied health staff.
The following is based on the analysis of the data from nine interviews with families and one focus group interview with the health professionals. The condensed meaning of the findings from the analysis (the final step) constitutes the headings in the presentation, underpinned by the codes.

1. Isolated–yet connected
   - left to oneself at home
   - feelings of connectedness in the music therapy
   - anticipation
2. Joint music-making
   - relationship
   - flexibility
   - fun
   - quality of life
3. Music therapy within hospital-at-home treatment
   - a meaningful activity
   - a home-based activity
   - multidisciplinarity

According to the procedure of analysis (see ‘Method of analysis’ section), the condensed meaning units (see step 4) are presented separately. These condensed meaning units are underpinned by specific codes (see step 3), that is, the codes emerging from themes (see step 2) and illustrated by direct quotes from the informants. In plain text, the quotes from the informants are merged into subthemes. These subthemes are thereafter merged into core findings, which present as headings in the text below.

Isolated–yet connected

The heading isolated–yet connected was underpinned by three codes. These codes were left to oneself at home, feelings of connectedness and anticipation.

The informants talked about being *left to oneself at home*. The illness of the child and being hospitalized at home affected the whole family. Examples were, ‘There is not so much we can do, really, because there are not many places we can go. Only some walking on our own, now and then. And sometimes attending kindergarten, only sometimes’ (3, P:F). Another parent said (1, P:F), ‘We have been so isolated, and still are’. It was threatening to go outdoors with the child, as the child was fragile and the family was ‘so afraid of getting infected’ by other people (3, HP:F). ‘They lack so much, they lose a lot’, according to another of the Nurses. Experiencing music therapy at home ‘made a big difference in a tough everyday life’, she claimed (4, HP:F).

Although isolation was an important theme, music therapy offered the feeling of connectedness at the family level. One parent said, ‘All of us can take part. It is great for everybody to participate’ (4, P:F). ‘Even her little sister can partake’ (9, P:M). Another drew attention to how wonderful it was to be ‘really seen’ (5, P:F). One father noticed that his son ‘became happy when we as parents joined him in singing’ (1, P:M). The parent of another child remarked that not only his daughter had been looking forward to music therapy, ‘It was for all of us!’ (3, P:M). ‘The whole family was gathered. And when he [the child] is happy, we are happy’, a mother expressed (6, P:F).

Several of the informants talked about *anticipation*. It was great to know that the Music Therapist was coming, ‘to have something to look forward to, it was important’, a mother said (4, HP:F). ‘It was a very enjoyable activity in an otherwise monotonous daily life’, another said (2, P:F). One mother drew attention to the advantage of the one-to-one contact. She enjoyed that ‘something was going to happen’ and added, ‘I would have liked to do music therapy more than twice a week’ (2, P:F). As a patient at home, her daughter had limited access to so many things but ‘she was very much looking forward to seeing the Music Therapist’ (3, P:F).

Joint music-making

The second heading, joint music-making, was underpinned by four codes. These codes were relationship, flexibility, fun and quality of life.

All the families reported on the importance of the *relationship* to the Music Therapist. Doing music therapy at home allowed for a ‘genuine one-to-one-contact’, according to one mother (1, P:F). Another said that her son enjoyed music therapy very much, when the Music Therapist was together with him (6, P:M). So, ‘it is worth gold that a Music Therapist arrives and that she actually manages to vitalize and inspire the child’ (4, P:F). It was amusing for the child to acquire some ‘diversion from the parents’ (5, P:F). One health personnel cited one parent who had asked if the nurses could do their job first, as the mother just wanted ‘the Music Therapist to get started’ (2, HP:F).

Several pointed to the necessity of *flexibility* within the framework of a Hospital-at-home setting. Having a sound clinical knowledge about the child’s condition allowed the Music Therapist to adapt the sessions to individual needs.
in different ways. For example, flexibility in the duration of the sessions which was appreciated by the parents. ‘The Music Therapist adapted the length of the session’, one mother happily noted (1, P:M). ‘Music therapy takes the child’s abilities into account’, a mother stated (4, HP:F). ‘It has to happen on the child’s premises’ (7, P:M), a father said. Elements of familiarity from their normal daily life was brought into sessions as the Music Therapist brought song cards, similar to the ones in kindergarten; ‘he could choose songs himself even though he does not speak’, a mother said (6, P:F). One parent told that her child preferred receptive methods, such as music listening while drawing: ‘It was very relaxing. Especially the first time, as I was a bit worn out’, the child commented during one of the interviews (7, C:F).

