Keeping Parents at the Centre of Family Centred Music Therapy with Hospitalised Infants.

Helen Shoemark, PhD RMT,  
Senior Music Therapist- Neonate and Infant Program,  
Royal Children’s Hospital, Melbourne  
Trish Dearn, BMus Grad.Dip. MT RMT,  
Mercy Hospital for Women, Melbourne

Abstract
Music therapy for hospitalised newborn infants is an emerging clinical field. While a clear picture is being built in the literature about effective methods for direct work with infants, it is more difficult to inform the clinical reality of providing services in a family-centred practice model. Beginning with a single case study, the authors engaged in lengthy discussion about the broader issues of providing effective clinical services to the families of hospitalised infants. The authors wrote their own narratives about working with families, using their practice wisdom as music therapists and their personal experiences of hospitalisation with family. These narratives were combined and framed into categories. After a rest period of several months, these categories were revisited and repetitious material was deleted and overlapping material was collapsed under major themes. Finally the authors sought validation of the content from a colleague with 15 years experience working with families in hospital. The themes include: The necessary character of the music therapist; music therapy is a triadic relationship; endurance - the long journey; parents experience joy during music therapy; music therapy acknowledges the “whole” developing child; the contingent relationship; a whole life.

Key words: music therapy, neonatal care, family-centred care, parent support programs.

For every family with a newborn infant, admission into a paediatric hospital is a crisis. The Neonatal and Paediatric Intensive Care Units (NICU & PICU) which receive critically ill infants are arranged to preserve physical life and immediately overwhelm even the most “psychologically sound parent” (Kraemer, 2006, p. 153). Parents struggle to adapt to the highly technological environment and complex care of their baby. Uncertainty about their baby’s prognosis may be compounded by a lack of knowledge and control regarding medical treatment, their on-going

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fatigue, and relentless fear and grief.

Currently it is acknowledged that paediatric hospitals should offer family-centred care which is a “health care model that places the patient and family at the centre of care given. This model of care emphasizes collaboration, empowerment and education” (Royal Children’s Hospital Clinical Guidelines, 2006). However, the real complexity of implementing family-centred care is only beginning to surface now as we try to integrate a real understanding of parents’ experiences (Hall, 2005; Hurst, 2001; Steinberg, 2006) with the practical reality of meeting their needs (Hurst, 2006; Peterson, Cohen, & Parsons, 2004).

In recent years, music therapists have established research and clinical programs in NICUs around the world. While the research begins to give clear indications about the direct work with the infants (Cassidy & Standley, 1995; Hanson-Abromeit, 2003; Standley, 1998), attention to parents has been contained to their roles as providers of live stimulation (Standley & Moore, 1995; Whipple, 2000, 2005) or recorded stimulation (Cevasco, 2006; Leeuwenburgh, 2000; Nöcker-Ribaupierre, 2004).

Simply put, infants cannot give permission for a service to occur, and we must therefore acknowledge the primacy of parents in all our work with infants. However this discussion can grow further to appreciate that music therapy for the infant in the context of the family, also has therapeutic benefits for the parents.

The focus of this discussion paper is to present the benefits which parents may derive from music therapy provided to their infant and how to maximise them. We propose key themes for building a therapeutic relationship with parents of a newborn infant in hospital. The case study of baby Jane and her parents Emma and Peter (names have been changed) illustrates aspects of the themes.

Literature Review

Stressors in the Neonatal Care Environment

The clinical pathway of hospitalised newborn infants is complex, unrelenting, and often unpredictable (Hurst, 2001; Prentice & Stainton, 2003). Peebles-Kleiger (2000) notes that an admission to the PICU or NICU qualifies as a traumatic stressor according to the criteria of the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (4th ed., DSM-IV; American Psychiatric Association, 1994). The admission is an event involving “actual or threatened death or serious injury, or a threat to the physical integrity of self or others” (p. 209).

