There Is More to Life Than Putting on Your Pants

From its beginnings and at its contemporary core, the occupational therapy profession has held good quality of life as the superordinate aim of therapy (Gifford, 1989; Townsend, 1991). Meyer (1922/1977) advocated the therapeutic blending of work and pleasure to produce "a program of wholesome living as the basis of wholesome feeling and thinking" (p. 641). Rogers (1983) suggested that treatment planning be organized around each patient's definition of the "good life" (p. 602), and Christiansen (1991) emphasized the link between ability to perform daily occupations, life satisfaction, and health as fundamental to our vocational definition. How then can we explain the fact that persons who have had stroke, the most frequent recipients of occupational therapy services (American Occupational Therapy Association, 1991), generally appear to have a poor quality of life (Ahlsio, Britton, Murray, & Theorell, 1984; Angeleri, Angelen, Foschi, Guarnette, & Nolte, 1993, Labr, Phillips, & Gresham, 1980; Thorngren, Westling, & Norving, 1990)?

Admittedly, this question raises more questions than it answers. What does quality of life mean? What contributes to quality of life? What do we know about a patient's quality of life after stroke, and how does rehabilitation enhance or fail to enhance it? These lofty questions aside, I suggest that occupational therapists may make erroneous assumptions about a causal relationship between patients' physical recovery after stroke and their quality of life. In so doing, we overemphasize the acquisition of physical skills, prematurely presume our work complete, and inadvertently fail to adequately address other factors that might also enhance quality of life for patients who have had stroke.

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The purpose of this article is to explore quality of life specific to occupational therapy and stroke rehabilitation so that we may better organize our evaluation procedures and treatment plans around this superordinate goal. After discussing the concept of quality of life, I examine literature specific to physical recovery and quality of life after stroke.

Quality of Life

Many authors have lamented the lack of consensus regarding the definition of quality of life and the resulting research problems (Adkins-Houglan, 1993; Holmes, 1989, Meeberg, 1993; Zhan, 1992). In this article, I leave the universal, explicit definition to theologians, philosophers, and scholars, and I review commonly accepted assumptions about quality of life and its contributing elements. I also describe Zhan's (1992) conceptual model of quality of life in order to frame some of my recommendations for occupational therapy practice.

Quality of life represents a multidimensional continuum marked by a person's satisfaction in physical, emotional, spiritual, social, occupational, and material domains. Appraisal of quality of life is both personal and dynamic (Holmes, 1989, Meeberg, 1993; Zhan, 1992). Factors that weigh heavily in my definition of a "good life" (to borrow from Rogers [1983, p. 602]) may differ from yours because of different cultural, ethical, and religious values (Zhan, 1992). Furthermore, the importance of various factors change with time and life experience, they lack temporal persistence (Holmes, 1989).

The individual and dynamic attributes of the concept of quality of life complicate efforts to define antecedents and consequences of a good life. For example, good or bad health is not consistently regarded as being closely related to life satisfaction (Holmes, 1989). Although initially rated negatively, illness may eventually be regarded as contributing to personal growth and ful-
fillment, thereby enhancing one's sense of personal well-being (Holmes, 1989). Quality of life represents not only "how an individual perceives his life at any point in time but also what quality his life may assume" (Holmes, 1989, p. 4).

**Operational Definition of Quality of Life**

Zhan's (1992) operational definition of quality of life includes four dimensions: life satisfaction, self-concept, health and functioning, and socioeconomic factors. Life satisfaction, or contentment, is the cognitive assessment of one's progress toward desired goals (Zhan, 1992). Influenced by personal characteristics, environment, and health status (Zhan, 1992), life satisfaction is determined by and reflected in our everyday tasks of living (work, play, and self-care) (Christiansen, 1991). Self-concept is the composite of beliefs and feelings one holds about oneself at a given time (Zhan, 1992). Encompassing sexual identification, body image, and self-esteem (Levine & Brayley, 1991), self-concept directs behavior and is influenced by perceptions of and competence in interpersonal relationships and purposeful activities (Fidler & Fidler, 1963). Health and functioning includes health status, self-care capabilities, and role functioning. Socioeconomic factors include occupation, education, and income.

