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Redefining Health for People with Chronic Disabilities

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The term health appears to be one of the recent recurring themes in allied health professions, including therapeutic recreation (TR). Although health is an important concept, little discussion has been made to examine the relevance of health in the lives of people with disabilities. Most health care agencies, and thus, TR service within health care systems, follow a medical view and/or World Health Organization’s (WHO) holistic concept. These concepts may not respond well in the context to the lives of people with disabilities. The medical concept excludes individuals with chronic disabilities who perceive and succeed in spite of their disabilities. The holistic concept sets unrealistic criteria for people with chronic disabilities who adapt to their circumstances. Accordingly, there is no definitive health state for individuals with these characteristics, and therefore, their health status thus remains undefined. In order to conceptualize health for people with chronic disabilities, an important conceptual premise—life story—should be woven into existing concepts of health.

Life Story

Life story combines the life plans in the past with the life plans of the future (see Brody, 1987; Kleiber, Brock, Lee, Dattilo, & Caldwell, 1995). For most people, current life story is a reflection of the recollected past and the desired future. Life story is defined as “a person’s story of his or her life, or of what he or she thinks is a significant part of that life” (Tilton, 1980, p. 276). The state of “illness” occurs when people with chronic disabilities experience a threat to their story. As they change, and as the physical and social world around them changes, they rewrite their stories accordingly. People with chronic disabilities constantly attempt to discover an alternative story to help them make sense of a life that involves adjustment and acceptance of limitations. One important conceptual suggestion focuses on the particular role individuals find for health in the new stories they write for themselves after illness/disability. In rewriting one’s life stories, Goffman (1961) offered two contrasting life stories that people with disabilities might write:

If the person can manage to present a view of his current situation which shows the operation of favorable personal qualities in the past and a favorable destiny awaiting him, it may be called a success story. If the facts of a person’s past and present are extremely dismal, then about the best he can do is to show that he is not responsible for what has become of him, and the term sad tale is appropriate (pp. 150-151).

The possible stories that people with chronic illness might write are either success stories or sad tales. When rewriting one’s life stories, it is a success story if one indicates successful adjustment to illness/disability, while sad tales would reflect unsuccessful adjustment to the changed circumstances. Identification of what stories one writes can be an important consideration for determining the health status of these individuals.

Reconceptualized Model of Health

Using the life story component in the concept of health, we developed a model of health that contextualizes the lives of people with chronic disabilities. Figure 1 represents our model, in which two dimensions are important: conditions in physical, mental, and social wellness (CPMS) and life story. The CPMS dimension (vertical) reflects existing concepts of health. In this dimension, one end signifies “well” and the other end “not well.” In the life story dimension (horizontal), one end indicates “success stories” and the other end “sad tales” (Goffman, 1963).

In cell I of figure 1, “success stories” in the life story dimension merges with “well” in the CPMS dimension. People who meet these two conditions can without doubt be considered healthy. This cell includes individuals without disabilities who are satisfied with their lives.

In cell II, “success stories” merges with “not well.” This cell represents those people who are able to write success stories in spite of their physical disabilities. These people feel healthy even though they do not meet traditional criteria for health. Therefore, they can be classified as healthy.

In cell III, “sad tales” merges with “well.” This cell represents people without disabilities who may be considered well under existing concepts but whose life stories place them in a questionable state of health. In our model, they are classified as unhealthy.

Cell IV represents people with sad tales who are not well. These people may not have accepted their
disabilities, and their life stories suffer accordingly.

This model reflects the reality of the lives of people with chronic disabilities and supplies a revised definition of health. Our definition of health does not negate existing concepts, but rather weaves them together with the concept of life story.

References

Reference


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