



# **A rationale for the use of songs with children undergoing bone marrow transplantation**

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## **Abstract:**

*Children who are undergoing bone marrow transplantation are at risk of developing specific psychological complications from both the illness and the treatment. This paper examines the medical aspects of childhood leukaemia, its side effects and psychosocial challenges as they impact the child; reviews the literature on the psychological and social factors associated with bone marrow transplant treatment for children; and examines music therapy intervention strategies, specifically the use of songs and songwriting, with this population. Finally, it is suggested that the use of songs in therapy may lead to better coping skills and may be an effective assessment tool.*

## **Introduction**

Bone marrow transplantation (BMT) now offers the prospect of cure to many patients whose diseases would otherwise be untreatable and probably terminal. Its use has extended beyond treatment for leukaemia, aplastic anaemia, and severe combined immune deficiency to a variety of immunologic and haematologic disorders (Atkins & Patenaude, 1987). The International Bone Marrow Transplant Registry reported a 20-fold increase in the use of this procedure from 1977 to 1987. 75% of transplants were for treatment of leukaemia (Colon, Callies, Popkin & McGlave, 1991).

Leukaemia is the most frequently diagnosed childhood cancer. Progress in oncology has raised the survival rate of leukaemia patients, transforming what was once fatal into a chronic life-threatening disease. Prognosis is still uncertain, thus stress and anxiety are often aroused when the disease is diagnosed (Van Dongen-Melman & Sanders-Woudstra, 1986).

Although a variety of immunological and haematologic childhood disorders are treated with BMT, childhood leukaemia is the disease most commonly treated by this method and therefore the various aspects of this disease will be described in depth in this paper. The side effects and psychosocial challenges for all BMT patients will be similar, regardless of the disease, and therefore those aspects discussed below can be generalised to other diseases treated through this method.

## **Childhood leukaemia – medical aspects**

Acute lymphoid leukaemia (ALL) is a cancer of the tissues producing excessive amounts of abnormal leucocytes (white blood cells necessary to fight infection) which invade various organs of the body. Eventually the leukaemic cells invade the bone marrow displacing the normal cellular elements, resulting in anaemia. Bleeding occurs as a result of decreased circulating numbers of platelets. Infections occur more frequently due to the decreased number of normal/healthy leucocytes (Betz & Poster, 1992).



Early signs and symptoms of ALL include: fluctuation in energy, appetite or temperament; fever and influenza-type symptoms; enlarged lymph nodes, liver or spleen; bone or joint pain; paleness, weakness, tendency to bruise or bleed easily; and frequent infections (Verhagen & Mosher, 1992).

Treatments for ALL include chemotherapy and BMT both of which aim at inducing a remission. Children with ALL have an 80% to 90% chance of obtaining a remission, and only 50% of these survive for three years or more.

Chemotherapy consists of three phases: induction, consolidation, and maintenance. During the induction phase (3-6 weeks) the child receives a variety of chemo-therapeutic agents in order to induce a remission. This most intensive stage of treatment is designed to destroy as many leucocytes as possible. This level of treatment is extended for two to three weeks into the consolidation phase to ensure eradication of any cancer cells which may have survived phase one. Maintenance therapy is then administered for several years in order to sustain remission. If the child has to undergo a BMT, this maintenance phase is shortened substantially. Side-effects of chemotherapy include nausea and vomiting, constipation, bloody urine, irritation to the lining of the mouth and gastrointestinal tract, lowered blood counts, hair loss, loss of appetite, depression, damage to vital organs such as sterility, permanent cognitive damage, and damage to the normal bone marrow. Radiation treatment is often used in addition to chemotherapy as a preventative measure against BMT (Verhagen & Mosher, 1992). Due to these side-effects, the treatments often seem worse than the disease.

