## **Voicing the Song of Music Therapy Cancer Support**

Mary H. Rykov, Ph.D.(C), MTA, F.A.M.I.
Centre for Arts Informed Research
Department of Adult Education & Counselling Psychology
Ontario Institute for Studies in Education
of the University of Toronto

**Abstract:** The song this article sings is derived from findings of an arts-informed inquiry that explored the meaning of music therapy cancer support and conceives therapy as education-about-the-self. It is consistent with lifelong learning as this pertains to cancer survivors and is applicable to other groups of learners.

#### Cancer

A cancer diagnosis is one of the most feared and serious of life events that produces stress on individuals and families. Cancer disrupts social, physical and emotional well-being and results in a range of emotions, including anger, fear, sadness, guilt, embarrassment and shame. Invasive treatment procedures can be stressful, painful and may result in permanent body changes. Themes commonly experienced by cancer patients are fear of death and disease recurrence, problems related to long and short-term effects of treatment, changes in personal relationships and economic issues. Family and friends can become overwhelmed by the crisis. (Daste & Rose, 2005)

According to Svenaeus (2001), illness is best understood as unhomelike ways of being-in-the-world:

Human life (*bios*) suffers (*pathe*) from a basic homesickness that is let loose in illness. If this unhomelikeness is taken as the essence of illness, the mission of health-care professionals must consequently be not only to cure diseases, but actually, through devoting attention to the being-in-the-world of the patient, also to open up possible paths back to homelikeness. (p. 104)

Frank (1995) says that serious illness is a loss of the "destination and map" that had previously guided the person's life. Once diagnosed, the cancer patient may never return to normal again but dwells forever in the remission society (Frank, 1991).

#### Problematizing the Mental Health Model of Psychosocial Cancer Care

According to Spiegel and Classen (2000), 50% of cancer patients experience stress that is serious enough to warrant a psychiatric diagnosis and a further 10% suffer severe maladjustments to cancer diagnosis and treatment and remain symptomatic for six years. Psychosocial treatment of cancer—referred to as psycho-oncology, psychosocial oncology or behavioural oncology—focuses on two major treatment areas. One is the interaction of cancer onset and progression with psychology, social issues and behaviour; the other pertains to effects experienced by patients, families, caretakers and professionals as a result of cancer (Holland, 1998). Both treatment foci share a theoretical orientation that is individualistic, decontextualized and deterministic where cancer is discussed as an objective disease entity rather than an illness uniquely experienced by people in various specific social locations and contexts.

The psychosocial oncology literature portrays a deficit model that blames patients for the emotional responses to their illness (Azarow et al., 2001; Butler, Koopman, Classen, & Spiegel, 1999; Classen et al., 2001; Giese-Davis et al., 2002; Goodwin et al., 1996; Hampton & Frombach, 2000; Koopman et al., 2002). There is no mention of the structural roots which underlie some clinical problems. For example, Cohen et al (2006) found that middle class depressed patients were almost twice as likely to respond to treatment as those who lived in poverty. These findings have implications in light of the financial burden of cancer.

Medical models of mental health tend to subordinate and pathologize people (Glasby & Beresford, 2006). Critique of the medical model of mental health care has been loudly voiced by psychiatric survivors (Burstow & Weitz, 1988). Criticism is voiced from within psychology (Maracek, 2002; Prilleltensky & Nelson, 2002; Sloan, 2000) and psychiatry (Bracken, 2003; Bracken & Thomas, 2001; Hopton, 2006; Pilgrim & Bentall, 1999), bolstered by the critical relational-cultural stance of feminist therapy models (Jordan & Hartling, 2002; Worell & Remer, 1996, 2003). This stance is not evident in conventional psychosocial oncology.

