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SPIRITUALITY, HOPE AND MUSIC THERAPY IN PALLIATIVE CARE

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Our spirit is the real part of us, our body its garment. A man would not find peace at the tailor's because his coat comes from there: neither can the spirit obtain true happiness from the earth just because his body belongs to earth.
Khan (1979, p. 76)

Behind us all is one spirit and one life. How then can we be happy if our neighbour is not also happy?
Khan (1979, p. 123)

I am taking the risk in this paper of using terms like "spirituality," "hope" and "creativity," not commonly voiced in the world of medicine. However, palliative care has a tradition of breadth in its understanding of health care needs and we find throughout the medical and nursing literature that the spiritual needs of patients are mentioned. My argument is that a time has come when such considerations can be voiced within the culture of the creative arts therapies. It is a careful, sober consideration of spirituality that I want to elaborate upon here, linking the promotion of hope to working creatively with music. While accepting that society is built upon the foundation of science and art, it would be a folly to ignore those streams of thought that refer to the spirit of humankind. Within these pages I hope to demonstrate that talking about spirituality can be brought into the discourse of patient care. By ignoring a concern of the very patients with whom we work, we are failing to meet their needs.

What I am proposing is that, in working with the dying and the chronically ill, we need to consider that which helps us to transcend our daily lives. Note that I am not separating practitioners and patients here, for we all surely face the great questions of life: "What is the meaning of life, what is the nature of suffering, why me, what can I do?" Even though it is a fact that is often forgotten, we are all facing death and in doing so we are all asked the question of how to live.

When we look at our lives from this perspective of how to live, we are faced with a crisis. I am using crisis here in a broad sense, to mean a judgment or discernment. Indeed, the difficulty faced in caring for dying patients is that although the problem appears to be that of chronic illness, in reality the challenges are acute and appear as a series of crises (Alter, 1994). Each crisis with a dying patient is a matter of identity—"Who am I? What will become of me?" (Simon & Haney, 1993).

We now have two questions, one concerned with existence and one with identity, and these questions have been the fundamental questions of all spiritual traditions. The practical ramifications of these questions are related to how we care for each other and how we recognize each other's quality as a person. To answer these questions we need to be alive to a new consciousness (Atnally, 1993).

The main emphasis of spirituality has always been that it will help us to achieve this new consciousness by transcending the moment. So, too, with the concept of hope, there is the expectation of a leap forward. In music therapy this transcending, expectant leap is made through the creative act. Through creative play, we can distinguish the inner world of ourselves. In this sense, consciousness is realized by doing.

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Creativity occurs in the realization of an idea as created form. In the same way that the thoughts and ideas presented here have their own architecture realized in words and, as the architecture of the cathedral is realized in stone, the architecture of music is realized in sounds. We can also be the architects of hope. By transcending the moment of suffering, a new consciousness is created. This new consciousness is realized concretely in the performance of music. We sing and play what we are. There is no precocious need to identify this as an emotional experience, rather to savor the experience in the moment itself.

Perhaps it is important to state here the main idea underlying my thinking regarding music. Our human identity is that of a piece of symphonic music continually being composed in the moment. In contrast to a mechanistic metaphor of humanity that sees the body as an entity to be repaired, this view sees each being as vital and open to creation. We are improvised as a fresh identity according to every one of life's contingencies. Our very identities are created anew although the theme may be repeated, and it is this repetition that gives us coherence as a personality. Put another way, we are each a song that is continually being sung. What sings that song is a matter of personal belief.

Music therapy is an activity that promotes the expression of this song. Each person is given the opportunity to creatively define themselves as they wish to be. What the person will become and how a personal future is defined, a future that is admittedly restricted and often tragically curtailed, are matters for joint therapeutic endeavor between therapist and patient (Aldridge, 1991b). The interaction between patient and therapist is creative in the sense that it is in interaction where momentary choices are made (Abra, 1994). It is possible to realize ourselves in the moment not solely as a body restricted by infirmity, but transcended as a soul realizable in the music. Even so, the end stage of our therapeutic endeavor is that the patient will die.

We know from clinical practice that the will to live is an important factor. Purpose and meaning in life are vital and all too often are not questioned when we are in good health. But should we fall ill, then purpose and meaning become crucial to survival. Illness may be seen as a step on life's way that brings us in contact with who we really are. The positive aspect of suffering has been neglected in our modern scientific culture so that we, as practitioners and patients, often search for immediate relief. Although the management of cancer pain has been a major contribution of the hospice movement, the understanding of suffering is still elusive in the literature. I am not suggesting that we actively seek out suffering or deny that pain is debilitating, rather to remind us that part of the human condition is indeed to suffer. In seeking to relieve suffering we can value the opportunity it brings to learn. It may well be that the difficulties reported in effectively relieving pain are the result of the failure to identify suffering.