Participants noted that the music and playing the instruments provided laughter and fun. One mother said, ‘it was very fun with drums and egg shakers’ (4, P:F). A father said, ‘He thinks it has been very exciting with instrument, guitar and drums and those kinds of stuff’ (1, P:M). ‘Music is fun’, according to one of the mothers (4, HP:F). The participants stressed that music therapy gave joy. ‘It looks as if he has enjoyed it very much’, according to a father (1, P:M). ‘He is smiling a lot and is really enjoying himself’, he added. Fun, stimulating, enjoyable, and valuable are words describing the music therapy experience. ‘It is sad it had to come to an end because it was so important for us [. . .] also the inclusion of his siblings’ (4, P:F). Although the patient ‘had a bad day . . . he looked forward to music therapy, which he enjoyed’. They wondered maybe music therapy was even more important on a ‘bad’ day than on a good day for the patient (4; P: F and M). Music therapy was ‘different and valuable’ because music brought ‘other emotions such as joy—for us [i.e. parents] too’ (3, P:F and M).

Music therapy seemed to promote quality of life. ‘You simply get help, really good help to promote quality of life’, a mother said (4, P:F). She added, ‘I am convinced that positive experiences and life quality is really important for the recovery process’. One of the children told the interviewer, ‘It gives me positive energy’. She could not remember that she had been tired when the music therapy session had come to an end (9, C:F). Her father confirmed her experience and said, ‘My impression is that you have not been tired after the Music Therapist has been here’ (9, P:F). One Nurse drew attention to the fact that the Music Therapist supported the patient during a medical procedure. ‘It calmed her down, she became happy, right’ (2, HP:F).

**Music therapy within hospital-at-home treatment**

The final heading, music therapy within hospital-at-home treatment, was underpinned by three codes. These codes were a meaningful activity, a home-based activity and multidisciplinarity.

All the participants considered music therapy to be a meaningful activity. One mother talked about how her son felt safe in music therapy (6, P:F). The boy became actively involved as he acquired the full attention from the Music Therapist, who attuned towards his needs here-and-now (6, P:M). Another mother stated that it was great to see her girl ‘unfold in music together with another person than with us as parents’, and ‘I could relax’, she added (5, P:F). Days at home felt like lonely and long days, obviously for many of the families. ‘It is wonderful with meaningful breaks, which does not include new medicine’, one father said (9, P:M). It was so ‘Great [. . .] and all the instruments!’,[10] another father enthusiastically added (3, P:M). It was an activity for the whole family. ‘Yes, everybody joined in and danced’ (6, P:M). During the interview, a health professional said, ‘I think—a part of the meaning, obviously, is to do something else [. . .] give the child a break from the illness [. . .] so they forget they are ill and do music instead’ (4, HP:F). ‘It made a great difference in a tough daily life’, one father stated (2, HP:F).

Several of the participants stated the ‘luxury’ of music therapy as a home-based (activity) intervention. ‘It has been a luxury to do music therapy at home’, one father said (3, P:M). A mother in another family stated, ‘And the Music Therapist came home to us, that was a treat, I feel. It was a fantastic offer and activity’ (4, P:F). The music therapy at home was ‘a supplement, which I hardly could believe as if it was very good to be true’, told another mother (5, P:F). ‘If we would have had to travel to music therapy, we would have missed it’, stated both the parents in a family (3, P:F and M). ‘It feels as if the outcome is bigger at home than at the hospital, due to unpredictability and chaos at the hospital’ (9, P:M), a father pointed out. One health personnel stated that ‘I truly hope one result of this study is music therapy within hospital-at-home treatment—even though the Music Therapists are short of time’ (3, HP:F), due to their many duties. Music therapy at home offers the families ‘the little breathing space [. . .] I have seen the parents revitalise because their child suddenly was really energetic’ (3, HP:F).