The blame-the-victim tenor of the individualistic adjustment and adaptation model of illness in psychosocial oncology studies is not appropriate for understanding the moral dilemmas and narrative reconstruction of identity that becomes the major psychological task of the cancer patient (Wilkinson & Kitzinger, 2000; Yaskowich & Stam, 2003). This medical treatment model is troubled by feminist standpoint theory of self-determination and empowerment (Sprague & Hayes, 2000) as this is applied to the cancer experience.

Trauma symptoms can be conceived as adaptive coping strategies (Burstow, 1992) to be explored for their personal meanings or as a means of achieving connection (Jordan & Hartling, 2002). There is no reason to doubt this is any different for cancer-related trauma. Burstow states that "trauma is properly understood as a series of responses to a concrete situation—not as symptoms or free-floating feelings or orientations—traumatic events and situations must be seen as concrete events within contexts" (Burstow, 2003, p. 1306). In addition to the trauma experienced by cancer patients resulting from their treatments, sources of trauma can be attributed to the stigma and fear imposed by the death-defying cultural discourse.

Cancer support and self-help groups provide a unique and needed function to counteract the deficit perspective of traditional cancer psychological therapies (Daste & Rose, 2005). The context of the self-help group is one way in which cancer patients express their dilemmas, narrate their stories and recover a "voice;" support groups are more prevalent for cancer patients than any other medically ill population (Yaskowich & Stam, 2003). Support groups offer a haven from a social world in which cancer patients feel misunderstood. Davison et al (2000) conclude this is because there is a strong relationship between social marginalization (embarrassment, disfigurement, stigma, life threat) and support group participation levels.

### **Music Therapy Cancer Support**

Music therapy is the skilful use of music and musical elements by an accredited music therapist to promote, maintain, and restore mental, physical, emotional, and spiritual health. Music has nonverbal, creative, structural, and emotional qualities. These are used in the therapeutic relationship to facilitate contact, interaction, self-awareness, learning, self-expression, communication, and personal development. (Canadian Association for Music Therapy, www.musictherapy.ca)

The purpose of the brief, time-limited, closed music therapy support group (Rykov, 2002) is to provide psycho-spiritual existential support for adults through active participation in music and related creative experiences. These experiences include instrumental and vocal improvisation, music listening, song choice and singing, group and collective guided imagery and music, art processing of music-evoked imagery, psychodrama and optional journals. Self-expression through improvised music facilitates group cohesion and provides a playful, aesthetic context that fosters an atmosphere conducive to building trust, empathy and intimacy.

#### The Meaning of a Music Therapy Support Group for Adults who have Cancer

Essential themes that emerged from a hermeneutic-phenomenological arts-informed inquiry about an 8-session music therapy cancer support group pertained to themes related to the burden of cancer and themes related to the music therapy support group experience. Themes that emerged about cancer pertained to financial concerns and job loss, acceptance/rejection of the "new normal," fear and isolation. Themes that emerged about the music therapy support group experience pertained to feeling better/calmed/uplifted, the importance of nonverbal, creative self-expression, experiencing control/validation/empowerment and connection/transcendence.

### **Theoretical Reflections**

Personal Empowerment: Any illusion of control I thought I had in my life was destroyed when I received my cancer diagnosis. In music therapy the music is neither directed nor controlled, but created—like a life. This was very empowering. The music therapy support group fosters personal empowerment in a milieu informed by feminist practice models where the helping process is one of "shared power" and "power with," and is "participant driven," with the professional becoming a "facilitator" or resource rather than an omnipotent director (Parsons & Gutier Cox, 1998). Early in the life of the group the facilitator actively provides structure (Lieberman & Golant, 2002; Toseland & Rivas, 2005). As participants become increasingly familiar with the music materials and each other, the content and direction of the sessions is increasingly determined by them.

The Musical Space: It was a very sacred space that was created, I think....Beating my hands on the drum was like a resonant sound that wanted to come from within the very core of my being. Music is a metaphorical container for all human experience (Kenny, 1989, 2002). Consistent with Lakoff and Johnson's (1999) theory of embodied cognition, Smiejsters (2005) theorizes that the music improvised in the music therapy clinical space is an analogy for intrapersonal and interpersonal experience that "sounds our inner being and our connection to the world" (p. 186).