Zhan's (1992) operational definition of quality of life emphasizes one of the promises of occupational therapy—doing as the foundation of self-actualization (Fidler & Fidler, 1978). This definition describes the influence of purposeful activity (occupation) on quality of life as the catalyst for motivation, satisfaction, sense of mastery, and performance (Wu, Trombly, & Lin, 1994). Zhan's model suggests that proficiency in activities of daily living (ADL) is but one factor that contributes to the good life. Zhan's model also reminds us that quality of life is more than the sum of its parts: Life satisfaction, self-concept, health and functioning, and socioeconomic factors (both actual and perceived) are inextricably interrelated.

In summary, quality of life is personally defined, multidimensional, dynamic, and intimately related to occupation. We must assume that the equations that we each use to evaluate the quality of our own lives will probably not be shared by our patients. Moreover, the way in which a patient weighs the factors contributing to quality of life before stroke may be different after stroke.

**Recovery Versus Quality of Life After Stroke**

Recovery after stroke is typically measured by the extent to which the patient is able to walk and perform self-care activities. The literature has suggested that most persons who have had stroke recover functional capabilities (Anderson, 1990; Granger & Hamilton, 1990; Greveson, Gay, French, & James, 1991; Thorngren et al., 1990), return home after inpatient rehabilitation (Granger & Hamilton, 1990; Thorngren et al. 1990), and maintain these gains for years (Anderson, 1990).

On the other hand, research has raised important questions about the degree to which the patient's recovery of physical skills affects the quality of life after stroke. Several studies have examined patients' mood and frequency of social and leisure activities to determine the long-term quality of life outcomes for persons who have had stroke. In their study of quality of life of patients an average of 3 years after stroke, Angeleri et al. (1995) reported that many patients who were independent in gait and ADL did not socialize even though they were able to do so. The findings suggested that many factors not linked to the disability itself contributed to patients' poor quality of life, including fear of being criticized, depression, loss of social role, and lack of self-confidence (Angeleri et al., 1993). Labi et al. (1980) and Thorngren et al. (1990) found that at 1 year after stroke, a significant number of subjects experienced decreased socialization outside the home despite good physical restoration. Ahlsko et al. (1984) examined the influence of physical and emotional factors on quality of life and found that most of their subjects reported a decreased quality of life 2 years after stroke. Although there was a correlation between changes in quality of life and ADL capacity, patients' ADL improved over time whereas quality of life did not. Vertigo, fatigue, memory, and cognitive impairments limited patients' opportunities for leisure and social functions. Apparently, independence in ADL did not indicate the absence of physical disability or predict good quality of life (Ahlsko et al., 1984).

**Enhancing Quality of Life After Stroke Through Occupational Therapy**

To improve quality of life for persons who have had stroke, we must modify the practice of occupational therapy in response to the personal, multidimensional, and dynamic aspects of quality of life. The following are suggestions for beginning this process.

**Quality of Life Is Personally Defined**

Define what quality of life means to you. I suggest that when I have articulated what a good life means to me, I will be better able to extricate it from my assumptions about others. Here are two ways to explore and consider your definition of a good life. Discuss questions about quality of life at a departmental staff meeting. For example, in what ways do Zhan's (1992) four dimensions contribute to the quality of your life at present? How has the relative importance of these factors changed with life experience and development?

Such discussion promises to illustrate individual differences, directions for personal and professional growth, and strategies for addressing this very personal topic with patients. For those interested in more private exploration, Covey (1989) has recommended writing a personal mission statement. Clearly reflecting the writer's vision of a good life, this statement of personal philosophy "focuses on what you want to be (character) and to do (contributions and achievements) and on the values or principles upon which being and doing are based" (Covey, 1989, p. 106). However accomplished, occupational therapists who understand their own beliefs about quality of life will be better equipped to discern and address quality of life issues with their patients.