We are all asked the ultimate question of what meaning and purpose our lives would have had if we were to die now. Most of our activities cut us off from this brutal confrontation except in the field in which we are working. Though the management of pain is often a scientific and technical task, the relief of suffering is an existential task. In the major spiritual traditions suffering has always had the potential to transform the individual. As Tournier (1981) reminded us, it is love that has the power to change the sign of suffering from negative to positive.

What is Spirituality?

The natural science base of modern medicine often ignores the spiritual factors associated with health. Health invariably becomes defined in anatomical or physiological, psychological or social terms. Rarely do we find diagnoses that include the relationship between patients and their God. The descriptions we invoke have implications for the treatment strategies we suggest and the way in which we understand how people can be encouraged to become healthy. Patience, grace, prayer, meditation, hope, forgiveness and fellowship are as important in many of our health initiatives as medication, hospitalization, incarceration or surgery. It is these spiritual elements of experience that help us to rise above the matters at hand so that in the face of suffering we can find purpose, meaning and hope.

Working as a psychiatrist, Hiatt (1986) offered an understanding of the spiritual in medicine that can also be worked with in psychological terms. "Spirit refers to that non corporeal and non mental dimension of the person that is the source of unity and meaning, and 'spirituality' refers to the concepts, attitudes, and behaviours that derive from one's experience of that dimension." He suggested that by taking such a framework, we can discuss and use spiritual healing "within a modified western framework (of medicine)" (p. 742).

In recent years the word spiritual has appeared in-

creasingly in the nursing literature (see Table 1) where spiritual needs have been differentiated from religious needs (Boutell & Bozett, 1990; Burkhardt, 1989; Clark, Cross, Deane & Lowry, 1991; Emblen, 1992; Grasser & Craft, 1984; Labun, 1988; May, 1992; Reed, 1987; Stuart, Deckro & Mandle, 1989). Within these approaches there is a core of opinion that accepts suffering and pain as part of a larger life experience and that they, too, can have meaning for the patient and for the carer(s) (Nagai Jacobson & Burkhardt, 1989). The emphasis is placed upon persons' concept of God, sources of strength and hope, the significance of religious practices and rituals for the patients and their belief system (Soeken & Carson, 1987). Spiritual well-being is also proposed as a hedge against suicide, providing some people with a reason for living (Ellis & Smith, 1991) and as a mediator of depression (Fehring, Brennan & Keller, 1987).

Spirituality, characterized by the idea of transcendence, has a broader perspective than religion. Religious care means helping people maintain their belief systems and worship practices. Spiritual care helps people to maintain personal relationships and relationship to a higher authority, God or life force (as defined by that individual), identify meaning and purpose in life and transcend a given moment. This idea of transcendence, the ability to extend the self beyond the immediate context to achieve new perspectives, is seen as important in the last phases of life where dying patients are encouraged to maintain a sense of well-being in the face of imminent biological and social loss. Ross (1994) noted three necessary components to spirituality—the need to find meaning and purpose, the need for hope and the need for faith in self, others and God.

Table 1
Meanings of Spirituality

Author	Description
Emblen, J. (1992)	". . . helping people to identify meaning and purpose in their lives, maintain personal relationships and transcend a given moment."
Hiatt, J. (1986)	". . . that aspect of the person concerned with meaning and the search for absolute reality that underlies the world of the senses and the mind and, as such, is distinct from adherence to a religious system."
Kuhn, C. (1988)	". . . those capacities that enable a human being to rise above or transcend any experience at hand. They are characterized by the capacity to seek meaning and purpose, to have faith, to love, to forgive, to pray, to meditate, to worship, and to see beyond present circumstances."
Smyth, P. (1988)	". . . that life has a purpose, of the search for meaning, of the attempt to interpret their personal illness in a way that makes sense of their world view."

Reed's study (1987) of spirituality and well-being in terminally ill hospitalized patients hypothesized that terminally ill patients would indicate a significantly greater spiritual perspective than non-terminally ill hospitalized adults with problems that were not typically life-threatening and healthy non-hospitalized adults. For the terminally ill patients there was a shift toward greater spirituality as indicated by a stronger faith and increased prayer.

Doctors, nurses and clergy have worked together to care for the dying (Conrad, 1985; Reed, 1987; Roche, 1989), and a community approach that includes the families of the patients and their friends appears to be beneficial (Aldridge, 1987a). These benefits are a lessening of anxiety, general improvement in feelings of well-being and an increasing spiritual awareness for the dying persons (Kaczorowski, 1989). In addition, comprehensive treatment programs for people with AIDS recommend that the spiritual welfare of the patients, and its influence on their well-being, be included (Belcher, Dettmore & Holzemer, 1989; Flaskerud & Rush, 1989; Gutterman, 1990; Ribble, 1989).