Experiential Learning: I realized just how scared I was to sing with people.... And then I found by the second time I sang and didn't care if I was going off key and so I didn't go off key and I was pretty impressed. Music therapy participants are not trained musicians and many have well-entrenched performance anxieties. It is through experiencing music-making in a safe and supported environment that they can overcome fears and claim their musicality. It is by learning through doing (Hunt, 1987; Kolb, 1984) that they come to know they are, indeed, musical by virtue of their human beingness.

Sounding the Unsayable: There was so much more of unspoken language with music ... that we can only talk about with music. Music was a tool we used to "explain" our feelings. Music is ineffable. The great dancer and dance teacher, Isadora Duncan

(1955), claimed that if she could "say it," she wouldn't have to dance it. Non-verbal means of self-expression enable communication of tacit knowings that are beyond expression by verbal language alone (Collins, 2001; Polanyi, 1958/1962, 1983/1966).

#### Therapy as Education-About-the-Self

If, as Knowles (1980) states, "the primary and immediate mission of adult education ... is to help individuals satisfy their needs and achieve their goals" (p. 23), this music therapy support group fails to cure anyone of their cancer. Rather, music therapy conceived as education-about-the-self describes experiential learning whereby individuals come to know themselves as the musical people they inherently are (Blacking, 1973; Byron, 1995; Nettl, 2004). This, in the face of existential uncertainty, is experienced as affirmation that fosters resilience and empowerment.

The interweaving of therapy and education is not new. If helping people learn is the basic mandate of the helping professions, "then every therapist is a teacher, and every teacher is to some degree a therapist" (Combs, Avila, & Purkey, 1978, 1971, p. 123). The individualistic adjustment and adaptation model of illness generally expressed in the psychosocial oncology literature perceives coping to be a function of the patient's achievement and/or performance. Perceiving therapy clients as learners and therapy as education-about-the-self expands the parameters of conventional cancer coping that is consistent with the empowerment perspective (Breton, 2004) of mutual aid engendered by self-help groups. This model can be applied to other learners participating in music therapy, both individually and in groups.

#### References

- Azarow, J., Han, W. T., Koopman, C., Classen, C., Morrow, G. R., & Spiegel, D. (2001). Traumatic stress, pain, and self-efficacy are related to breast cancer patients' satisfaction with care. *Psychosomatic Medicine*, 63(1), 1130
- Blacking, J. (1973). How musical is man? Seattle: University of Washington Press.
- Bracken, P. J. (2003). Postmodernism and psychiatry. Current Opinion in Psychiatry, 16(6), 673-677.
- Bracken, P. J., & Thomas, P. (2001). Postpsychiatry: a new direction for mental health. *British Medical Journal*, 322(7288), 724-727.
- Breton, M. (2004). An empowerment perspective. In C. D. Garvin, L. M. Gutierrez & M. J. Galinsky (Eds.), *Handbook of Social Work with Groups* (pp. 58-75). New York and London: The Guilford Press.
- Burstow, B. (1992). *Radical feminist therapy: Working in the context of violence*. Newbury Park, CA: SAGE Publications.
- Burstow, B. (2003). Toward a radical understanding of trauma and trauma work. *Violence Against Women*, 9(11), 1293-1317.
- Burstow, B., & Weitz, D. (Eds.). (1988). *Shrink resistant: The struggle against psychiatry in Canada*. Vancouver: New Star.
- Butler, L. D., Koopman, C., Classen, C., & Spiegel, D. (1999). Traumatic stress, life events, and emotional support in women with metastatic breast cancer: Cancer-related traumatic stress symptoms associated with past and current stressors. *Health Psychology*, 18(6), 555-560.
- Byron, R. (Ed.). (1995). *Music, culture & experience: selected papers of John Blacking*. Chicago and London: University of Chicago Press.
- Classen, C., Butler, L. D., Koopman, C., Miller, E., DiMiceli, S., Giese-Davis, J., et al. (2001). Supportive-expressive group therapy and distress in patients with metastatic breast cancer A randomized clinical intervention trial. *Archives of General Psychiatry*, 58(5), 494-501.
- Cohen, A., Houck, P. R., Szanto, K., Dew, M. A., Gilman, S. E., & Reynolds, C. F. (2006). Social inequalities in response to antidepressant treatment in older adults. *Archives of General Psychiatry*, 63(1), 50-56.