### **Bone marrow transplantation procedure**

Due to the damage caused to the normal bone marrow in chemotherapy, it is often necessary to perform a BMT. There are three types of grafts: allogeneic — taking bone marrow from someone other than the patient; autologous — using bone marrow from the patient him/herself while in remission; and syngeneic — taking bone marrow from a chromosomally identical twin. The donor's bone marrow must contain matches in at least four out of seven antigens (chemical structures on cells which are recognised by the body as foreign, thus stimulating immune reactions).

The pretreatment procedure includes chemotherapy and total body irradiation. The aim is to kill all the cancer cells but in the process the immune system is destroyed. Therefore, after the transplant, the child must be placed in sterilised isolation for one to three months, given antibiotics in anticipation of infection, and blood transfusions because the chemotherapy has attacked not only the white blood cells but also platelets and red blood cells. The final stage in the procedure is the marrow infusion in which the bone marrow moves to the appropriate parts of the body and engraftment takes place.

Complications from BMT include infections, graft-versus-host-disease, bleeding, liver complaints, BMT failure and graft failure. Some of the long term effects may be cataracts, infertility, and secondary cancers (Verhagen & Mosher, 1992).

### **The effects of hospitalisation**

Hospitalisation is especially difficult for children. Admission results in their separation from family, friends, home and school. Their normal level of activity is restricted



and they are forced into dependence on others for tasks which they could normally do independently. Additionally, the appearance and sounds of technological apparatus can be very frightening. Reactions to hospitalisation may include anxiety, withdrawal, regression and defiance (Brodsky, 1989; Froelich, 1984).

### **The effects of isolation**

In addition to hospitalisation, children undergoing BMT are isolated in a sterilised environment for six to twelve weeks in order to reduce the risk of infection. Contact with others is at a distance: people may only enter the sterile space in sterilised cap, mask and gown. Therefore, these children are subjected to decreased social contacts, lack of stimulation, and fewer physical activities. Their emotional responses to being placed in isolation are similar but more intense to those of being hospitalised only, and include loneliness, depression, rejection, anger and confusion (Brodsky, 1989).

### **Psychosocial aspects of paediatric bone marrow transplantation**

For children undergoing BMT, increased dependency on adults, loss of control over various aspects of their environment and their lives, decreased participation in academic and extracurricular activities, and alterations in physical appearance and function, challenge their capacities for healthy development. This puts them at risk for difficulties in psychosocial adjustment (Sanger, Copeland & Davidson, 1991).

Additional stressors include those specifically related to their disease. Chesler and Barbarin (1987) list these as: (1) understanding the diagnosis, prognosis and treatment; (2) adapting to treatment and side effects; (3) relating to medical staff; (4) relating to family and peers; and (5) dealing with two worlds — illness and health, specialness and normalcy.

Further psychosocial difficulties include flattened affect, loss in self-esteem and self-identity, altered body image and awareness, fear of pain and separation, withdrawal and isolation and fear of death (Brodsky 1989, Fagen 1982, Hodges 1981, Sanger *et al.*, 1991). Children are often aware of the life-threatening nature of their disease and the treatment and learn to define themselves as dying through watching other children in the hospital die before them (Wass, Berardo & Neimeyer, 1988).

Exposure to these multiple stressors may affect the child adversely which in turn may inhibit his/her recovery from the intense treatment. Therefore it is important for these children to find adequate coping mechanisms. Children vary greatly in both the extent to which these psychosocial challenges affect them, and in the adequacy of their coping responses.

### **Strategies for coping with the psychological challenges**

Coping consists of both action-oriented and intrapsychic efforts to manage environmental and internal demands which strain or exceed a person's resources (Caty, Ellerton & Ritchie, 1984). Three coping methods delineated by Caty *et al.* (1984) are:



(1) *Information seeking*: Adults often try to protect children by not communicating with them about the illness. When children sense the difficulty for parents to talk about their disease, they often fall into a mutual pretence in an attempt to protect the parents and repress their feelings and questions. This can then lead to problems in psychosocial adjustment. Kupst (1992) found that children's ability to cope with the stresses of the disease was significantly related to the adequacy of the parents' coping. In addition, Sanger *et al.* (1991) found that early identification of problems in psychosocial adjustment, and intervention by means of finding adequate coping strategies, may improve the quality of functioning of the child not only during but after the course of treatment.

