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All in Good Time: A Music Therapist's Reflection of Providing a Music Therapy Program in a Pediatric Cancer Center Over 20 Years

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Abstract

This is a reflective article, based on the author's 20 years of experience working as a music therapist in the field of pediatric cancer care at the Royal Children's Hospital, Melbourne, Australia. During this time, the music therapy program has evolved from a 5-hour a week consultation into a successful, integrated service comprising 45 hours per week. Reflections include details of how the program has developed over time, reflections of what has influenced this, and some significant aspects of music therapy service delivery identified by the author. These reflections may be useful to others providing similar services in the field of pediatric cancer care, and will offer recommendations for starting out in this field, by expanding the way we envision working within the field.

Keywords

pediatric, cancer, music therapy, children

Introduction

I have worked as a music therapist in pediatric cancer care in one hospital for 20 years. Reflecting on my clinical work over those years, I have noted how the music therapy program has evolved and developed considerably over time, and furthermore that these reflections could be relevant to other music therapists who are developing, or trying to establish, music therapy programs with pediatric patients with cancer. As I examined the services I have provided within the music therapy program, aspects of time were commonly represented in observations of my music therapy work with pediatric patients with cancer. These include the significance of the timing of music therapy service provision, different approaches required at different times of the child's cancer journey, how children experience time, and the importance of a familiar and creative experience. All of these have implications for daily service provision.

My observations of the relevance of aspects of time in my own work are reflected in the research by Daveson.[1] She examined the phenomena of time within music therapy by highlighting and investigating incidental and direct references to temporal phenomena within the literature. She theorized that time has acted as a dynamic factor to influence, inform, and guide interventions, clinical directives, and research as reported by therapists and clients.

Changes in Pediatric Cancer Care Over Time

The first pediatric music therapy program in Australia began at the Royal Children's Hospital (RCH) in Melbourne, Australia, 20 years ago. Much has changed over the past 20 years, both in pediatric cancer care and music therapy. It is not possible within the scope of this article to cover all of the changes that have occurred within that time, so only some are highlighted below as they represent the main influences of music therapy services provided at the hospital (see Table 1).

Death rates from cancer have declined in Australia by 38% from 1997 to 2010. In the last decade, medical advances and technological improvements in cancer diagnosis and treatment have resulted in improved survival and a clear decline in mortality among children, despite the cancer incidence rate remaining unchanged.[2]

At RCH, children who are in end stages of palliative care are referred to community-based palliative care so they can be cared for in the familiar surroundings of home supported by family and friends. In 2000, when the palliative care service started at the hospital, only a handful of families had been cared for by a community-based palliative care service in the preceding year. Currently, 70 to 80 families are referred out to these services annually (unpublished data from RCH palliative care service). For music therapy services in the hospital, this has meant that the focus is more on working with children during

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Table 1. Changes in Pediatric Cancer Care and Its Influence on Music Therapy Services

1991	2010	Influence on Music Therapy Services
Community palliative care service did not exist in 1991. In 2000, when the service began only a handful of patients were referred	In 2009, 70 families were referred to the community based palliative care service	Less work with dying patients, more with patients in active treatment phases
Majority of treatment given as inpatient	Some treatment given during day visits without requiring overnight admission	More focus on procedures
Inpatient beds—4 in a room	Mostly single rooms	Less groups, more individuals
Little recognition of psychosocial issues, few psychosocial services provided	Psychosocial issues acknowledged as important. More psychosocial services provided	More music therapy hours provided

their active treatment or maintenance phases. Work with palliative patients is relatively uncommon, as those children are now referred to community-based music therapy programs.

In the early 1990s, it was common for most treatment to be given as inpatient treatment, necessitating the child to be admitted often for long periods each time they required treatment. At the current time, some of the treatments can be given in a day visit to the hospital without the children having to be admitted for a lengthy period. For music therapy services, this has meant that the music therapists have become more involved with helping children to cope with procedures during day visits, in addition to helping those children who do need to be admitted for long term, whereas in the 1990s music therapy services were mostly provided for only the long-term admissions.