Parents rarely experience relief from their fears and uncertainty
about their baby’s survival (Hurst, 2001; Prentice & Stainton, 2003). Several qualitative analyses have provided listings of parents’ experiences of hospitalisation with their infant and children (Hall, 2005; Kirschbaum, 1990; Lasby, Newton, Sherrow, Stainton, & McNeil, 1994; Peebles-Kleiger, 2000; Seidemen, Watson, Corff, Odle, Haase, & Bowerman, 1997). In their own comparison of NICU and PICU parents, Seidemen et al. (1997) found that both groups reported greatest stress related to the alteration in parental role, and parents in NICU also reported high stress about their infants’ behaviours. A lack of choice and control, and attachment difficulties may lead to feelings of intimidation, grief and inadequacy (McGrath, 2001). Mothers commonly reported a feeling of powerlessness and that they were unable to do anything to ease their babies’ distress (Fenwick, Barclay, & Schmied, 2001; Hurst, 2001; McGrath, 2001; Vandenburg, 2000).

A lack of medical knowledge compounds these feelings experienced by parents (Fenwick et al., 2001; Hurst, 2001; Lasby, Newton, Sherrow, Stainton, & McNeil, 1994; McGrath, 2001; Vandenburg, 2000). Further, a lack of understanding of the different behaviours displayed by premature infants can cause withdrawal, rejection or resentment of infants which can have consequences for the long term attachment relationship so important to the infants’ development (Van Beek & Samson, 1994; Vandenburg, 2000).

The fragmentation caused by the hospitalisation may be diminished by supportive care, thus facilitating better long-term coping in families (Prentice & Stainton, 2003). We know that mothers need strategies to a) reduce the stress in seeing their infant so medically compromised and, b) support them in developing their identity as mothers (Hurst, 2001; Miles, Holditch-Davis, Burchinal, & Nelson, 1999; Parker, Zahr, Cole, & Brecht, 1992). Acknowledgement that this situation is traumatic for everyone may assist parents to accept additional information and support (Peebles-Kleiger, 2000).

While there is concern that early hospitalisation may have a long-term impact on the connection between infants and parents (Minde, 1999), family-centred care promotes the empowerment of parents in caring and advocating for their infant (Shoemark, 2004). The Institute for Family-Centered Care defines family-centred care as “an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families” (Institute for Family-Centered Care website, 2007). This means that during a hospital admission, care is planned around the whole family, not just the individual child (Shields, Pratt, Davis, & Hunter, 2007). Importantly, families are encouraged to actively participate in the processes of decision-making, planning and provision of their child's care.
(Ahmann & Johnson, 2001). Additionally, supportive services which provide encouragement, respect, education, and active listening will offer containment to parents and will in turn help them to contain and support their infants (Harris, 2005; Robertson, 2005).

**Music Therapy within Family Centred Acute Infant Care**

The focus of music therapy research in neonatology has been quantitative studies to measure outcomes for infants. This literature is well summarised in meta-analyses by Dileo and Bradt (2005) and Standley (2003). More recently medical researchers Blumenfeld and Eisenfeld (2006) measured the “contingent effects” of mothers singing to their preterm infants during feedings. They reported no statistical difference between infants who received maternal singing and those who did not. However, they noted that fewer than 20% of mothers who had agreed to participate actually completed the protocol due to scheduling difficulties and excessive anxiety about their infant, also noting shyness and inhibition as factors. The reluctance of participants highlights the lack of recognition that while singing might be “normal”, it certainly is not so in the hospital context, and that parents need instruction and support to implement this simple but potent strategy.

In support of the role of music for families, Hanson-Abromeit (2003) noted that the flow-on benefit of using familiar recorded music with infants is an acknowledgement of parents’ values and preferences and potential for fostering their confidence. More specifically, she suggested that instruction to parents on how to use music with their babies sustains a family-centred approach.

In an investigation of infant-directed singing with mothers and older healthy infants, de L’Etoile recommended that as mothers become more proficient at meeting their infants’ emotional needs through infant-directed singing, this success will set “in motion a meaningful cycle of synchronized interaction that improves the mother’s perception of herself as an effective parent.” (de L’Etoile, 2006, p. 468).

The concept of working therapeutically with the parent has been reported by a few clinicians. Shoemark (2000, 2004) states that the aim of intervention should be to “promote family coping strategies by supporting healthy interaction and practical care.” (2004, p. 144) and specifically the role of the music therapist is to “empower the parents to nurture their baby through auditory and tactile stimulation.” (2004, p. 144).