(2) *Direct/indirect action*: This dimension includes all noncognitive behaviour directed toward managing the self or the environment. Children need to be given opportunities to gain mastery and control over situations experienced in the past or during the current hospital stay. Verbal, nonverbal and motor activities that provide release or reduction of hostility or frustration are also very important. Other noncognitive coping mechanisms include: self protection and self comforting behaviours (such as thumb sucking, using a security object); turning to others for help, comfort or approval; and expression of emotions.

(3) *Intrapsychic processes*: This dimension comprises the defence mechanisms, behaviours and mental processes designed to regulate emotion and defend against anxiety. These include identification with others, projection, denial, displacement, regression, and intellectualisation.

### **Enhancement of coping mechanisms through the creative arts**

There is increasing recognition that children need to communicate about their hospital experiences in order to cope with them (Brodsky, 1989). Parish (1986) believes that when working with children in hospitals, verbal communication and understanding is often inadequate. For instance, younger children often lack the appropriate verbal skills, whereas older children frequently find verbal communication to be inadequate when trying to understand and cope with their illness. They often feel confused, inhibited and withdraw from expressing the multitude of feelings that are evoked by the experience. Furthermore, chronically ill patients, in particular, often become adept at hiding their emotions. Segal (1984) suggests the use of the expressive arts as symbolic communication for expressing overwhelming feelings and coping with stress. He reports that the expressive arts often draw out unguarded responses because they involve tactile, visual, aural and kinaesthetic senses, which are a part of the involuntary nervous system.

Many creative arts therapies have been used with children with cancer to help them express their thoughts and feelings about themselves and their illness. Music therapy is seen as very effective in providing opportunities for self-expression, anxiety reduction and the encouragement of verbalisation. In a study with hospitalised children, Froelich (1984) found that music therapy was more effective than medical play therapy in facilitating verbalisation of children's hospitalisation experiences. Marley (1984) examined the effectiveness of music in decreasing stress behaviours exhibited by hospitalised infants and toddlers and found that music plus interaction with a music therapist effectively reduced stress-related behaviours.



### **Music therapy with hospitalised children**

The deep and instant appeal of music for most children makes it a natural medium for establishing a relationship with the hospitalised child. Songs, instruments, and musical games are familiar and a source of security in a strange setting. The novelty of new musical activities can delight, surprise and stimulate a child to explore and this special kind of involvement increases the sense of mastery of the environment and decreases feelings of helplessness. This is an important element in coping with stress and contributes to the child's successful adaptation and psychological growth (McDonnell, 1983).

For children in hospital, songs may be selected by the therapist to give reassurance, to deal with separation anxiety and isolation by offering comforting images of home and family, to stimulate expression of feelings, and to instil hope about recovery. Alternatively, children may create their own songs. The songwriting process can enhance a child's expression of feelings.

C. is a nine-year-old girl who was hit by a car and consequently was in traction for 4-6 weeks. She has a bright personality and was eager to participate in music therapy sessions. After a couple of sessions she became interested in finding out about all the possible activities in music therapy. On hearing songwriting as an option she asked if she could try it because she loves writing poetry. We planned to write a song in the next session. At first she wanted the therapist to choose the topic and the musical structure but was encouraged to take responsibility for these herself. The lyrics she wrote were:

The first thing I remember,  
Was being dragged across the street,  
My friends were all hysterical  
I didn't know why that was.  
The next thing I knew  
A stretcher was by my side,  
My friends were all there watching  
And my Dad was holding my hand.

"I'm sorry Erin it's all my fault  
I wish it never happened,"  
Was all that I could say  
On my way to the hospital.  
They carried me in  
And then they x-rayed my leg  
And then they put me  
In my hospital bed.