_Multidisciplinarity_ was highly valued both by the health personnel and the families. One Nurse said,

Great. Maybe this is the most important, having multidisciplinary cooperation, to be able to offer something of the same to patients both inside the hospital and within the hospital-at-home setting. We always have to bear the patient’s best interests in mind—at all times. [. . .] Keeping the dialogue open between the Nurse and the Music Therapist is important. (1, HP:F)

The interviews revealed that the patients had some of the same needs at home as at the hospital. ‘We need multidisciplinary comprehensive care [. . .] the same opportunities at home as in hospital’ (3, HP:F). Music therapy also proved to be a unique source for assessment; namely, music therapy supported Nurses with new and updated important information about the different patients’ daily condition. ‘Wow, he actually did not manage to participate in the music, he must be
really tired’ (4, HP:F), one Nurse remembered. While one parent drew special attention to the patient’s needs at home, ‘It seems her individual needs have really been met’ (5, P:F). Besides, there seemed to be a mutual appreciation of the cooperation between the Nurses and the Music Therapist.

Discussion

The aim of the study was to investigate parental and allied health professionals’ experiences of music therapy in a hospital-at-home setting. The participants drew attention to the feeling of being isolated—yet connected due to music therapy. They talked about anticipation, namely, having ‘something to look forward to’. All the families reported on the importance of the relationship to the Music Therapist, the flexibility within the various interventions and the pure fun of making music together with the Music Therapist. The joint music-making seemed to increase their quality of life. Music therapy within hospital-at-home treatment was reported as a meaningful and highly appreciated activity offered at home. Also, the multidisciplinary teamwork was highly valued by the Nurses, the Music Therapist and the families. The researchers were intrigued and found it noteworthy that the families only reported on positive feedback.

Facing life-threatening or and/or life-shortening illnesses is known to be connected to stress and anxiety in the everyday life of the families. In this pilot study, music therapy was unanimously reported as a useful and vitalizing therapeutic approach, successfully supporting patients and their families. It provided the child with a chance for personal choice and control and afforded a tool for self-expression within their own family context. This is in line with literature reporting that typical areas for the Music Therapists are pain relief, symptom management, self-expression, creation of memories, self-esteem, provide an opportunity for choice and control, normalization, coping strategies, family support, stimulation (Aasgaard, 2001; Clark et al., 2014; Hilliard, 2003; Lindenfelser, 2013; Lindenfelser et al., 2012). More specifically, the present study reported how music therapy was able to draw upon the child’s own personal resources fostering joy and vitalization, and was a treasured positive input for the patients and their families.

A well-functioning multidisciplinary team surrounding the family is of utmost importance to meet the various needs of the child and family. The flexible and inclusive music therapy approach afforded a meaningful activity based at home, a vitalizing and supportive survival kit. Staff commented on how children and families have the same needs at home as in hospital when it comes to psychosocial support. In addition, hospital experiences also include school and leisure activities and socializing with other children, providing the families with a milieu where they can interact and live. Music Therapists can represent several elements and meet psychosocial need. One example is to offer building-blocks to the family’s ‘toolbox’ for meaningful interaction. To be able to communicate the outcome of the music therapy sessions efficiently to other staff when appropriate is vital to agree upon relevant approaches and ensuring the best possible outcome for the patient (Dileo, 2015). Through music, the child may be able to identify coping strategies and their own resources and increase resilience, that may be used in other challenging (medical) situations, and which may be accessible for other staff to implement in their care (Steinhardt and Ghetti, 2020). For other staff members, this may be to either learn more about when to include a Music Therapist during procedures, or to use established coping strategies themselves as indicated by the Music Therapist.

It is important to note how music therapy sessions helped counteract isolation for the families, when being treated at home. Isolation, to prevent infections or due to the child’s medical condition, poses a severe limitation in the daily life for patients and their parents in this context. Parents of severely ill patients say they experience a lack of energy and feel stressed due to isolation and feelings of loneliness as they cannot visit other people or participate in daily life activities. A meta-study by Abad et al. (2010) reports that isolation can harm a patient’s mental well-being and behaviour, including patients reporting a higher scores for depression, anxiety and anger when isolated. Studies also show that the negative effects of isolation probably are linked to uncertainty and loss of control, which derives from multiple sources, but ultimately stems from isolation itself (Gammon, 1999).

Music therapy afforded parents with new energy to cope with the situation, not least due to seeing their child engage with in joint music activities. It served as a bridge to normality and proved to be a natural way to allow the child and family to connect with their personal inner resources. Music therapy could provide the patients with a safe and stimulating platform to interact with their healthy siblings. When appropriate, parents, grandparents and friends of the families often joined the sessions. Some were singing, some dancing and some just wanted to watch and listen to the music. This implies a need for a flexible, yet respectful and sensitive approach as the Music Therapist enters the family home with all its variations in terms of patients’ needs, participants in the sessions, context and atmosphere.