It is not only for the dying that spirituality plays a role. For the widow who must adapt to the loss of a partner, the ability to express her spirituality can, along with other criteria, play an important role in enhancing well-being. For young and old groups of widows, attention to spiritual needs, physical exercise and a willingness to be self-indulgent all contributed to satisfy emotional and sexual needs.

Spirituality and religion, then, appear to be mediating factors for coping with an impending loss of life and to be positive factors for maintaining well-being, particularly in older patients. When we consider patients in palliative care, it is appropriate to consider

what we can also do for their families and friends. Our patients rarely die alone, and surely the caregivers, familial, filial and professional, must be included for they, too, suffer and it is they, too, who must transcend the moment.

Maintaining Integrity and Hope

The true joy of every soul is in the realisation of the divine spirit; the absence of realisation keeps the soul in despair.

Khan (1979, p. 105)

Positive emotions, which include the qualitative aspects of life—hope, joy, beauty and unconditional love—are known to be beneficial for the process of coping with the diagnosis of cancer during the course of treatment and for post-operative recovery. This realm of positive emotion is precisely the ground in which the creative arts generally can have their own being. Patients can express themselves in a way that is creative and not limited by their disease. From such a perspective we may expect that, although physical parameters may fluctuate or deteriorate, life-quality measures or existential indicators will show improvement.

A significant beneficial factor in enhancing the quality of life is hope. Hope has been identified as a multi-faceted phenomenon that is a valuable human response even in the face of a severe reduction in life expectation. Yates (1993) offered six dimensions of hope: the sensations and emotions of expectancy and confidence, a cognitive dimension that comprises positive perceptions, a belief that a desired outcome is realistically possible, a behavioral dimension where patients act on their positive beliefs to achieve their desires, a contextual dimension that links expectations with those of the family and friends, and a temporal dimension looking forward or even backward.

Hope was defined by the nurse-researcher Herth (1990) as an ''inner power directed toward enrichment of 'being'.'' With the exception of those diagnosed with AIDS, overall hope levels among subjects were high and were found to remain stable over time. Seven hope-fostering categories (interpersonal connectedness, attainable aims, spiritual base, personal attributes, light-heartedness, uplifting memories and affirmation of worth) and three hope-hindering categories (abandonment and isolation, uncontrollable pain and discomfort, devaluation of personhood) were identified. Of the hope-fostering categories, we can translate six of them into activities pertinent to the creative music therapy situation (see Table 2).

Hope, like prayer (Saudia, Kinney, Brown & Young, 1991), is a coping strategy used by those confronted with a chronic illness that involves an expectation going beyond visible facts and seen as a motivating force to achieve inner goals. These goals change. Although a distant future of life expectancy no longer exists for AIDS patients, life aims can be redefined and refocused. With the progression of physical deterioration, the future becomes less defined in terms of the body and time, but more defined in the meaning attached to life events in relationship with family and friends. In later stages there is a shift toward less concrete goals and a refocusing on the self to include the inner peace and serenity necessary for dying (Herth, 1990).

The true meaning of hope is that of an inclination toward something that we do not know. There is a longing for the unknown. We are all waiting for a change, even if it is a material change of circumstance, and this expectation is hope. Such hope cannot be touched and often not understood. It is an attainment that may be described as beyond happiness and above death.

Music Therapy and the Creative Act

Each individual composes the music of his own life. If he injures another he breaks the harmony, and there is discord in the melody of life.

Khan (1979, p. 65)

Table 2
Dimensions for Fostering Hope

Dimension of Hope*	Music Therapy Context
Interpersonal context, relationship with others	therapeutic relationship
Beliefs and cognition, identifying attainable aims	
Spiritual base	uplifting music, the traditional role of sacred music, transcending the moment
Personal attributes	being creative, being musical
Light-heartedness	play in therapy
Uplifting memories	listening to music, playing and singing remembered songs
Affirmation of worth	activity of mutual music making

*after Herth (1990).

Music therapy, with its ability to offer an experience of time that is qualitatively rich and not chronologically determined, is a valuable intervention. We are aware that music has soothing properties and is employed successfully as an anxiolytic (Aldridge, 1993a,b). Yet music can also be inspiring and uplifting (see Table 3). In its sacred practice, music has been used to transport the listener to other realms of consciousness and is used thusly in the final stages of dying (Schroeder-Sheker, 1993). Indeed, the power of music is that it has the ability to calm us or to stir us in so many dimensions (Khan, 1983).