That night in my bed  
I was so frightened, I was sick,  
Although my Dad was with me  
I could not go to sleep.  
All I really wanted  
Was to go back to my home,  
It made me feel very sad,  
Which made my leg hurt much more.



Hospital is not as Bad  
As I used to think,  
People bring lots of chocolates  
For me to eat.  
I'm doing lots of crafts  
And I'm learning the guitar,  
I'm meeting more new friends  
That I wouldn't have mixed with before.

C. was very proud of her song and shared it with family and friends. The next week her mother thanked the music therapist because C. had previously refused to talk about her accident or her feelings about being hospitalised. Since writing the song she has shared her feelings more openly and become concerned with helping her friend to feel less guilty.

Instruments may be used to accompany songs or may be used improvisationally to express happiness, sadness, anger, fear, loneliness and other emotions. The use of instruments may also enhance physical interaction between the therapist and child. Music therapy also provides many outlets for the child's motor urges which is vital for the maintenance of self-esteem. Mahler (cited McDonnell, 1983) purports that motor release is the soundest device of the growing child to serve ego growth, obtain balance and to form a reliable safety valve against anxiety. Hospitalisation limits the possibilities of motor activities and therefore appropriate outlets for this expression are essential. Musical games may include rhythm games, mirroring games and voice pitch games (Marley, 1984). For the reduction of anxiety and the reduction of pain, the use of music combined with relaxation/imagery may be beneficial.

### **Music therapy with bone marrow transplant patients**

General goals which may be included for music therapy interventions for children with leukaemia or other disease treated by BMT are: (a) to provide a normalised environment promoting self-expression, release of tensions, and relaxation; (b) to initiate social interactions with peers in age appropriate activities; and (c) to work through issues related to their medical conditions and their conception of death (Brodsky, 1989). The specific areas music therapy must address for these children are those concerning their isolation, the physical consequences resulting from the illness, and the terminal nature of the illness.

Bailey (1984) lists the goals of music therapy with cancer patients as attempting to meet their needs for tension release, control, expression of feelings, instillation of hope, and being heard. Munro & Mount (1978) stress that music therapy activities must aim to build an environment that attempts to satisfy the patients' needs, as well as develop trust and improve quality of life. Singing, song selection, song communication, life review, lyric substitution, songwriting, improvisation, relaxation and imagery have all been cited as beneficial music therapy techniques to use in order to achieve these goals (Brodsky, 1989; Gilbert, 1977; Munro, 1984; Munro & Mount, 1978; Bailey, 1984; Fagen, 1982; O'Callaghan, 1984 & 1990; Slivka & Magill, 1986).



When children undergo a BMT procedure, they are not only left isolated but are very lethargic and experience intense pain. At this stage, music therapy techniques requiring less active participation are most valuable. These may include:

- (1) Music and relaxation — the use of sedative music together with relaxation techniques;
- (2) Music and imagery — the use of music together with imagery techniques;
- (3) Songs — (a) song communication — the patient's or therapist's selection of pre-existing songs to sing/listen to and discuss, or (b) songwriting — the patient may create his/her own songs.

### **Songs with bone marrow transplant patients**

Brodsky (1989) describes three overriding issues for music therapists working with children with cancer. The first concerns the child's level of participation. He points out that even as the child deteriorates, s/he will be able to be involved in music therapy in some way. The second issue concerns the effectiveness of pre-recorded versus live music. He reports that for paediatric oncology patients, live music contact is more effective than taped music as it allows more for the subtle communication of thoughts and feelings, as well as a multitude of gestures, acts and facial expressions. Finally, the third issue concerns the particular use of songs and song activities.

M. is a four-year-old boy with leukaemia who was undergoing a BMT. In music therapy songs were used in order to enhance his opportunities for choice and control over his environment. In addition, small percussion instruments, with the appearance of various animals, were sterilised and placed with him in the laminate air flow. More instruments were available for family and friends to use outside the laminate air flow. M. would choose if he wanted music therapy or not on a given day, and he would choose which songs to sing and orchestrate who could play, what they would play and when they would play (family members were often orchestrated into the session). In a situation in which he had minimal control, he and his family benefitted greatly from the freedom allowed during music time.