In 1991, rooms on the cancer ward for inpatients had 4 or 6 beds in them. In 2010, most rooms are single rooms. With multiple beds in a room, it was possible for music therapy to include all the children in the room in a group session, even if they were required to be bed bound. With single rooms, the sessions must necessarily be individual, unless the children are allowed to leave their rooms and meet together in a common area (such as a playroom). But this (group music therapy) happens less now on the ward as most children who are hospitalized are there because they have infections, are undergoing a bone marrow transplant, or have other complex needs, and therefore interaction with other children is often restricted. Group music therapy usually occurs in outpatient or day patient waiting areas where patients are waiting for appointments or procedures.

Psychosocial care has taken on a greater significance in the support of children with cancer and their families. In 1991, the psychosocial services consisted of one (part time) music therapist, one school teacher, one educational play therapist (child life worker), and 2 social workers. It was rare for a referral to be made to the consulting mental health workers. Over time, there has been a shift to where psychosocial services are considered as important as the medical treatment, and a major review undertaken in 2007 recommended an increase in all the supportive care services.[3] Currently, the psychosocial team consists of 2 music therapists, 4 social workers, one educational play therapist (child life specialist), one art therapist, 2 school teachers, one family support worker, 2 psychologists, one consulting psychiatrist, and 3 procedural support workers. These services are offered to every family without exception.

Previously there were fewer services for the same number of families so only some families received some services and other families missed out on services. Today, the pediatric oncology service is provided by the Children's Cancer Centre, which is part of the Royal Children's Hospital in Melbourne, Australia. It is a purpose built 28-bed inpatient facility and also has a co-located day oncology service that treats up to 35 children per day. There is an outpatient area where children and families have appointments with their consultant. In addition, 2 general anesthetic clinics are held in day surgery center per week for children having procedures under anesthetic such as lumbar punctures and spinal taps and sometimes infusaport access.

The Development of the Music Therapy Program Over Time

The music therapy service provided to the cancer ward was initially one clinician for 5 hours per week in 1991. In 2010, there are 2 music therapists employed in the cancer center for a total of 45 hours of service per week. This increase in hours was achieved incrementally over time. Beginning with 5 hours per week, the service increased to 8 hours in 1998, then 16 in 2002, 22 in 2004, and to the last significant increase to 45 hours per week in 2009. This was enabled by the cancer center sourcing a single reliable ongoing philanthropic funding source for music therapy services rather than the smaller contributions from a variety of sources. The funding for music therapy has always relied on a variety of philanthropic sources, with minimal input from the hospital's ongoing funding. The hospital supports music therapy by providing the infrastructure for the program, such as administration, office space, equipment, and supplies.

Each increase in hours seemed to have a cumulative effect: the more I was available on the ward and the more services were provided, meant that staff became more aware of the possibilities of music therapy and made more referrals. The longer I have been there, the more acceptance I have from the staff in the cancer center.

A major psychosocial review project[4] undertaken in 2007 involved focus groups and surveys of stakeholder groups such staff, patients, and families across several different hospital sites in Melbourne, Australia, in addition to undertaking a literature review. The project identified some inconsistency of, and

service gaps in access to services such as music therapy. A psychosocial services model was developed that identified music therapy, and other services such as play and art therapy, as playing an important role in creating a normal environment for children and adolescents with cancer and reducing the impact of the disease and treatment on both them and their families. A proactive approach by the Children's Cancer Centre was adopted to gain more sustainable funding.

Timing of Music Therapy Service Provision

The staff of the Children's Cancer Centre recognize the value of music therapy service delivery at particular times across the course of a child's treatment. There are specific times when music therapy services are recognized to be valuable such as immediately post diagnosis. At other times, it has appeared that my involvement may be serendipitous, and there is a need to adjust the provision of services according to the need of the child in the moment.

In my role as music therapist, I have the opportunity to work with the child and family around the time of diagnosis through to the time when they are no longer receiving treatment and beyond. That early contact is often crucial.[5] The initiation of music therapy contact with the child and family early in their journey around the time of diagnosis, even pre diagnosis, when they are scared, anxious, fearful of the unknown, and what is going on around them can influence the child and family's long-term experiences. The music therapists can be a calm and confident influence, ease anxiety, and present alternative adult behavior, when often what the child is witnessing around him or her are anxious and upset parents and often solemn and serious medical staff.