There seemed to be a need for a ‘togetherness’ in the families, which was especially important when the family received treatment at home, due to isolation. The joint music-making seemed to encourage the whole family to participate and allowed for different appropriations of each other in the musical interaction. The music-making also allowed for the families to actively discover new skill sets and ways of being together (Abad and Edwards, 2004).

Evaluation and further recommendation

This study is a qualitative one, with a small cohort, using interviews as data material for the analysis. Hence, the study allows for singularities and no general conclusion (Robson, 2002 [1993]). The results, however, were interestingly homogeneous, which may be due to the positive attitude from the participants who chose to partake in music therapy in the pilot study.
From a research point of view, we suggest the interviews be performed closer to the last music therapy sessions in time, allowing for fresh memories to be captured. One limitation of the study was that it did not actively investigate the individual effect of the music therapy sessions. This was due to limited funding and to allow the pilot study to be completed within the Music Therapist’s employment at the hospital. The interviewer also invited the participants and the Nurses to explore negative feedback during the pilot. No concerns or negative comments were expressed, which might be due to the familiarity with the Music Therapist. For further research, it could be interesting to have a neutral interviewer. Due to the nature of music therapy, the children’s experiences are more observable in the music therapy session itself. A useful research methodology might have included video recording, to observe the children’s direct response to the joint music-making.

From a clinical point of view, due to the patient’s health condition, there was always a risk that the patient’s medical situation might change. On this basis, it was of vital importance that every single music therapy session made a complete closure. The families highlighted the relationship with the Music Therapist as a key factor. The Music Therapist in the pilot study was already employed at the hospital and experienced in the paediatric field, and also in the manner of cultural diversity (Forrest, 2014) and multidisciplinary teamwork. Such an approach implies a flexible (Hodkinson et al., 2014) and experienced Music Therapist containing the families’ complex and dynamic needs within a hospital-at-home setting. With a flexible approach, the Music Therapist can meet the patients’ needs while also delivering sessions with focus on the physical (often unfamiliar) setting, including other family members without setting the patient’s individual needs aside.

It is recommended that multidisciplinary teamwork, medical knowledge, reflexivity, and personal and professional competence, in addition to musical skills, are some of the requirements for the Music Therapist (Dileo, 2015). In the present setting, the Music Therapist also used the opportunity for supervision with an experienced Music Therapist during the course of the pilot study. Another recommendation for the future is that it is beneficial for the Music Therapist to also work with the same families in inpatient care when possible, to counteract the negative trajectory of social isolation for the families (Howard et al., 2014).

For future studies, it would be of interest to expand the number of sessions in the study and also elaborate the study design to include a more specific focus on the patients’ perspective. It would also be valuable to include the voices of other family members, such as siblings and/or grandparents to investigate their experience of the sessions. Another topic for further investigation would be to compare patients who receive music therapy both at home and in the hospital setting and investigate similarities and differences, which then could inform clinical practice in how to prioritize for the future.

Conclusion

This research pilot study investigated music therapy in a hospital-at-home setting for children receiving palliative treatment. The music therapy service, which already was established within the hospital, was then transferred, and performed in the patient’s house. The present text explores how this location change was perceived by the families and nursing staff involved in the patients care.

Results revealed that the participants drew attention to the feeling of being isolated—yet connected due to music therapy. All the families reported the importance of the relationship to the Music Therapist, emphasizing trust, flexibility and joint music-making. Music therapy within hospital-at-home treatment was reported as a meaningful and appreciated therapeutic approach, while the importance of the multidisciplinary teamwork was highly valued by both the other health personnel and the families. The results demonstrated the need for a dynamic music programme adapting not only to the patients’ individual needs, but also to their shifting locations. We suggest music therapy within a hospital-at-home context to provide a unique opportunity for continuity of care.

Declaration of conflicting interests

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

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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Notes

1. For the purpose of this article, we will not include the scope of ‘end of life care’, as this concept does not apply to any of the participants in the present study.
2. The first number refers to the coded number of the participating family, P refers parent, F/M refers to gender and C refers to child. The abbreviation HP refers to Health Personnel, while the number in front of an HP means number of a participant in the focus group interview.
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