A new discourse initiated by O’Gorman (2005, 2006) explored the theoretical structures from the mother-infant mental health literature as they relate to music therapy for mothers and infants in Intensive Care. She concluded that the “paradoxically powerful yet gentle” infant-directed
singing (2005, p. 28) offers the mother empathic means by which to meet her infant's expectations and needs (2006). Additionally, Barcellos (2006) noted that familiar popular song may be the easiest song form for parents to sing with their infants outside sessions with the therapist.

This article serves to frame clinical practice in a way that is not yet represented in the literature. Through a set of themes, it offers an exploration of basic interpersonal processes and experiences shared between the music therapist and parents of hospitalised infants. Because of space restrictions, it does not include those parents who are largely absent from the hospital. However, it does include families of premature and full-term infants who may be cared for on wards other than the Neonatal Intensive Care Unit.

"Jane" and her Family

The themes presented below are given clarity through the story of "Jane" and her family. The family is introduced first to give a real context for the themes.

Jane’s parents Emma and Peter knew before she was born that Jane had a severe heart defect called Hypoplastic Left Heart Syndrome (HLHS) which would require urgent surgery just for her to survive. Jane was born full term at an interstate metropolitan hospital and was immediately transported to the Royal Children’s Hospital which at that time was the only surgical centre in Australia which provided the necessary surgery. On arrival, she had the first in a series of three surgeries required to repair the defect.

Emma and Peter were well-educated and articulate people, with good extended family support. They had a four year old son who stayed with them throughout their hospital admission. Their natural style of parenting was attentive and beautifully attuned to Jane, but their long and challenging hospital journey caused them to be highly vigilant and in need of empathic support.

After two months in the Intensive Care Unit (ICU), Jane was transferred up to the Cardiac Ward for specialized long-term care while she waited for the next surgery at age 4 months. It was at about this time, that the family was referred for music therapy because of their long-term status. The authors attended the first session together and the second author served as music therapist to Jane and her family.
Themes in Working with Families which Include a Hospitalised Newborn Infant

The themes presented here categorise the clinical considerations and actions重要 to a productive relationship with families in hospital. They provide a picture of the parent’s experiences in music therapy and how this informs the services we provide. While it may not be exhaustive, it is intended to deepen the discussion about truly family-centred care.

The themes originated in the clinical case study of Jane and her family. When the authors revisited this case for publication, their discussions about family-centred practice extended beyond the case study to reflect insights developed through clinical and personal experiences (as families in hospital) in the interceding period. Each author wrote about their insights and then over a series of discussions, synthesized a long list of issues under categories. The whole article was then put aside for some months before the content of the categories was revisited, and repetitious content was removed and overlapping content was collapsed into major themes. Finally the authors sought validation of the concepts by having them rigorously reviewed and validated by a colleague with 15 years experience working with families in hospital. The final themes are:

1. The necessary character of the music therapist
2. Music therapy is a triadic relationship
3. Endurance - the long journey
4. Parents experience joy during music therapy
5. Music therapy acknowledges the “whole” developing child
6. The contingent relationship
7. A whole life

The Necessary Character of the Music Therapist

It may seem presumptuous to dictate character traits of any person. Our intention is to bring to consciousness in the reader’s mind, the practical manifestations which are perhaps hidden behind the global label of the term professional. During the writing of this article, the second author experienced repeated hospitalisations with her seriously ill young child, giving her a parent’s experience of receiving services from many staff members. As part of the lengthy discussion process described above, these personal experiences were considered in a professional framework and synthesised along with the practice wisdom of the primary author.

The original list of nine character traits was distilled down to the following five: poise, approachability and personability, consistency of character, and maintaining boundaries.
To encourage a productive working relationship with families, we propose that the core characteristic of the therapist is poise. The Macquarie dictionary (Delbridge, Bernard, Blair, Butler, Peters, & Yallop, 1997) variously defines poise as composure, self-possession; steadiness, stability; to balance evenly. These characteristics are essential in the many first meetings we have with parents. Alongside an approachable and personable style, it is also vital to bring an assured and composed self which will justify the parents’ investment of energy in trying to understand what we offer and a trust in us as a member of their baby’s team.

