

Indiana University - Article



ILLiad TN: 574012

Journal Title: Journal of physical education,
recreation & dance

Volume: 67

Issue: 9

Month/Year: 1996-11-01

Pages: 64-

Article Author: Lee, Youngkhill,

Article Title: Redefining health for people with
chronic disabilities.

Imprint: EBSCO:Academic Search Premier
IU-Link

Call #: GV201 .J7 v.67 1996

Location: B-HPER Journals

Notes:

Youngkhill Lee (ylee)
HPER Building 133
Indiana University
Bloomington, IN 47405

Notice: This material may be protected by US
copyright law (Title 17 U.S. Code)

FILLED
AUG 05 2008
IU Libraries

Redefining Health for People with Chronic Disabilities

Younghill Lee
Thomas K. Skalko

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 persevere 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, one 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 for 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 may include 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

Figure 1.

		Life Story	
		Success Stories	Sad Tales
Conditions of Physical, Mental, & Social Wellness	Well	I Healthy (no illness/disability)	III Unhealthy (no illness/disability)
	Not Well	II Healthy (chronic disability)	IV Unhealthy (chronic disability)

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

Brody, H. (1987). *Stories of sickness*. New

Haven, CT: Yale University Press.
 Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.
 Kleiber, D. A., Brock, S., Lee, Y., Dattilo, J., & Caldwell, L. (1995). The relevance of leisure in an illness experience: The realities of spinal cord injury. *Journal of Leisure Research*, 27(3), 283-299.
 Tilton, J. T. (1980). The life story. *Journal of American Folklore*, 93, 276-292.

Younghill Lee is an assistant professor of School of Recreation and Sport Sciences at Ohio University, Athens, OH 45701; Thomas Skalko is a professor and chair of Department of Health, Physical Education, and Recreation at East Carolina University, Greenville, NC 27858-4353.

Editor's Note: Because of space limitations, this article has been condensed. An in-depth article on the subject is planned for future publication. Contact the author for more information.

Continued from page 63

Previous programming efforts only directed at encouraging high-intensity, fitness-directed exercise have served only a small portion of the American adult population. Therefore, programming efforts should be directed at: (1) dispelling misconceptions that preclude involvement in physical activity; (2) raising awareness of previously inactive individuals that they can be physically active without engaging in formal exercise but by incorporating at least 30 minutes of moderate-intensity physical activity into activities of daily living; (3) identifying an individual's placement on the PAC; (4) planning subsequent programming in response to that placement; and (5) incorporating behavior management strategies into programming efforts.

References

ACSM & CDC summary statement (1993).
 Caspersen, C. (1985). Physical activity, exercise, and physical fitness: Definitions and distinctions for health-related research. *Physician and Sports Medicine*, 13, 162.
 Dishman, R. K. (1986). Exercise compliance: A new view for public health. *Physician and Sports Medicine*, 14, 127-145.
 Hooper, J., & Veneziano, L. (1994). A university employee physical activity incentive program: Initial participation results. *Wellness Perspectives*, 10(3), 45-53.
 Kasper, M. J. (1990). Emphasis on cardiovascular fitness as a barrier toward mobilizing the sedentary individual. *Journal of Health Education*, 21, 41-44.
 LeUnes, A. D., & Nation, J. R. (1989). *Sport psychology: An introduction*. Chicago: Nelson Hall.
 Shephard, R. J. (1985). Motivation: The key to fitness compliance. *Physician and Sports Medicine*, 13, 89-101.

Song, T. K., Shephard, R. J., & Cox, M. (1983). Absenteeism, employee turnover, and sustained exercise participation. *Journal of Sports Medicine and Physical Fitness*, 22, 392-399.
 Swedburg, R. B., & Izso, B. (1994). Active living: Promoting healthy lifestyles. *JOPERD*, 65(4), 32-35, 48.
 United States Department of Health and Human Services, (1996). Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion.

Jacqueline M. Hooper is an associate professor of human performance and the chair of the Department of Human Performance and Leisure Studies at the University of Southern Colorado, Pueblo, CO 81001-4901. Ed Leoni is a professor of recreation in the Department of Health and Leisure at Southeast Missouri State University, Cape Girardeau, MO 63701.