

GUEST EDITORIAL

Changing images, changing visions, changing practices

“By interpreting reality, the artist transforms our perceptions of what we see, just as the trained medical eye interprets what it reads from the body. Neither the artist’s nor the scientist’s eyes merely record as do technological devices.” (Winkler, 1992, p. 217)

Good health care, readers of this journal know, requires more than the physician practicing “evidence-based” medicine, using the wizardry of modern technology in combination with honed diagnostic skills to identify medical troubles and their treatment. It depends on the physician’s understanding of the patient’s emotional and social needs, and requires skill and sensitivity in relating to patients and their family members.

In no case is this more true than in the treatment of the elderly, especially the infirm elderly. The loss of respect afforded to them, particularly as they grow less abled, means that many of them feel more and more excluded from the social circles in which they were once treated as valuable members. This sense of exclusion is accentuated by the efficiency-seeking institutions of modern society, from the doctor’s office to the superhighway.

As a social scientist I know that the physical and mental illnesses that people of all ages display are not simply the results of changes in their biology. Rather, symptoms experienced and reported and the trajectories of disease are profoundly affected and shaped by the responses of those around them – professionals and non-professionals alike. These responses may be and should be helpful and enabling. But too often the responses of others are based on negative or incorrect stereotypes of certain illnesses and conditions and the kinds of persons who suffer from them. The consequences of such “disabling responses” frequently include the promotion of further disability: those to whom we offer little hope and whom we treat as helpless may lose hope and become more helpless.

Disabling responses occur more frequently in the treatment of the aged, whose abilities are thought to be limited, whose futures are believed to be short, and whose illnesses are premonitory of departure. In societies that value productivity, speed, task accomplishment, efficiency, and the future, we learn to be hypercognitive, literal, and uncomfortable with those who do not “keep up the

pace”. The stigma of aging leads to social exclusion and exclusion leads to psychological isolation and often to despondency.

These attitudes disfavor many elderly people, but people with Alzheimer’s disease and related disorders who face more severe cognitive challenges suffer from this stigma more than older people whose cognitive functioning is less compromised. Alzheimer’s Disease International’s *World Alzheimer’s Report 2009* speaks of the global issue of fear and lack of understanding, identifying stigma as a contributing factor to cultures in which help is neither sought nor offered. The first page of the Dementia Advocacy and Support Network (DASNI) website includes the statement that “The stigma of dementia is very real, very cruel and widespread ...” (<http://www.dasninternational.org/>).

Negative visions of aging and illness and dying are often reinforced by visual imagery in the form of sketches, photographs, or films. In *The Journey of Life* (1991), Thomas R. Cole argues that negative images of the aged were historically so much a part of American culture that people didn’t think much about them. This contributed to widespread ageism. He illustrates the argument with two Currier and Ives prints on the stages of life of men and women which were widely purchased as both good art and “true” depictions. I recognized them as prints that hung in my grandmother’s apartment until she was placed in the Alzheimer’s unit of a nursing home at age 90. Then my mother hung them over her bed where they remained until she died at the age of 86. I gave them away as soon as they became my property.

About three years ago I undertook a quick examination of more than 500 books and pamphlets on dementia in the library of the French Gerontology Institute to better understand what imagery is presented of the syndrome and those with it. Only 12% of these publications had any visual imagery and only 6% had even a single photograph. The most common photograph was a brain scan. Among the others were a few images of Alois Alzheimer, two of Auguste D (Alzheimer’s first patient), one of Iris Murdoch, and a few head shots of the books’ authors. Several of the images highlighted the emotional and physical difficulties of the caregiver.