Include quality of life as a component of the occupational therapy evaluation process. If the ultimate treatment aim of occupational therapy is good quality of life, our evaluation
procedures must illuminate the patient’s definition of a good life so that we will know when our work is complete. For example, asking the patient or family member to give an hour-by-hour description of a typical day (premorbid or since hospital discharge) offers the therapist many insights into the patient’s choices of and satisfaction with daily activities. The Canadian Occupational Therapy Performance Measure (COTPM) (Law et al., 1991) is another means of determining those performance areas that matter most to patients and their families. The COTPM asks patients to rate the relative importance of various self-care, productivity, and leisure activities in order to provide insights regarding their priorities and a measure for tracking changes in quality of life. If occupational therapy is to truly influence patients’ quality of life, these discussions must be viewed as being as important to the evaluation process as is measuring range of motion and coordination.

Quality of Life Is Multidimensional and Dynamic

Emphasize outpatient programming in the rehabilitation continuum. Emotional reactions that often accompany stroke may sabotage a patient’s ability to fully profit from acute rehabilitation. Sandin, Cifu, and Noll (1994) suggested that denial is usually present throughout inpatient rehabilitation. Although denial is protective to the patient (Ewert, Witty, Herrick, & Hoffman, 1991; Sandin et al., 1994), it interferes with his or her ability to meaningfully participate in goal setting and treatment prioritization. Depression also appears to undermine the effectiveness of inpatient rehabilitation. Galski, Bruno, Zosowitz, and Walker (1993) cited an alarming incidence of depression (20% to 63% of inpatients) during acute stroke rehabilitation. Parikh et al. (1990) noted that depression during inpatient rehabilitation can negatively influence a patient’s motor recovery and independence in ADL as long as 2 years after stroke.

I believe that emphasis on the outpatient phase of the rehabilitation process promises to enhance quality of life for persons who have had stroke and to reduce cost by shortening the more expensive inpatient rehabilitation. Outpatient therapy has been shown to improve patients’ physical skills (Dam et al., 1993; Tangeman, Banattis, & Williams, 1990) and frequency of work and leisure activities (Teasdale, Christiansen, & Pinner, 1993) months to years after stroke. Furthermore, this schedule of therapy may provide benefits over acute rehabilitation:

- Comments from the patients indicated that the stress of the acute stroke phase prevented them from benefiting completely from the acute inpatient rehabilitation. A period at home provided the patients with the opportunity to directly experience how the stroke affected their daily lives, and they had renewed interest in improving skills and level of independence” (Tangeman et al., 1990, pp. 870-880).

Because the period between 3 months and 12 months after stroke is thought to be pivotal in developing life satisfaction (Sandin et al., 1994), occupational therapists must be available during this time to help outpatients use their improving physical skills to perform activities that really matter to them. Occupational therapists find ourselves at the center of promise and disappointment in the area of stroke rehabilitation. In general, the literature (Anderson, 1990; Granger & Hamilton, 1990; Greveson et al., 1991; Thornberg et al., 1990) has suggested that we have succeeded in facilitating the recovery of patients’ physical skills after stroke but not in advancing their resolution of the social, leisure, and productive activities that make life worth living. If the superordinate goal of occupational therapy is, in fact, optimizing quality of life, our job must not end with patients’ proficiency in self-maintenance. Rather, occupational therapy treatment programs must help patients employ their improving physical capabilities in the context of activities that contribute to improved life satisfaction, self-concept, and, ultimately, socioeconomic status.

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References


Recommended Readings

Two autobiographies illustrate the challenge of renegotiating a good quality of life after stroke. In Reappropriate a Memoir, Agnes de Mille, a renowned choreographer who had a severely disabling stroke, lovingly describes the dehumanization associated with hospitalization, the disdain for her disabled body, and the healing effects of occupation. In After the Stroke A Journal, Max Sarton, poet and novelist, describes the enormous impact of minimal stroke residuals on her sense of self and the life-preserving qualities of her personal daily routines.


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