Music therapy, with the potential for bringing form out of chaos, should offer hope in situations of seeming hopelessness and, therefore, a means of transcendence. This idea of transcendence, the ability to extend the self beyond the immediate context to achieve new perspectives, is seen as important in the last phases of life where dying patients are encouraged to maintain a sense of well-being in the face of imminent biological and social loss. Even in the midst of suffering it is possible to create something that is beautiful. This aesthetic expectation of self-in-relationship is positive; it is hope made manifest.

Significantly for many AIDS patients, personal relationships are deteriorating. Either friends die of the same illness or social pressures urge an increasing isolation. Spontaneous contacts are frowned upon and the intimacy of contact is likely to be that of the clinician rather than the friend. Music therapy offers an opportunity for intimacy within a creative relationship. This relationship is both nonjudgmental and equal. The patient is encouraged to creatively form a new identity that is aesthetic even in the face of disfigurement.

Working together in a creative way to enhance the quality of living can help patients make sense of dying (Aldridge, 1987b,c). It is important for the dying, or those with terminal illness, that approaches that integrate the physical, psychological, social and spiritual dimensions of their being are used (Feifel, 1990; Gary, 1992; Herth, 1990). In addition, how we care for the sick and dying, no matter how they contracted their disease, is a matter of our own personal responsibility and a collective measure of our humanity (Aldridge, 1987a,b, 1991a,b).

In music therapy, patients are required to be active self-defining agents. The requirement is that they are moral (i.e., actively partaking and self-defining) when they are sick and suffering, not that they be subjected to our morality and definition.

Music therapy, with its emphases on personal contact and the value of the patients as creative productive human beings, has a significant role to play in the fostering of hope. Hope involves feelings and thoughts and requires action (i.e., like music, it is dynamic and susceptible to human influence). Stimulating the awareness of living, in the face of dying, is a feature of the hospice movement where being becomes more important than having. The opportunity, offered by music therapy, for patients to be remade anew in the moment, to assert an identity that is aesthetic, in the context of another person, separate yet not abandoned, is an activity invested with that vital quality of hope. Hope, when submitted to the scrutiny of the psychologist and not conforming to an established reality, can easily be interpreted as denial. For the therapist, hope is a replacement for therapeutic nihilism, enabling us to offer constructive effort and sound expectations (Menninger, 1959).

Any therapeutic tasks must concentrate on the restoration of hope, accommodating feelings of loss, isolation and abandonment, understanding suffering, forgiving others, accepting dependency while remaining independent and making sense of dying. Music therapy can be a powerful tool in this process of change. Change can be accommodated within the overall rubric "quality of life." Although the elusive life qualities inherent in creative activities—joy, release, satisfaction, simply being—are not readily susceptible to rating scales, we can hear them when they are played and feel them when they are expressed.

Music therapy appears to open up a unique possibility to take an initiative in coping with disease or to find a level to cope with near death. It is this opening up of the possibilities that is at the core of existential therapies (Dreyfus, 1987). Rather than patients living in the realm of pathology alone, they are encouraged to find the realm of their own creative being—and that is in the music.

Table 3
Different Dimensions of Music

Popular	inducing motions of the body
Technical	satisfying the intellect
Artistic	that which has a tendency to beauty and grace
Appealing	that which pierces the heart
Uplifting	that in which the soul hears the harmony of the spheres

Conclusion

If the progress of disease is an increasing personal isolation, then the music-therapeutic relationship is an important one for maintaining interpersonal contact, a contact that is morally nonjudgmental, where the ground of that contact is aesthetic. For the sick, maimed, disfigured and stigmatized, the opportunity to partake in a greater beauty is important. Furthermore, the therapeutic question is not "What am I?" a question that lies in the realm of categorization and cognition, but "How am I?," which is one of being.

It is necessary to emphasize how important it is to keep our idea of creativity broad. A patient, when asked about the values of the various arts therapies he had recently had, commented, "I did not want to be so intensely creative (as in the art therapy), but I did enjoy the music therapy where I could sing." If being creative is used as a metaphor for new growth and understood solely in its material implications, no wonder that it will be rejected by some patients for whom new growth is a sign of a deterioration in health. Creativity can be used in the non-material sense, as in making music, as transcending the moment. In this transcendence, the essence of spirituality, we take a leap, which is hope, into a new consciousness. That this new consciousness is not bound up with our bodies, our instincts, our motor impulses nor our emotions, awakens our awareness to another purpose within us.

Finally, in our treatment initiatives and research projects, it appears prudent to include the caregivers of the patients. Although this may be alien to some individual therapeutic directions, the overwhelming burden of care and suffering of daily living lies outside the clinic. If we consider the course of life, which includes dying, as a developmental process, that process will have a personal ecology. This ecology is relationship.

To return from where I began, when hospice care becomes necessary, we must include ourselves and colleagues, too, in that ecology as we accompany our patients, in faith and hope, on that long journey that awaits us all.

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