The use of songs is one of the most common approaches in music therapy, whether it be singing, song recall, song communication, or songwriting. Songs consist of both verbal and musical components and therefore stimulate cognitive, physical, emotional and spiritual aspects of an individual. Brodsky believes that the use of songs with children who have cancer effectively provides important means for support and tools for change. As the song lyrics represent verbal communication there is an inherent association between the songs and human contact. When a child is in isolation, human contact is invaluable. The songs also provide a framework for enhanced communication, as the child may be able to express through a song, issues s/he may have had difficulty expressing on his/her own. Berg (1953) indicates that individuals under stress are able to temporarily displace their conflict through song material. It has also been suggested that the content and structure of the words and melodies may facilitate the unconscious integration and organisation of one's personality (Schulberg, 1981). It seems that the manner in which a person associates with song lyrics is related to unconscious processes and



may in fact be highly metaphorical. Therefore, song material may have diagnostic potential. Bailey (1984) states:

People choose to hear and participate in songs which support their needs and which convey the mood and messages they want to hear. Valuable information about the physical, emotional and spiritual needs of [clients] can be gained by paying close attention to the songs they choose and the reasons for their choices. The music therapist can use the verbal messages within the songs to promote enhanced exploration of inner thoughts and feelings (p. 7).

For children, songs are potentially excellent projective and imaginative stimuli. The metaphoric techniques of Heimlich (1983) and the projective techniques of Crocker (1955) serve as a means of revealing inner fantasies, fears, illogical or disassociated thinking and egocentricity. Both lyrics and metaphors make frequent use of imagery and it is perhaps through this imagery that we can get in touch with the client's perceived experience. Bailey (1983) lists nine themes most often represented in songs selected by people with cancer and adds possible implications:

- (1) Hope: the instillation of hope and focus on God; a reawakening of self-confidence.
- (2) Pleasure: the development of coping mechanisms to deal with stressful events.
- (3) The World: the feeling of universality through refocus of attention from self to others.
- (4) Reminiscence: the refocus of feelings and thoughts towards previous periods of life.
- (5) Relationships: the denial of isolation and expressed need for support.
- (6) Needs and Desires: the validation and legitimisation of needs and desires.
- (7) Feelings: the seeking of permission to feel; to express what one is feeling.
- (8) Loss and Death: the alleviation of fear and anxiety; the promotion of inner peace in preparation for death.
- (9) Peace: the eventual resolution with personal loss and death.

An important aspect to consider when working with songs is: who is the client identifying with when engaged in song discussion — the lyricist, the performer, the subject of the song, or the receiver of the song? Each of these will have different implications for the therapist in understanding the client more fully.

Bailey's themes evolved out of work primarily done with adults, and Brodsky perceives them to be pertinent to children as well. However, to date, there has been little research into the major themes and issues of children with terminal illnesses or the stages of psychological strategy through which they progress. Fagen (1982) began exploring this area suggesting several alternatives to well known stages developed from work with adults, such as Kübler-Ross' (1970) stages (describing a progression through denial and isolation, anger, bargaining, depression and acceptance), and Oremland and Oremland's (1973) stages of fear, anger and guilt in terminally ill patients. Fagen describes the issues she believes to be significant to children. These are fears related to drug-induced hallucinations; withdrawal and apathy; isolation from the family; sensitivity to hospital routine; and fear of sleeping related to a fear of death. Although a significant start, there is little evidence that these are the most significant issues for these children, and the





issue of stages of psychological strategy experienced by children facing possible death has not been adequately addressed.

One way of discovering pertinent issues for children undergoing BMT, and whether there are in fact distinct psychological stages through which they progress, may be through the analysis of their song choices, and/or their original songs.

