Letter to the Editor

RESTORING DIGNITY: COMMUNITY ARTS IN LEPROSY CONTROL

The evolution of health care is closely linked with the community arts. In Greek mythology, Asclepius, son of Apollo, is commonly referred to as the god of medicine and healing. The World Health Organization and most professional health organisations use, as the traditional symbol of healing and medicine, the staff of Asclepius, which is depicted as a single serpent encircling a staff. The serpent signifies the ideal of healing as renewal, as the serpent sheds its skin. The history of art in hospitals has been extensively documented in many European countries since the 14th century, a time when religious imagery, architecture and aesthetics were as important for healing, as the provision of medical care. Today, active hospital arts charities in the United Kingdom and Australia are focussed on providing hospital environments that enhance the therapeutic, recreational and occupational opportunities for those in medical care.

Community arts projects are created through collaborative processes, and typically involve artists and non-artist members of the community with a shared sense of values and practices based on geographic location and/or identity actively participating in the making of a work of art for aesthetic, personal development, community development or educational purposes. Community arts involve an understanding of communities and how art can function as an agent of social change and enhancer of community vitality. Participatory arts projects provide opportunities for community engagement and capacity building, particularly among disadvantaged groups.

Apart from its general contribution to improving health and wellbeing, community arts has been adapted to enhance the coping strategies and self-image of people affected by breast cancer and human immunodeficiency virus (HIV), as well as improve fundraising activities to control these diseases. In individual and group settings, art therapy has shown positive outcomes for women diagnosed with breast cancer, such as an increase in self-esteem and cohesion, a decrease in anxiety and depression and significant improvements in overall health and wellbeing. In community settings, campaigns such as breast cancer awareness month, utilise a wide array of community arts, symbols and murals to change adverse community perceptions towards people affected by the disease. In relation to HIV, community arts projects have played significant roles in stigma reduction, and translating research into practice.

In contrast, the legacy of community arts in leprosy control is contested, with current community arts efforts largely neutralised by centuries of adverse artistic depictions of leprosy and the people affected by it. Misrepresentation of serious dermatological conditions, such as leprosy, originated from a misleading translation in the Bible of the Hebrew word ‘nega tsdra’ath’ as ‘a plague of leprosy’. Biblical descriptions of what was referred to as leprosy are documented in Leviticus chapter 13, which provides a crude diagnostic algorithm for ‘leprous sores’, with those diagnosed being certified as ‘unclean’. For centuries these biblical descriptions have served as an important perceptual lens and repository of knowledge for community artists depicting people living with leprosy, and have also influenced public perception of individuals affected by leprosy in the Christian world since the renaissance. The sculpture of leprosy in the Cistercian Abbaye de Cadouin exemplifies the use of...
community arts in the pre-20th century era to stereotype leprosy-affected individuals as maximally damaged, at least dermatologically. The clapper, collapsed bridge of nose, lepromatous nodule on forehead, and swollen foot with clawed toes were apparently incorporated into the sculpture to illustrate the biblical parable of Lazarus.10

In the last several decades, particularly since the implementation of multi-drug therapy for leprosy, a commendable paradigm shift has occurred in the artistic representation of those with leprosy. Leprosy imagery is now created in such a way as to keep the dignity, complexity, and the feelings of those with the disease sufferers intact. One of such shifts is illustrated on the Photophilanthropy website: http://photophilanthropy.org/gallery_tags/leprosy/ as well as in the images promoted by LEPRA, the British leprosy charity: http://www.flickr.com/photos/47089549@N08/sets/72157624085994634/. Rather than creating a sense of shock or revulsion in the viewer, which serves to dehumanise those with leprosy, these images focus positively on the person behind the disease.

Effective use of community arts in health activism entails the synergistic adaptation of social epidemiology principles and strategically conceptualised and disseminated works of art to change adverse public perception about a health problem, improve disease control, enhance positive self-image among people affected, and promote community health.11 Since health activism involves disadvantaged and vulnerable groups challenging encumbrances to personal and community health, empowerment of those directly affected by health-related encumbrances is one of its core components. Empowering people affected by HIV as self-advocates was critical to the remarkable improvements in stigma reduction in relation to HIV/AIDS. While the usefulness of this strategy is recognised in leprosy-related stigma reduction,12 far less resources have been devoted to the leprosy sector to implement it.

At least until the 1980s, health activists and those with leprosy appeared to have ‘internalised’ leprosy stigma to create maximum effect for fundraising purposes. Such stigma induced ‘dehabilitation’ actions invariably lead to intentional treatment delays and poor self-care.13 As depicted, until recently, in Hollywood films such as ‘City of Joy’, some pre-1980s leprosy fundraising activities presented a somewhat racist pornography of leprosy-related suffering, which were inadvertently put on public display in the quest for fundraising and public entertainment.14 This is reinforced by the use of self-stigma, as signposted by leprosy beggars, to engage in fundraising activities.

It is noteworthy that since the early 1990s, members of the International Anti-Leprosy Associations (ILEP) have worked constructively with charities and national leprosy control programmes to discourage fundraising initiatives which may inadvertently stigmatise people living with leprosy. Consequently, most 21st century fundraising imagery of those with leprosy produced by ILEP member organisations are largely ennobling, as exemplified in the photography of Yan Seiler (http://www.phase.com/yanseiler/lepr) and in promotional materials produced by the Leprosy Mission (www.leprosymission.org.uk/resources/).

It is apparent that leprosy health workers and people living with leprosy have not made optimal use of community arts approaches to reverse negative stereotypes, raise funds for prevention and cure of leprosy, and to change community and political perceptions regarding leprosy using edu-entertainment and other health activism strategies. In contrast, HIV/AIDS and breast cancer patients and workers appear to have optimised the use of community arts to achieve similar objectives.7,15

As highlighted in South’s 2006 evaluation study of a ‘community arts for health’ programme in the United Kingdom, “the challenges in delivering effective community arts initiatives and building partnerships across different sectors should not be underestimated”.16 Such challenges include bridging the limited awareness of the common ideological origins and complementary paradigms between community artists and public health activists. There are several mechanisms through which effective partnerships can be established for community arts initiatives. Firstly, health professionals could be trained in community-based art methods to facilitate their participation in the development of
community-based art advocacy. Secondly, community artists and health advocates could be incentivised to approach each other as equal partners in joint planning of health activities, with positive mutual awareness of the roles and values of participants. Thirdly, funders should consider payment arrangements that equitably reflect the contributions of all partners.  

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References  