Being approachable and personable is more complex than it sounds. Whether the first meeting is early or later in the admission, not every family is pleased to meet yet another person, nor might they be interested in music therapy or perhaps able to understand why they are receiving information which seems extraneous to their baby’s survival. This seeming indifference or aloofness may really be a manifestation of overwhelming fear and loss of self which the therapist may experience as a sense of trespassing (Steinberg, 2006, p. 134).

The music therapist should strive to be consistent in character with the family. While the music therapist seeks to vary what s/he does to support the family, s/he should be predictable in character, ready to be supportive and helpful and involved in the journey every time. In counterbalance however, the music therapist should anticipate that the parents may be inconsistent and unpredictable. Over extended periods in hospital, parents function with minimal sleep, extreme worry, poor nutrition, little exercise and they are perhaps living away from family or other social support. The music therapist should be mindful that these concrete factors impact deeply on parents and that they may swing between ambivalence, rejection or even confrontation one day, and warm greetings the next.

Because this work involves a lot of direct contact with parents often over an extended period of time, the relationship can become quite intimate and maintaining boundaries can be challenging. It is helpful if the therapist is mindful that this is a temporary relationship, and over-familiarity may cause complications for all involved when it comes time to withdraw for discharge from hospital. It is strongly recommended that supervision or intervision (de Backer, 2004) with a suitable colleague is under-taken. As always, the therapist should also be aware of counter-transference issues arising from being an infant or mother, which will inevitably impact on a therapeutic relationship.
Music Therapy is a Triadic Relationship

We acknowledge that it takes courage for parents to let yet another person into their intimate space and experience. This is not always easy to remember when parents present with different coping facades (passive, assertive, anxious etc.). In our experience, parents use precious energy and fatigued mental capabilities to assess how much access they will give the therapist to their infant and themselves. If the music therapist has managed to make the processes and potential of the therapeutic relationship palatable to the family then a triadic relationship – infant, parents and therapist – may be established. In this section we will consider the expanded capability of the relationship, physical and emotional respite for parents, and working directly with parents.

Expanded Capability

Mother-infant psychiatrist Edward Tronick (1998) uses the term dyadically expanded consciousness to mean that when two people (the dyad) work together, their combined capabilities to complete a task are much greater than if they tried to do it alone. For example, when a baby has an intravenous needle taped into her arm she may not be able to move it to touch a toy suspended above her, but the adult can position her so she can access it. In the therapeutic triad we work with parent and infant with a triadically expanded capability to build experiences which the parents might not be able to build on their own. The therapist opens channels of creativity, fun and joy and affirms the parents’ actions.

The music therapist was able to offer validation of Peter and Emma’s enthusiasm to read and sing with Jane on the ward:

One session when I arrived, Emma was reading a book to Jane and asked me if I would do the vocal sound effects. She laughed as I roared, sang and spluttered which Jane responded to with smiles and gurgles. This provided stimulation for Jane but also empowered Emma’s decision to read to her. Emma commented, “Now I can say that the music therapy department supports me in what I’m doing.”

Validation of the parents’ efforts to support and nurture their infant expands their potential beyond the immediate time-frame of the session.

Physical and Emotional Respite for Parents

The music therapist will at times be the primary adult attending to the infant, and the parent who is present can take a literal and symbolic step back into enjoying the role of companion and witness to their baby’s happiness or processes with an attuned adult. In our experience there may
be times when parents feel that they have no energy left to engage with their baby and the music therapist can provide a renewal of creative and personal energy.

Alternatively, when the parent trusts the music therapist, they may schedule a physical break from the bedside, using the session time to rest quietly or complete other tasks. The schedule itself may even hinge on the therapist coming at a time when the parent simply cannot be bedside. Knowing that their infant is being attended to by an attuned adult might enable the parents to schedule time away from the bedside for important activity. It is important to note that whether physically present or not, the parents are always held in mind by the clinician when working with their baby.

The music therapist notes an occasion for Emma:

One day when I arrived, Emma was very angry and Jane was extremely distressed. With evident exasperation, Emma explained, "I went to the toilet for five minutes and the ultrasound guy has come and unwrapped Jane and tried to do an ultrasound on her. He doesn't know her schedule, and didn't even ask me so I sent him away. Look at her now!". Jane continued to expend energy being distressed for some time.