A small number of the volumes presented “positive” images of a person with Alzheimer’s, but these were most frequently to be found in advertisements by pharmaceutical companies extolling the benefits of their medication. The large majority of the drawings or photographs reflected the “empty shell” image of the person with dementia. They were fully consistent with Jesse Ballenger’s description of the stereotypical view of the person with dementia as a stranger, a ghost or shadow, a non-person:

“The idea that the Alzheimer’s victim was in some fundamental way already gone despite the unnerving persistence of the body was an almost ubiquitous feature of representations of the disease both within the Alzheimer’s disease movement and in the popular press.” (Ballenger, 2006, p. 137)

This tilt in the visual representation of dementia is not just past history. A well-respected art book by the German photographer Peter Granser (2005) shows people in the advanced stages of Alzheimer’s who seem to have little continuing self and little humanity. These and similar representations are troubling to me as they shape how we think of people with dementia:

“How we think of people with dementia is not without practical and ethical significance. How people with dementia are positioned, how they are considered and referred to, can itself affect how they are as persons, how they behave, and how they interact. Reminding them of their continuing self-identity then can be seen as a moral imperative.” (Hughes *et al.*, 2006, p. 5)

There is another possible route: using imagery to challenge the stereotypes and to educate people about the possibilities. While photography has been used infrequently to educate or reduce stigma, or to inspire people to believe that it is possible to maintain quality of life despite dementia, it can be brought to the service of a new vision.

“Perhaps it is no longer sufficient that photographers simply take photographs in a world of mediated communication where fiction and sensationalism far outstrip mere social or material fact ... we need more of the kind of work that amplifies and intensifies the documentary approach, combining pictures with historical and social context, advocacy, and analysis.” (Squiers, 2005, p. 16)

In the past two decades, thousands of books have been authored by people who are ill, people who have survived a serious illness, and the spouses or children of someone who suffered from an

illness. Writing these “illness narratives” can be cathartic to the writer, and many of the resulting texts also offer insight, guidance, and solace to others who find themselves in a similar situation. In contrast, visual narratives of illness using still photography are relatively rare, though recently several good ones have appeared. The best of the visual narrative books take people with illnesses out of the closets and attics and bring them face to face with us. Shown as humans with feelings, dreams, and value they are at least symbolically reinserted in the larger community as included, respected members.

I have been a passionate viewer of photographs since I saw the “Family of Man” exhibition at the Museum of Modern Art as a teenager. That exhibition convinced me that photographs have powerful educational potential. Almost ten years ago I decided to leave my position as Professor of Sociology at Rutgers to pursue some dreams. One involved photography; I wanted to learn how to use a mix of text, my primary medium until then, and photography, a medium I had practiced only occasionally, to open people’s eyes, literally and figuratively, to help them “face” issues that are generally avoided.

Since 2001 I’ve directed my energies to two photographic projects, one on Alzheimer’s disease and one on palliative care. I’ve visited sites in the USA, France, India, Japan, the Dominican Republic, and Canada where high quality care is offered. My experience in homes, memory clinics, day centers, residential centers, and hospitals have made me a believer in the argument by William Thomas, founder of the Eden Alternative, that

“Current practice in long-term care is based on a confusion of care, treatment, and kindness. Lying at the root of this confusion is the medical model’s fixation on diagnosis and treatment. It guarantees that the majority of our resources are spent on the war against disease, when, in fact, loneliness, helplessness, and boredom steadily decay our nursing home residents’ spirit”. (Thomas, 1996, p. 1)

While much documentary photography highlights bad practices in the hope of provoking change, I’ve chosen a different route. Through illustrated lectures, exhibitions, and *Alive with Alzheimer’s* (Greenblatt, 2005) and a forthcoming book, *Love, Loss and Laughter: Seeing Alzheimer’s Differently* (Greenblatt, in press), I have been showing photographs of life-affirming care that contributes to the maintenance of confidence, capacities and communication and also yields more

moments of joy and connection. I am betting that change can be provoked through inspiring examples.

There are few secrets here, few things that readers of this Journal don't already know. But if a picture is worth a thousand words, 108,000 words worth of photos in *Love, Loss and Laughter* send forth this message: acting more generously and optimistically with people with dementia is not just worth doing because it shows us to be more decent human beings; it is worth doing because we can make a real difference in the trajectory of their disease and in their quality of life. We can enable people who have dementia to fare well, without having to wait for magic bullets or technical fixes.

I hope my photographs will contribute to a new vision, one that will open minds and doors to better practices and better public policy.

“Photography is the only way to kill death.” Jean Cocteau

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