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[Home](#) / [Research & Publications](#) / [CultureWork](#) / [Current Issue](#)

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An Expressive Arts Hospital Program for People with HIV/AIDS: A Description, Two Stories, and Explanations

by Julia Kellman

Introduction/Description

The Carle Hospital Arts Program, sponsored by the Department of Psychiatry of the University of Illinois School of Medicine for people with HIV/AIDS, is moving into its fourth season. It began with a pilot program with three participants who were seen individually for art instruction once a week for a three and a half month period in the medical school computer lab which served as a makeshift art room. Supplies and projects were stored in the office of the soon to become Head of Psychiatry and her office partner.

Since these early beginnings, the program has developed into a regularly scheduled, weekly four hour class with a core group of three to five people who meet together in an education room in the hospital to make art. We have purchased an art cart with the help of two small grants and loaded it with a variety of art supplies; and we have been given access to a closet on the first floor of the medical school where we can park the cart and store art materials and projects.

Though enrollment remains stable and small during each workshop period, twenty people in all have taken part in the program; two former class members periodically visit to see what people are doing; and one man maintains close social ties to individuals in the group.

Besides the participants, other changes have occurred over time, too. Significantly, programming is now driven by consensus as the participants choose projects, plan field and sketching trips, picnics, and dinners. My role has shifted, too; and I, teacher/researcher, have become a facilitator and colleague.

The most significant changes, however, are in the lives of the participants. What follows are stories of some of these people and the alterations in their lives.

New Stories/New Lives



The class provides an opportunity for many kinds of growth for individuals taking part. For one man in his sixties, a first time art maker, it opened a world of new skills and experiences, weekly interactions with similarly interested individuals, and the pleasure of selling a watercolor in the yearly Artists Against Aids show. For a woman, it was the weekly delight in process, in a time set aside for glue and scissors, companionship, and in finding and cutting out images of her favorite subjects from the stack of magazines. For others, however, the learning and growing moved far beyond the level of new studio skills and shared experiences, for their lives changed in substantial ways during the time that they attended class. For these people, at least, the community that developed during the art class seemed to serve as a bridge or transition point to an expanded more satisfying life.

Two exemplars will serve here, Pat and Roger, for they portray growth from relative isolation to full engagement with the social world, the role of art in this alteration, and the place of the art class/community that seems to lie at the heart of their development.

For Roger, charming, energetic, with a shock of grey/blond hair, and an abiding concern for others, participation in the art class was a natural undertaking, since his undergraduate degree was in art education. Because he had not made art for an extended period of time, however, Roger, like anyone else when they start something new, was cautious and unsure where to begin his reentry into the world of colored pencils, paper, and paint.

Even during his first hesitant projects, Roger would sometimes remark, "I'm so relaxed," "The time has really gone fast," and, "I haven't thought of anything else the whole time," an indication that, for him at least, the class provided momentary relief from pressing health problems at the same time it offered the encouragement to again take up art making in his spare time.

Most importantly, however, as Roger's art became more vigorous and based on his imagination, his life, too, took a similar turn, as he shifted from a position of relative social isolation to involvement with the greater community AIDS coalition and other activities. He moved from a small efficiency apartment to take the role of on-site manager of the HIV/AIDS group home, and then, after several months, to an apartment with a friend. He joined the coalition advisory board and the food bank. He took a computer course and a Spanish class. He redecorated the group home, planted flowers in its garden, and planned its social activities. Roger's energy and social involvement carried other members of the art class along, too, bearing them up with his new energy and enthusiasm. In

their turn, the class members, now frequent companions on work days at the shelter, at coalition meetings, support groups, and social occasions encouraged and sustained him as he moved into the wider world.

Though Roger's increasing involvement with art making may arguably be the result of his developing sense of confidence and his reentry into life after his initial catastrophic illness and not their cause. These two changes, nonetheless, appeared in tandem, suggesting a link between them and the possibility of a mutually reinforcing system of interactions. Significantly, this pattern can be found in the lives of other class members.

Pat is just such an exemplar. Encouraged to join the class by my presentation at the hospital's annual AIDS conference, he shyly appeared the following week with a sack of art supplies. Articulate, insightful, and reflective, with sophisticated art skills, and a degree from a well known art school, Pat immediately became a valuable member of the class. His superb studio abilities and his sensitivity to the needs of others made him a mentor for the other students and the unofficial class monitor.

Pat, like Roger at the beginning, was just now taking the first hesitant steps away from the self-imposed isolation and the depression that follow the medical catastrophes that herald the activation of the AIDS virus; and he also was suffering through a period of profound despair. Nonetheless, as the weeks passed, Roger was able to coax Pat into a variety of activities--movies, meals out, and other social activities. The other class members played a role, too, nudging Pat to take part. Carried on the winds of the art class's support and Roger's charm, Pat flourished. He began to relax and chat in class. His art too seemed to become more daring, mirroring and reinforcing his life's new direction; and he began to make art at home.

Though it is important, as it was in Roger's case, to consider that joining the class may have been an indication of the process of change in Pat's life and not its cause, there is no reason to suppose that the positive aspects of the class--its warm supportive nature, and the opportunity it provided to see himself, at least part of the time, as artist, not patient, creator, not passive sufferer--did not also play a role in the changes he experienced.

These personal alterations were not simply my imagination, either, for they were affirmed late one afternoon in class. In the silence broken only by the rustle of papers Pat suddenly spoke in a voice full of wonder, "I'm back." "I'm back," he said to himself, as much as to us. "Welcome home, Pat," I replied.

Outcome/Significance

What is the significance of the hospital art class for its members; and what have I come to believe about the role of teacher/researcher in such an undertaking?



What is most important, it seems to me, is the class itself, not just the art making. For the class provides opportunities to develop a new sense of self based on accomplishments and is itself a small community of familiar people who weekly strive to create new narratives to mend their lives. This later point is an especially significant undertaking for people who are ill, for as medical anthropologist Gail Becker (1997) suggests, people who undergo the chaos of illness need to tell the, "Stories in terms of which their lives made sense" (p.25). The art class allows its members to do just that, providing a means and place to take charge of, and to tell, a new story of themselves within the shelter of a supportive community of acceptance and concern.

And who am I, the researcher/teacher? I am the old woman who lives in a hut on the edge of a small stream next to a tiny bridge. I'm the one who cleans the hut and repairs the bridge. I'm the one with a pocket full of oddments--bits of ribbon, countless stories, paper, pencils, brushes, glue, and paints. I am the vulnerable observer (Behar, 1996) whose life is inexorable tangled with the lives of the people I teach and touch. I am the woman who performs acts of personal witness, and who, like the poet Theodore Roethke (1961) "learn[s] by going where I have to go" (p.104).

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