While the technician was probably on a tight schedule, had he stopped to ask Emma how to proceed, the outcome may have been much smoother for everyone.

Working Directly with the Parent

Parents' coping styles will range from total avoidance through to an unsustainable focus on each and every detail (Kirschbaum, 1990; Seideman et al., 1997). Parents will vary as to when feelings emerge, in how expressive they can be about those feelings, and how they manage them (Peebles-Kleiger, 2000). Some may wish to talk openly, some to be left alone, and some will close down to protect themselves from further pain (Kirschbaum, 1990). Some may cope by focusing on processing the emotion, and others will focus on the problems (Seideman, 1997). The music therapist considers these aspects of the parent when offering direct support, remembering that parents are often isolated from their normal support network throughout their admission. The therapist has an opportunity to provide a "psychological nest" (Mendelsohn, 2005) in which empathic listening and support can be contained within the boundaries of this temporary relationship.

After some complex medical occurrences had arisen on weekends, Emma and Peter became anxious as weekends approached and this
translated into a taxing hyper-vigilant care for Jane. One Thursday
Emma said to me, “At least you get what it’s like for us. On the
weekend, no one else seems to. It’s a very lonely feeling.” The
support I offered, within the limitations of my position, was to listen
to their concerns and ask them each Thursday if I could provide
more music for them to listen to on the weekend, both as a relaxation
strategy for themselves and as a continuation of the service when I
was not available.

Being a music therapist for families is not always about making
music, but about being an attuned and empathic partner with a uniquely
positive presence.

*Endurance - The Long Journey*

Not only is the hospitalisation of a newborn infant outside the realm
of normal life, it can be a journey of hope, fear, denial, acceptance,
commitment, and withdrawal which can take several months to unfold.
Each turn of events demands something more from parents.

Jon Casimir (1999), the father of two week old Naomi who has
oesophageal atresia wrote:

> When we get home, she [his wife] breaks down in the kitchen,
> standing against the pantry door sobbing and moaning. I can’t do
> this any more, I can’t do this any more. I hear fear, panic, heartache
> and fifteen flavours of personal hell rolled into each word. There is
> nothing I can say, so I just hold her. (p. 170)

At one point the music therapist met with Emma and Peter and they
were both extremely tired and distressed:

Jane hadn't slept for 24 hours and when I mentioned that they
needed to look after themselves too, Peter said “What can we do?
We can't leave her here in pain and we can't leave when she is that
sick that anything could happen. We’ve already done that once and
she had to be resuscitated while we were running towards her in the
corridor. We don't really want to go through that again.”

The protracted journey asks parents to call on many capabilities
from their own life. Not everyone’s life experiences equips them for
“normal” parenthood (van IJzendoorn, 1995), yet alone such trauma. In
the long and often frustrating journey towards discharge, the music
therapist is one of a handful of people who builds a collection of joyful
experiences for infants and their parents. S/he repeatedly returns to the
family to keep the possibility and potential of these experiences available.
The cumulative impact is one which at discharge, many parents report as
invaluable.

The following sub-sections outlines the issues in providing music therapy throughout the long journey: the consistency of the service, earned trust, services regardless of status and location, and resourcing the family for other times.

The Consistency of the Service

When providing a psycho-social service in a hospital, flexibility in scheduling is at the mercy of infant and family priorities. The pragmatic implication of this flexible scheduling is that it is unwise to take on so many clients that there is no time to reschedule and accommodate each family. Predictability and reliability of the service may be vital for the parents for whom music therapy provides anticipated emotional or physical respite. Additionally, valuable support is achieved for parents when they know that the service is available when they need it or for as long as they need it, within the bounds of the hours worked by the music therapist.

For some families, services may not be needed throughout the admission and sessions are discontinued. In this case, it is desirable to always greet the family upon sight, to acknowledge the journey that you shared with them.

Earned Trust

Parents bring exquisitely fragile trust to their relationship with all hospital staff. For some, their trust in the staff will be all too easily compromised through mistakes in their infant’s care, complexities of the environment or unconsidered interactions. Peter noted “I feel like I have to be vigilant. You come in, you trust them, and then things go wrong.” For others, their pre-existing interpersonal style may be tightly defensive making it difficult for them to invest much trust in an optional service provider. Providing consistent, reliable, empathic, and skilled companionship over time builds the possibility of trust.