Case Example

Often a patient's first visit to the day surgery center is the time when the diagnosis will be confirmed, so often parents are highly anxious at this time. The waiting area includes other children and families who have been there many times before and are comfortable in the environment. I run an open group in this environment and invite any child to participate. I recall a particular child, whose parents were highly anxiously waiting for the confirmation that their child had leukemia. The young 3-year-old boy was in his stroller. The parents sat in a far corner of the room and turned the stroller away from where the music group was happening, and politely but firmly declined my invitation to participate in the group. However, as the other children and I sang and laughed, the child's head appeared around the side of his stroller as he sought out what the fun was about. After some time, the parents gradually moved the stroller so the child could see more easily and I quietly without fuss left an instrument at his side. He picked it up and started playing. After the group session had concluded, I went over to him and engaged him with some of the other instruments, and by the time it was his turn to go in for the procedure we were laughing and singing and having fun together. I accompanied him to his anesthetic induction still playing and singing, and though he displayed some uncertainty at the appearance of the anesthetic mask, this first experience overall was a positive one. He was admitted as an inpatient on the ward after this procedure where I met him the next day for some more music together. Each time now he comes to have his lumbar puncture, he boldly and confidently joins in the group, specifically requesting his favorite instrument. The experience for him has always been a positive one. The wide ranging implications of this are that he is more compliant with staff for his treatment and therefore easier to treat, but that also his ability to engage readily in his environment has meant his capacity to cope is improved.

However, even if it is not possible for music therapy services to be involved in a child's early experiences of hospital, it is still possible to have an impact. It may simply take a longer time and may involve initially dealing with some of the trauma they have already experienced.

Case Example

A 4-year-old girl was reported to have endured some traumatic experiences early in her treatment and was fearful of staff, becoming distressed and difficult to manage each time she had to have a procedure of any kind, screaming any time anyone came near her, and constantly whimpering or crying while waiting for procedures. When she came to the day surgery center for her lumbar puncture, she would not leave her stroller in the waiting area. She would not look at me when I invited her to join the group, despite her mother displaying some enthusiasm and trying to encourage her, and she would not accept any of the instruments. During the music group, unlike the boy in the previous example, she appeared to show no interest in what was happening and remained disengaged. It took several sessions to gain her trust and shift her perception of the hospital. I discovered that if I could meet her outside the door to the center when she first arrived and engage her there with a few little instruments (which she still would not play but instead made her mother play for her), then she would be prepared to come into the center and sit on the periphery of the group and watch but not participate. Over time she began to smile when I greeted her, and eventually did sit with the group and play with a select few instruments. Her compliance with treatment improved and her mother reported it was easier for them all to cope when they had to come to hospital.

In addition to music therapy for patients having procedures in the day surgery center, music therapy services are also provided for inpatients on the ward. The scheduling of sessions for these patients for an appropriate time is often difficult. Children can be sleeping, or off the ward, for example, for an X ray. Occasionally I may be present serendipitously just before a child is to have a procedure. This means that I can involve the child in an absorbing activity and help them to avoid focusing on the upcoming procedure. This also helps the child to stay calm and prevents his or her anxiety from escalating. If I arrive immediately after a stressful procedure when a patient is distressed, then the aim may be to help re-focus and settle the child.

In my experience, different approaches at varying stages of the cancer journey and at different moments in the day are required. The timing of the music therapy intervention will influence how the music therapist proceeds and what the intervention will involve.

A Child's Experience of Time

A child's experience of time is important in the frequency, length, and type of interventions offered.

One day to a 4-year-old child would be approximately 1/1460th (or 0.07%) of his life, while one day to a 44-year-old is only about 1/16 660 (or 0.007%) of her life. An entire day is a more significant portion of the child's life so far lived.

Sometimes children are admitted to hospital for lengthy periods of time for treatment (such as a bone marrow or stem cell transplant). The music therapist sometimes may be unable to see the child for a week—perhaps due to a heavy caseload, or the child is asleep or off having a test. For a 4-year-old who has only experienced 200 weeks in his entire life, a week between sessions could feel like a very long time.

Further to the point that time is relative, the proportion of time spent with a child is also of interest. If a week is a long time for a child, is providing only one-half hour music therapy session a week of any worth?

