An Invitation to a Conversation on Quality of Life in Dementia

Quality of life is arguably one of the most important treatment outcomes for people who have dementia. Literature is available that speaks to the importance of quality of life versus quantity of life in conditions that have no cure. Quite a few instruments have been developed that claim to measure this construct. A number of interventions have been tested that supposedly improve quality of life. But at the end of the day, do we really understand what makes for quality of life in people with dementia?

In 2007, The Pennsylvania State University’s Rock Ethics Institute hosted a 2-day conference to commemorate the 100th anniversary of the identification of Alzheimer’s disease as a diagnostic category. “Untangling Selfhood: The History and Experience of Alzheimer’s Disease” brought together some of the world’s leading scholars in the humanities and health and social sciences to address the often neglected experience of people with cognitive impairments. Speakers representing anthropology, psychiatry, history, nursing, psychology, theater, and dance shared their insights about cognitive impairments disentangled from the disease. This thought-provoking exchange happened across disciplinary boundaries that are seldom crossed in academia; it is an exchange that is ongoing and one that would benefit from nursing’s voice. A website was developed to accommodate this conversation and is listed below; first, by way of background information, let me share some thoughts about the discussion that occurred during the 2007 conference.

Alzheimer’s disease emerged as a major diagnostic category at a time and against a sociocultural backdrop that saw an increasing emphasis on cognitive disorders. At the start of the modern world (circa 17th century), individual competence and autonomy became the basis for citizenship and personal status. This cultural perspective is still evident today in our public discourse: We view cognitive impairments as stigmatizing (in fact, victims themselves note how stigmatized they are by their impairments), and our language characterizes cognitive impairments as “robbing” its victims of selfhood—People with dementia are no longer “really there.” It is no wonder that dementia is one of the most feared diseases of older adults. It is hard to imagine having any quality of life when diagnosed with an illness that threatens the core of selfhood.

For the most part, work on defining, measuring, and improving quality of life in dementia has been done from the perspective of the unafflicted. There has been a historical reluctance to consider the insights of people with dementia because their responses have not been seen as reliable. This view has not advanced our understanding. Slowly, it is becoming apparent how essential it is that we listen to the voice of those with dementia. There are a number of challenges that health professionals, in particular, face in this regard. Our first challenge, in the words of Basting (2009), is to “forget memory”—symptoms get in our way. The second challenge is to understand that there really is no comforting distance between us and them—there is only us.
In coming to grips with these challenges, it helps to think of dementia as a socially embedded phenomenon rather than a medical one. Dementia is a problem because its manifestations are not compatible with our cultural expectations and values around competence and autonomy. While science and technology cannot answer questions about what constitutes selfhood, recent advances are leading us to some very provocative questions about self and quality of life. We now have the capability to diagnose people not only with very early-stage dementia and mild cognitive impairments but those who have no symptoms at all (pre-clinical stage.) The boundary between normal and disease (us and them) is blurred. Who is the “patient,” and is quality of life any different on either side of this thinning membrane?

Obviously, thoughts on quality of life are best taken from those who are living with dementia. A growing number of studies (primarily qualitative) document the experience of living with cognitive impairments, in which the perspective of the person with the illness is elicited (de Boer et al., 2007; Harman & Clare, 2006; Steeman, de Casterlé, Godderis, & Grypdonck, 2006). Important aspects of quality of life identified across studies by the participants were (a) general well-being, (b) ability to take part in activities and friendships, and (c) having a sense of purpose in life. This latter factor is of central importance to people with dementia but is rarely mentioned as a key domain of quality of life by caregivers. Does nursing have anything to offer here? How do we respond to the collective voice that says “I want to be me!”?

For those who would like to participate in this ongoing dialogue around the social and psychological aspects of living with dementia, Dr. Jesse Ballinger, the organizer of the 2007 conference, has created a collective blog called Al(t)zheimer’s (http://alt-alzheimers.com). The idea is to amplify the work that the conference participants and others are doing around the issue of selfhood in dementia. You are invited to contribute to this dialogue and use it as a venue to publish abstracts/excerpts of and links to material you have written elsewhere to magnify its visibility and impact.

I also encourage a visit to the website that houses the 2007 conference proceedings, which includes video streams of presentations: http://rockethics.psu.edu/education/disability/alzheimers/presenters.shtml. It is a wonderful source of ideas for researchers and practitioners interested in improving quality of life for a significant number of the older adults we care for. Enjoy the stimulating exchange!

REFERENCES


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