The development of this trusting relationship means that in times of crisis such as acute pain or distress, that the music therapist may stand with parents and offer real support or an expanded capability, to cope in a situation that is overwhelming and terrifying. This is a time when the therapist’s prior experience of similar events may convey the sensibility that “I have seen this before. I am here to go through this with you”.

The music therapist supported Jane’s family through many painful events. She writes about one such instance:
Peter mentioned how difficult it was to see Jane in pain and not be able to help her... One time in ICU Jane became very distressed so I assisted Peter in trying to calm her by physically containing her. As he gently rocked her, I physically supported her arms and legs and stroked her hair, chanting “it’s alright, it’s alright” in a rhythmic soothing tone and singing descending phrases on the vowel sound “ah”. As she fell asleep, he told me how helpful this had been, “just to have you there.”

Shared experiences of trauma can build a mutual understanding that does not need to be expressed, but forms a cornerstone of the therapeutic relationship for the long journey. In the unfortunate event that these occasions of trauma recur, the consistent support of the therapist may further confirm and enhance the strength of the relationship.

*Services Regardless of Status and Location*

The music therapist stays involved throughout the admission regardless of where the infant is located.

Jane returned to PICU repeatedly for acute monitoring and surgeries associated with malrotation of her bowel and stomach complications. The PICU is a highly technological environment designed to sustain physical survival. Jane was usually unable to participate due to sedation. On the ward, the core of her music therapy had been singing so Peter and I would sing softly to her, but the time was more about the parents, and offering them a thread of familiarity and support.

By witnessing these critical moments, the music therapist was part of the experience and the parents did not have to describe it to her later. They knew that she had seen just how sick Jane was during these episodes and understood how hard that part of the journey had been.

*Resourcing the Family for Other Times*

The music therapist actually attends to the family for relatively little time throughout the admission. Recorded music and other items of the service (such as a songbook individually tailored to their infant) not only provide on-going resources, but assure the family that we hold them in our minds beyond the moments we are there. Such devices sustain the sense of support particularly at times when no services are available in the evenings and weekends.
Parents Experience Joy during Music Therapy

Perhaps the music therapy experience most often observed by others on the ward, is the joy that may be shared by the family making music together. This section discusses the potential for retaining a "normal" experience despite the extraordinary circumstances, and defying the negatives through being open to the possibility of joy.

Celebrating the "Normal" Experience

In her role as a parent-infant psychotherapist in a NICU, Steinberg (2006) related the story of meeting a new mother and her very sick premature baby for the first time. At her first introduction the mother showed little acknowledgement of Steinberg. However when she congratulated the mother on the birth of her baby, the mother "softens a bit, looks at me, and says that no one congratulated her..." (Steinberg, p. 134). It is very easy to abandon the joy of a baby's birth amidst the harrowing medical crisis. While any opening conversation with a parent must be carefully considered in the moment, an expression of joy itself should not be dismissed.

The expectation before birth is that there will be singing and music for relaxation and play-times (Custodero, Britto, & Xin, 2002). In this extraordinary post-birth experience, music is one experience from the "fantasy" of the healthy baby that can be retained. While the fundamentally nurturing acts of hugging and rocking may not be available, singing is. It is valuable to acknowledge that while this is a complex situation, there are still normal things that parents can experience and control.

In their first conversation, the music therapist established that Emma and Peter enjoyed singing to Jane. She wrote in her case notes:

I discovered they had a repertoire of songs that they had sung with their older child. Both parents mentioned to me that, as much as possible, they would like her to have the same experience her brother. Emma commented that "having music is something we really love in here because it is the only nice thing in our day and it gives her a link with her brother."

For Emma and Peter, the simple task of singing with their baby sustained a sense of "doing normal things with her".
Defying the Negatives

Although music therapy will not alleviate the fears and anxieties that parents have, active participation can offer a real release from them for a few minutes. During music therapy, their attention is given over to positive pursuits and sometimes moments of joy. It should be noted however that shifting the “energy”, even from negative to positive requires a parent to relinquish some containment of emotion. This may open a gate to unexpected or unwelcome emotion and the music therapist should proceed cautiously, to help them contain and gain perspective. Additionally, when singing lullabies which contain the infant, the attuned music therapist may also provide some containment and nurturing to the parent (Barcellos, 2006).

