

Humanities: Art, Language, and Spirituality in Health Care

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Creatively Caring: Effects of Arts-Based Encounters on Hospice Caregivers in South Africa

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Abstract

International literature and experience suggest that arts-based encounters can be effective in reducing stress and burnout in health care workers. Are these principles universal? Are they as applicable and effective in resource-constrained situations in Africa as in other parts of the world? We describe the impact of creative and arts-based encounters on a group of hospice caregivers at South Coast Hospice in KwaZulu Natal. An experienced facilitator built a caring and trusting relationship with the participants over a three month period through a variety of means, including a singing and songwriting intervention specifically designed to empower and give voice to the hospice caregivers, most of whom were Zulu women. We documented the process through several rounds of interviews, extensive field notes, and audio recordings. This article is a reflection on the experience and draws from the interviews, correspondence among researchers, field notes, and a performance piece written by the facilitator one year after completion of the study. We found that the songwriting and other creative activities of the engagement provided affirmation and acknowledgment of the caregivers as well as an opportunity to release stress, grief, and pain. They experienced changes in terms of hope and freedom both for themselves and their patients. The conceptual themes that emerged from the interviews with the caregivers were interpreted in terms of their inherent cultural assets, a release of agency, a sense of revelation, and transformation. The expressive arts can have a significantly beneficial effect on hospice workers and their patients, and clinical engagement can be enhanced through creative encounters, even in resource-constrained situations. If such creative processes were to be promoted among a wider group of health workers, daily routine work in health care could be not just a repetition of well-rehearsed utilitarian rituals but rather a series of creative and transformative encounters. J Pain Symptom Manage 2014;47:946–954. © 2014 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

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Prelude

From field notes: March 18, 2011

One of the community health care workers pulled me aside and wanted to talk about the death of her 32-year-old daughter from AIDS, the fact that her 12-year-old granddaughter (the same daughter's daughter) is HIV positive and taking antiretrovirals but does not know why, that financially every month is a terrible struggle, and that she is trying to save R500 (ca. \$50) per month so she can buy an inexpensive car to drive her very overweight mother to doctors' appointments and so on. She thanked me over and over again for the support saying that no one asks her how she feels and certainly never asks how she feels about her daughter who will have been dead two years ago this coming October.

South African hospice workers face enormous challenge and stress particularly in rural areas where health care resources are limited and where the prevalence of HIV infection can be up to 50% in the reproductive age group. Many of these providers suffer from profound and cumulative grief having worked with the dying through the early years of the AIDS pandemic, when they often experienced multiple deaths on a daily basis.

From field notes: February 21, 2011

The nurses' stress was compounded, not only by the continuing high rate of HIV infection but also by the poverty and lack of food. Many of their patients could not take the antiretrovirals that would keep them alive simply because they did not have as much as a bowl of cereal to take them with. Nonetheless, every morning they carried on and sang their hymns before heading out into the rural areas—and they sang beautifully, with great passion and in multiple harmonies. I wondered what would happen when they started singing their “inner voices.”

This article is a reflection arising from a study that aimed to assess the impact of creative and arts-based encounters on the morale, motivation, and productivity of nurses and community health care workers at a hospice in South Africa.¹ Developed by the University of New Mexico's

Arts-in-Medicine Program and adapted from Rollo May's *The Courage to Create*, the creative encounter proposes that in “meeting and joining an other without judgment or expectation, something new can be born, in body, mind, or spirit”.^{1, p39} May speaks of artists and creative persons as “the ones who express being itself...their creativity is the basic manifestation of a man or woman fulfilling his or her own being in the world”.^{1, p39} He contrasts the difference between “art as decoration” or “making life prettier,” and “giving birth to some new reality.”^{1, p39}

In this study, we hoped to establish a creative, caring, and trusting relationship between the facilitator and participants through which a new or different way of being might become possible. Based on the results from existing research²⁻⁵ and the success of the Arts-in-Medicine Program at the University of New Mexico Hospitals (<http://artsinmedicine.unm.edu>), we knew it was possible, but we had no idea whether “creating a new or different way of being” was feasible and beneficial in an African context where resources are far fewer and an HIV/AIDS epidemic continues to rage. We also knew that Zulu women loved to sing.⁶

From field notes: March 19, 2011

Regardless of what songs get written (or not), my relationship with the nurses and community health care workers has become increasingly close and what they see as “supportive.” When they are called into a meeting with bosses (other than Fanny who is Zulu and their immediate supervisor), they completely shut down and a profound disconnect happens (within themselves and between themselves and management). So the songs, the photos, the massages, and the recordings have all contributed to allowing them, just for moments here and there, to be who they are—not who they are supposed to be. This disconnect, I think, is reflected in their malaise, their fatigue, their immediate and chronic illnesses, their deadpan faces much of the time, and their constant complaint about low salaries.

Theme and Variations

It was suggested that we approach South Coast Hospice (SCH) as a site for the study

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