- Collins, H. (2001). What is tacit knowledge? In T. Schatzki, K. Knorr-Cetina & E. von Savigny (Eds.), *The practice turn in contemporary theory* (pp. 107-119). London: Routledge.
- Combs, A. W., Avila, D. L., & Purkey, W. W. (1978, 1971). *Helping relationships: basic concepts for the helping professions, 2nd edition.* Toronto: Allyn and Bacon, Inc.
- Daste, B. M., & Rose, S. R. (2005). Group work with cancer patients. In G. L. Greif & P. H. Ephross (Eds.), *Group work with populations at risk, 2nd edition* (pp. 15-30). Toronto: Allyn & Bacon.
- Davison, K. P., Pennebaker, J. W., & Dickerson, S. S. (2000). Who talks? The social psychology of illness support groups. *American Psychologist*, 55(2), 205-217.
- Duncan, I. (1955). My life. New York: Liveright.
- Frank, A. W. (1991). At the will of the body: reflections on illness. New York: Houghton Mifflin.
- Frank, A. W. (1995). *The wounded storyteller: body, illness, and ethics*. Chicago & London: University of Chicago Press.
- Giese-Davis, J., Koopman, C., Butler, L. D., Classen, C., Cordova, M., Fobair, P., et al. (2002). Change in emotion-regulation strategy for women with metastatic breast cancer following supportive-expressive group therapy. *Journal of Consulting and Clinical Psychology*, 70(4), 916-925.
- Glasby, J., & Beresford, P. (2006). Who knows best? Evidence-based practice and the service user contribution. *Critical Social Policy*, 26(1), 268-284.
- Goodwin, P. J., Leszcz, M., Koopmans, J., Arnold, A., Doll, R., Chochinov, H. M., et al. (1996). Randomized trial of group psychosocial support in metastatic breast cancer: The BEST study. *Cancer Treatments Review*, 22(Suppl. A), 91-96.
- Hampton, M. R., & Frombach, I. (2000). Women's experience of traumatic stress in cancer treatment. *Health Care Women Intern*, 21(1), 67-76.
- Holland, J. C. (Ed.). (1998). Psycho-oncology. New York: Oxford University Press.
- Hopton, J. (2006). The future of critical psychiatry. Critical Social Policy, 26(1), 57-73.
- Hunt, D. E. (1987). *Beginning with ourselves: in practice, theory, and human affairs*. Cambridge, MA: Brookline Books.
- Jordan, J. V., & Hartling, L. M. (2002). New developments in relational-cultural theory. In M. Ballou & L. S. Brown (Eds.), *Rethinking mental health and disorder: Feminist perspectives* (pp. 48-70). New York/London: The Guilford Press.
- Kenny, C. B. (1989). *The field of play: a guide for the theory and practice of music therapy*. Atascadero, CA: Ridgeview Publishing Company.
- Kenny, C. B. (2002). Keeping the world in balance music therapy in a ritual context. In C. Kenny & B. Stige (Eds.), *Contemporary voices in music therapy: Communication, culture, and community* (pp. 157-170). Oslo: Unipub forlag.
- Knowles, M. (1980). The modern practice of adult education: From pedagogy to andragogy, revised and updated. Chicago: Follett Pub. Co.
- Kolb, D. A. (1984). *Experiential learning: Experience as the source of learning and development*. Englewood Cliffs, NJ: Prentice-Hall, Inc.
- Koopman, C., Butler, L. D., Classen, C., Giese-Davis, J., Morrow, G. R., Westendorf, J., et al. (2002). Traumatic stress symptoms among women with recently diagnosed primary breast cancer. *Journal of Traumatic Stress*, 15(4), 277-287.
- Lakoff, G., & Johnson, M. (1999). *Philosophy in the flesh: The embodied mind and its challenge to western thought.* New York: Basic Books.
- Lieberman, M. A., & Golant, M. (2002). Leader behaviors as perceived by cancer patients in professionally directed support groups and outcomes. *Group Dynamics-Theory Research and Practice*, 6(4), 267-276.
- Maracek, J. (2002). Unfinished business: Postmodern feminism in personality psychology. In M. Ballou & L. S. Brown (Eds.), *Rethinking mental health and disorder* (pp. 3-28). New York/London: The Guilford Press.
- Nettl, B. (Ed.). (2004). Excursions in world music, 4th edition. Upper Saddle River, NJ: Pearson Prentice Hall.
- Parsons, R. J., & Gutier Cox, E. O. (1998). A model for empowerment practice. In L. M. Gutierrez, R. J. Parsons & E. O. Cox (Eds.), *Empowerment in social work practice: A sourcebook* (pp. 3-19). Pacific Grove, CA: BROOKS/COLE PUBLISHING COMPANY.
- Pilgrim, D., & Bentall, R. (1999). The medicalisation of misery: a critical realist analysis of the concept of depression. *Journal of Mental Health*, 8(3), 261-274.