Music Therapy Acknowledges the “Whole” Developing Child

The hospitalised child or infant is always a patient with a series of medical problems. While the medical and nursing teams take primary responsibility for treating the medical issues, the music therapist can stimulate the parents’ sense of the infant as a whole child. The context of music therapy acknowledges the infant’s spirit and potential and, in Winnicott’s terms (1971), she is “good enough” as she is. Parents have the opportunity to enjoy their baby as a baby instead, of making him/her “better”.

Direct interaction between therapist and infant can give parents the chance to see their infant positively engaged - actively participating, being spontaneous, and showing independence of will. This is a rare opportunity to observe the developing personality of their infant.

This raises the side issue of modelling interaction for parents. While the extraordinarily disempowering experience of hospitalisation destroys so many intuitive processes, assumptions should not be made about parents’ ability to access intuitive parenting with their sick infant. Sometimes, the experience of seeing their infant respond, can unlock the parent’s own potential (Thomson-Salo, 1996). Is modelling necessary? Sensitive and cautious discussions with parents in early meetings combined with astute observation of parent-infant interactions should provide the therapist with the answer.

It is rare that the therapist has greater success than a parent in engaging an infant, but should that occur, the therapist can counter the parents’ fears with explanations that this success is only extra rehearsal for their on-going loving and nurturing relationship.

The music therapist participated in many sessions with Jane and her father:
As Peter and I sang together, Jane offered clear facial and gestural reactions, indicating her level of coping. Peter would often talk through the sessions, not really observing Jane’s responses. Over a series of sessions, I encouraged him to look at the progression of her behaviour over the session particularly as it moved into behaviours of over-stimulation (D’Apolito, 1991). I would explain how I was interpreting her behaviours and close the session. Between sessions, Peter began to notice this behaviour at other times and respond more appropriately. He felt more able to care for her well-being and thus support their attachment (Fenwick, Barclay, & Schmied, 2001; Vandenburg, 2000).

The Contingent Relationship

Steinberg argues that “the private experience of getting to know your newborn is violated in the NICU” (2006, p. 134). While it is beyond the scope of this article to discuss the deeper issues of attachment, we can say that the loss of parenting opportunities in hospital may result in the loss of opportunity for valuable contingent interaction (the basis of attachment). Thus with only traces of normality available, the music therapist is charged with the task of constructing alternative experiences in which families may experience each other in contingent, or attuned, ways.

The medium of contingent singing (Shoemark, 2006) offers many opportunities to rehearse and discuss both the role of parent and infant in successful interaction. The importance of positive vocal behaviour and creating a space for the baby to be heard are considered within the following sub-sections.

Positive Vocal Behaviour

Jane’s parents came to understand how important their voices and even words were for her.

Jane’s use of distress vocalisations and crying were well-honed through frequent bouts of pain and discomfort. I used contingent singing with Jane to encourage non-distress expression and developmentally appropriate interaction. Jane’s expressive capabilities were intact and she responded positively. Her parents were delighted and encouraged to engage with her in this way, affirming their voices as the “beacon” of nurturing and positive experience for Jane. We talked about how much Jane could pick up emotionally from the way they talked to her. I explained some details of infant-directed speech and singing and modelled it for them.
Peter noticed that whenever I sang Jane’s name she responded by smiling and focusing her gaze, raising her eyebrows as a clear sign of engagement. He started singing her name more often and added lyrics about her curly hair to which she smiled and so this was included as a new verse.

In their expanded capability as a triad, valuable information and experience provided the stimulus for enhanced interaction.

*Creating a Space for the Baby to be Heard*

As the journey continues, infants may have periods of wellness in which they make progress in their cognitive, motor, and communication skills. Ironically, sometimes parents find it difficult to adjust to their baby’s new capabilities and in this instance, the music therapist may be an advocate for the baby.