The following anecdote helped me with this dilemma:

> A lecturer, when explaining ways of anxiety relief to an audience, raised a glass of water and asked, "How heavy is this glass of water?"
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> Answers called out ranged from 20 g to 500 g. The lecturer replied, "The absolute weight doesn't matter. It depends on how long you try to hold it." "If I hold it for a minute, that's not a problem. If I hold it for an hour, I'll have an ache in my right arm. If I hold it for a day, you'll have to call an ambulance. In each case, it's the same weight, but the longer I hold it, the heavier it becomes."
>
> She continued, "And that's the way it is with stress relief. If we carry our burdens all the time, sooner or later, as the burden becomes increasingly heavy, we won't be able to carry on. As with the glass of water, you have to put it down for a while and rest before holding it again. When we're refreshed, we can carry on with the burden holding stress longer and better each time practiced . . . " (Original source unknown).

Involvement in activities with a music therapist may offer a child a moment to put down his or her "glass of water"; provide a break from the stress of his or her daily medical routines and feeling unwell, to focus on something else, so when a child must return to the daily routines, he or she returns refreshed and better able to deal with his or her experiences.

Music Therapy Can be a Familiar and Creative Experience

For a child, the hospital can be a chaotic environment—unpredictable, unfamiliar, and insecure. This can challenge the child's sense of control, so to counterbalance this the child needs clear expectations and consequences, things that are familiar and predictable and that have structure and order. The more structure the context provides, the more the child will respond to distress with active attempts at problem solving.[4]

Music provides order and predictability, fostering feeling of security in children and enabling them to reengage with their environment at times of stress. This is done through the natural structure of music. Songs, for example, have a predictable start and end, phrasing is predictable and the rhythm provides order. The songs are familiar and the words and actions are predictable and can be accurately and successfully anticipated. Regular sessions with a child when they are admitted to the ward contain a similar structure and order of songs with familiar repertoire. I am known and familiar to most of the children and this also reduces anxiety.

I see patients and their families time after time after time—sometimes over a period of years. A relationship is built and often involves repeating the same activities at each meeting.

However, each time the activity is repeated it will actually be different. For example, take singing a song: the song is essentially the same—same structure, melody, and rhythm—but can be played differently. There may be a different accompaniment; different people may be present to sing with us, the contexts may be different each time. Depending on what was happening at the time and how the child is feeling, the song might be played differently, or used to achieve various aims.[6]

Case Example

A 3-year-old boy had undergone a bone marrow transplant and had been involved in music therapy over the course of his treatment since he was 18 months old. He had a particular "set" of songs he liked to play with me. He would pick up the "props" (such as animals for Old Macdonald's farm) or instruments such as the duck castanets for 5 little ducks and indicate that he wanted me to play that song. Each time it was the same order and the same songs. If I played a different song he would get angry and refuse to participate. If I brought in a new instrument he did not seem interested in playing it. So mostly we kept to the same songs, in the same order. As he grew older and his condition started to improve, I was able to make slight changes and introduce new aspects to songs. This included introducing new verses or different words. New songs and instruments were gradually introduced. These successful experiences were able to help him grow more confident with himself and his environment, enabling a greater capacity to cope.

Sharing an Experience in "Same Time"

Cross states that music "enables a joint sense of shared action that is oriented around commonly experienced temporal regularities."[6(p121)] For a child who is isolated or bed bound, for example during bone marrow transplant, socialization is reduced and limited. This opportunity to have a shared action

in a commonly experienced song with another expands their awareness of others and allows for a successful social experience.

Case Example

A 4-year-old child, a coworker, and myself were all singing and playing together. We were all playing the same song at the same time. The child was completely absorbed, involved, and engaged. However, at one point the coworker ''takes over'' the song and starts singing his own words. The child stops singing and disengages by lying down. She feels disconnected—''out of sync.'' After a few moments, the coworker realizes what is happening and returns to the original song with the words known to the child. The child sits up and resumes playing with us. She is feeling able to participate because we are successfully doing it together.

Conclusion

As a music therapist who has worked in pediatric cancer care in the same hospital for the past 20 years, I have witnessed changes in pediatric cancer care and treatment over time, and this has influenced the provision of music therapy services. These changes have also been influenced by a gradual increase in acceptance and support of the music therapy program over time. In my experience, the successful provision of music therapy services relies on being aware of the significance of the timing both in terms of providing a service early in the child's diagnosis and also being aware that different approaches are required at different times of the child's cancer journey. In addition, being mindful of how children experience time, and an increased awareness of the importance of a familiar and creative experience has implications for daily service provision.

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Bio

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