### **Songwriting with children undergoing bone marrow transplantation**

Although there are numerous reports of the use of songs with adult people with cancer, there has not yet been much research into the use of songwriting with this population. Songwriting may be viewed as a combination of music and poetry. As music is known for its therapeutic values, so too is poetry. Stainbrook (1978, cited in Jaskoski, 1980) suggests that "in its optimum potential the merger of poetry with therapy may result in the revitalising and remoralising of the self by providing a wholeness of consciousness — an integration of emotion, cognition and imagery — with which to create and maintain personal meaning" (p. 275). When their artform is linked to music the resulting effect may be even more powerful as the music can reflect and deepen the expressed words. In fact, the music may at times be more expressive of the emotions felt than the words which may be censored more by the person's conscious defences.

When using songwriting with children, projective techniques or creative fantasy may be utilised. Wheeler (1987) states that the use of metaphoric techniques provide opportunities to express and work through anxiety-producing experiences without confronting them directly. Aigen (1991) also talks about the importance of metaphoric techniques or creative fantasy when working with a child because they reveal a great deal about the child's view of what is going on. Often the solutions in the child's story will provide solutions to the child's own inner conflicts. Therefore, a belief in the child's inner resources and ability to find solutions given a supportive, creative context, is essential when using songwriting with children undergoing BMT.

There are a number of approaches to songwriting which have been outlined in the music therapy literature. These include:

- (1) The "Cloze Technique" — the child fills in the blanks in lyrics provided by the therapist.
- (2) Song Parody — the child writes new words to pre-existing melodies.
- (3) The Blues — the child's song adheres to the musical and lyrical form of the blues style (this may also be done with Rap).
- (4) Original Songs — the child creates both the music and the lyrics. This process may be spontaneous as in Song Improvisation or may involve the reworking of music and lyrics until the child is satisfied with the final product.

A. is a sixteen-year-old girl diagnosed as having a brain tumour and admitted for BMT treatment. While in the laminar air flow (Isolation unit) she requested to learn the guitar. Arrangements were made to have a guitar and stand sterilised. Her wish was to learn "Stairway to Heaven". This choice indicated a wish to express her feelings and fears around the possibility of her death. Unfortunately she became too weak and was in too much pain to pursue playing



the guitar for long. She still wanted to actively engage in music therapy and decided to write a song. This was a lengthy process because of her low level of physical energy. Despite this she maintained a positive attitude.

Am C  
When life seems at its lowest  
D Am  
And everything seems wrong,  
D Am  
All you can think of is yourself,  
Am C  
Well just remember this  
D F  
There are others worse than you  
Am E Am  
So remember how lucky you are.

These lyrics were aimed at herself and not at other people. During the first session, as she was writing the lyrics the doctor came in to inform her that she may soon come out of isolation. In the second session, she added the music and as we were singing it the nurses came in and turned off the sterilised air and we all celebrated. She commented that writing this song seems to bring her luck. In the third session she had planned to add further verses but as we started she was informed that she could go home. The moment was so emotionally charged that we abandoned the session. She decided that this was her “good luck” song.

### **Conclusion**

There is little research involving music therapy with children undergoing BMT and less involving the use of songs and songwriting in order to more fully understand the issues pertinent to the child. Given the multitude of issues which arise with the diagnosis and treatment of childhood leukaemia and other diseases treated by BMT, it would seem that this medium (song communication/songwriting) would be very effective in allowing the child the opportunity to express his/her thoughts and feelings in a therapeutic setting. This could lead to better coping skills for the child and hence may enhance recovery from the treatment/disease. It would also provide the therapist with valuable information about how the child is adjusting to the illness and coping with the treatment, which may assist in better understanding and working with the child.

In reviewing the existing literature it is apparent that there is indeed great potential for the use of songs with children undergoing BMT, and a need for further research into the benefits of this music therapy intervention both in the assessment and treatment of these children. It is hoped that this paper will stimulate and generate more research into the use of music therapy, and more specifically the use of song communication and song writing, with this population.



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