Peter and Emma were so accustomed to advocating for Jane, it took them time to understand that she could also advocate for herself. As Jane became mature enough to use her voice to express herself positively, her parents had to learn a new way of being with her:

I noticed that Emma and Peter had become accustomed to “giving voice” to Jane’s behaviours. When I would ask Jane how she was today, she might move her arms and legs and Peter would say “I’m having a great day thanks [therapist’s name]”. Jane’s mouth and body movements indicated that she was ready to vocalise, but she needed time to produce the utterances. In an attempt to sensitively model this interactive behaviour, I discussed playing the “space game” with the parents, where I described that we would leave gaps in the songs and ask Jane questions. Both parents responded well and began to leave her spaces. Peter subsequently noted that he “always answered for her, and didn’t give her a chance to speak for herself”. Jane responded by smiling, gurgling, snorting, sighing, waving her arms and imitating the sounds we made. Her enthusiasm for “conversing” ignited a new phase of interaction for them all.

*A Whole Life*

There is always a chance that the baby might not survive. Parents want to squeeze as many joyful moments and positive experiences into the baby’s life as possible. It is a privilege then, to be allowed to share some time with the family in this fragile context and with that comes a responsibility to empower, encourage, and support with non-confronting music activities that will provide positive memories. Parents have
anecdotally reported that joyful moments do help to counter-balance the horror of not knowing what the health outcome is going to be for their child.

One day Emma and Peter were telling the music therapist about interacting with Jane on the ward:

They said that they felt “over the top” reading and singing to Jane but that they wanted to “squeeze it all in just in case”. Emma added “At least we can show Jane what it would be like if she was at home. You know, I look at her and I feel greedy but I want forever.”

It is hoped that the final outcome of a baby’s admissions to hospital is the baby’s ever-improving health and a discharge with his/her family to home. The inevitable complexity of becoming a supportive partner to a hospitalised family over a long period of time is that closure may prove to be difficult and challenging for both parties. It is essential then, that the therapist remains aware of the need to protect parents throughout this arduous journey from becoming too dependent upon the relationship.

Preparation for closure may include affirmation of the parents’ skills, knowledge and insights about their baby, visualisation of relocating successful interactions and use of music to the home environment and preparation of resources to take home (eg. copies of CDs).

As if by fate, the music therapist finished at the hospital on the same day that Jane and her parents were discharged. She writes of those last days:

Two days before discharge, the family moved into the family accommodation unit in the hospital where they cared for Jane 24 hours per day. Peter and Emma were very anxious about looking after Jane by themselves but were excited that they would soon be home. When I went to say goodbye on the final morning, Peter came to the door with baby Jane (now six months old) in his arms. I noted with delight to Peter that Jane was free of tubes and monitoring. Peter smiled and expressing his amazement and gratitude, he said “You haven’t had a real hold yet and you really deserve one.” As he handed Jane to the music therapist, he offered tenderly, “Here is my little girl, going home.....going home”. It was a profound moment which acknowledged the difficulties overcome, and a journey travelled together.

Conclusion

The provision of music therapy services to hospitalised infants must essentially involve the parents who serve as the voice of their child. The music therapist has the opportunity to ensure that the potency of the
relationship with parents is not an incidental by-product of service to their infant, but a pivotal service to the parents themselves.

The music therapist must be poised, personable, and consistent to encourage trust and investment in the process from the parents. Music therapy is a triadic relationship with the parents and the infant in which they share an expanded capability together, and the music therapist may serve as a source of respite or direct support for the parents. The long journey of an admission for complex care will require a consistent partnership which resources the family regardless of location or intensity of experience. Within this, the music therapist has the rare opportunity to provide and support moments of joy in which the infant is good enough as she/he is, and parents can feel the wonder of their emerging child.

Music therapy supported Emma and Peter in coming to know Jane and provided opportunities for them to experience joy and pride at a time when her life was very tenuous. The experience of singing together acknowledged Jane's emerging capabilities, while also supporting her through repeated crises and trauma.

Not all music therapy with hospitalised infants is so complex but there is always potential for impacting a family's emotional trajectory which necessarily requires great care and integrity on the part of the therapist.

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References


Kraemer, S. (2006). So the cradle won’t fall: Holding the staff who hold the parents in the NICU. Psychoanalytic Dialogues, 16(2), 149–164.