- Polanyi, M. (1958/1962). *Personal knowledge: Towards a post-critical philosophy*. Chicago, IL: University of Chicago Press.
- Polanyi, M. (1983/1966). The Tacit Dimension. Gloucester, MA: Peter Smilth Publisher, Inc.
- Prilleltensky, I., & Nelson, G. (2002). *Doing psychology differently: Making a difference in diverse settings.* New York: Palgrave Macmillan.
- Rykov, M. H. (2002). *Sick mode, dying mode: music therapy in the continuum of cancer treatment.* Paper presented at the Dialogue and Debate Conference Proceedings of the 10th World Congress on Music Therapy, Oxford, England.
- Sloan, T. (Ed.). (2000). Critical psychology: Voices for change. New York: St. Martin's Press, Inc.
- Smeijsters, H. (2005). Sounding the self: analogy in improvisational music therapy. Gilsum, NH: Barcelona Publishers.
- Spiegel, D., & Classen, C. (2000). *Group therapy for cancer patients: a research-based handbook of psychosocial care*. New York: Basic Books.
- Sprague, J., & Hayes, J. (2000). Self-determination and empowerment: A feminist standpoint analysis of talk about disability. *American Journal of Community Psychology*, 28(5), 671-695.
- Svenaeus, F. (2001). The phenomenology of health and illness. In S. K. Toombs (Ed.), *Phenomenology and medicine* (pp. 87-108). Dordrecht: Kluwer Academic Publishers.
- Toseland, R. W., & Rivas, R. F. (2005). An introduction to group work practice, 5th edition. Toronto: Allyn & Bacon.
- Wilkinson, S., & Kitzinger, C. (2000). Thinking differently about thinking positive: a discursive approach to cancer patients' talk. *Social Science & Medicine*, 50(6), 797-811.
- Worell, J., & Remer, P. (1996, 2003). Feminist perspectives in therapy: Empowering diverse women, second edition. Hoboken, NJ: John Wiley & Sons, Inc.
- Yaskowich, K. M., & Stam, H. J. (2003). Cancer narratives and the cancer support group. *Journal of Health Psychology*, 8(6), 720-737.

Note: This writing, excerpted from my Ph.D. thesis, is supported by the Canadian Cancer Society through the National Cancer Institute of Canada for a Research Studentship and operating grant from the Sociobehavioural Cancer Research Network, Palliative Care Team.