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# Quality of Life Issues in Life Care Planning

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***Abstract.*** *The purpose of this article is to suggest an expanded view of life care planning as a discipline and to initiate a discussion around the issues of quality of life, autonomy and life satisfaction. The authors propose a place for these concepts in life care planning.*

*Life care planning as a specialty practice has been constantly evolving in terms of basic concepts and theoretical underpinnings. This article attempts to:*

1. *Briefly explore the evolution of thinking in healthcare, rehabilitation, and life care planning.*
2. *Continue the redefinition of the language used in life care planning.*
3. *Assist in developing a framework in which to integrate "Quality of Life" thinking into our work as life care planners.*

## Introduction

Life Care Planning is a field that has been growing, evolving, and "professionalizing" for nearly thirty years. Paul Deutsch, in the foreword to *Life Care Planning for Spinal Cord Injury, (Blackwell, Weed & Sluis Powers, 1994),* states that "Life care planning entered onto the rehabilitation scene in the late 1970's and early 1980's and brought with it a consistent methodology for analyzing the disability and the resulting needs. The initial goals of consistency of assessment techniques, organization of resource information and analysis of supportive literature have certainly been met."

By the middle 1990's, theorists in the field of life care planning were adding new dimensions to the overall concept. Weed & Field (2001, p. 146) indicate that "Life care plans address quality of life issues, long-term comprehensive needs for patients and family, complications of the conditions and non-medical issues, such as transportation or architectural renovations for home care." Blackwell, et al. (1994, p. 2) state "...life care planning provides an organized framework of services, recommendations and requirements for long-term disability case management and recognizes the rehabilitation needs of the person with the disability in terms of quality of life, long-term comprehensive rehabilitation and familial considerations."

By the turn of the century, the International Academy of Life Care Planners developed a widely accepted definition of a life care plan as a "dynamic document based upon published standards of practice, comprehensive assessment, data analysis and research, which provides an organized, concise plan for current and future needs with associated costs for an individual who has experienced catastrophic injury or who has chronic health care needs" (IALCP, 2000, p. 1).

In their seminal work, Murphy and Williams (1999, p. 10) state that planning for a person's future care needs means addressing all aspects of life that give it meaning. They go on to say that "Medication, surgery, therapy, and other care options may not be justifiable in terms of quality of life, even when on first blush, they appear to have value for restoring physiological, emotional, or mental function. Quality of life is the conceptual equivalent of holistic, wellness thinking." They further state that "...enhancement of quality of life leads to enhancement of possibilities and removal of barriers to growth."

During the last thirty years, the fields of rehabilitation and healthcare, from whence sprang the field of life care planning have been moving along a continuum.

Brethauer (2001) postulates the following movements in the healthcare field.

1. Care Taker to Care Giver.
2. Institutional Care to Home Care.
3. Isolation to Integration and Main streaming.
4. Vertical Health Care Team to Circular Health Care Team.

The movement from care taker to care giver refers to the change in healthcare from the point at which individuals were simply expected to do as they were told by the physician to a point at which the individual is presented with options for care, expected outcomes are described, questions are answered, and he or she participates in decision making. In addition, and part and parcel to that movement, each member of the healthcare team, including the recipient of care, has expanded responsibilities in terms communication and information gathering.

The movement from institutional care to home care has become an across the board feature of medical care in the United States. Patients are hospitalized primarily for acute care. Recovery and rehabilitation takes place in the home or outpatient setting. This phenomenon has triggered an explosion in home care and outpatient services. It has also required intense focus on reimbursement for these services and created new approaches to cost containment (Kontosh, 2000; Alston, Bell, & Leung, 1997; Buchanan & Alston, 1997; and Huntt & Growick, 1997).

The movement from institutionalization to integration refers to the fact that it is no longer acceptable to confine the individual with a serious disability, terminal illness or catastrophic injury to an institution or the "back room." Patients and persons with disabilities are, by law, integrated with the population as a whole in education, housing, leisure and work activities. Dart & West (1995, p. 47) state that "The ADA affirms that disability is a natural part of the human experience. It rejects the notion that disability is somehow an experience separate and different from the experience of being human."

The movement from vertical healthcare team to circular team refers to a new paradigm in the manner in which treatment decisions are made. Formerly medical treatment was designed to be performed in a hierarchical manner. The physician gave orders to the Nurse, the Physical Therapist, the Occupational Therapist, etc. Now care is approached much more in a team fashion with each specialty recognized for its own area of expertise, and the patient taking an integral part in the decision-making.

Hertz and Anschutz (2002, p. 168), describe the importance of *self-care knowledge*, defined by the statement "...that at some level each person knows what will promote growth and health. Perceived control and life satisfaction are delineated as two of six essential components of self-care knowledge."

According to the Standards of Practice of the International Academy of Life Care Planners, it is expected that life care planners "follow appropriate relevant ethical guidelines within their areas of professional practice and expertise." (IALCP, 2000, p. 18). The authors come to life care planning with differing professional foundations, but with an equal commitment to quality of life. The ethics statements of many professional organizations have evolved to include reference to quality of life issues. Included among these organizations are the American Holistic Nurses' Association, the American Nurses Association, the American Association of Critical Care Nurses, and the National Association of Social Workers.

The field of rehabilitation is more and more becoming aware of the importance of autonomy and quality of life in serving consumers. The Code of Professional Ethics for Rehabilitation Counselors adopted in June 2001, describes five principles of ethical behavior. The first of these is "Autonomy: To honor the right to make individual decisions" (CRCC, 2003). Recent literature in the field of rehabilitation is replete with articles describing the importance of quality of life issues in the rehabilitation and counseling processes (Lustig & Crowder, 2000; Pain, Dunn, Anderson, Darrah, Kratochvil, 1998; Boswell, Dawson, & Heininger, 1998; Chase, Cornille, & English, 2000; Salkever, 2000; Lawford, Volkava, & Eiser, 2001; Lawford & Eiser, 2001; Christopher, 1999; and Myers, Sweeney, & Witmer, 2000). Murphy & Williams (1999, p. 30) state that "the rehabilitationist is concerned not with the treatment of the condition, but with the impact of the condition on the person's physical, intellectual, social, vocational, economic, or emotional functioning."

Nurses are expected to "assist people to assume responsibility for self care" and become "therapeutic partners with individuals, families and communities" (American Holistic Nurses Association, Jan. 2000). In addition, the ethics statement of the Association states that "the client is an active participant in health care and should be included in all nursing care planning decisions".

**Operationalizing the Construct of Quality of Life through Interventions which Enhance Function and increase Life Satisfaction**

The thought which the authors propose for life care planners to have in the forefront of their minds as a plan is developed for each individual is simple: The life care plan should be structured to provide the maximum quality of life for the individual. The life care plan must be crafted to establish a framework of services, which will empower a disabled individual to make his or her own life choices, act on them, and accept the consequences for them. Although it relies on the assessments and recommendations of medical providers, the plan should assume that the differently-abled individual will take as active a role as possible in planning for and achieving his/her goals. Technology, medicine, psychology, and rehabilitative therapies are adjunctive in nature and designed to maximize health, autonomy and quality of life for the individual who has experienced a major life challenge (Brethauer, 2001).

What then is "Quality of Life"? Murphy and Williams (1999, p. 23) indicate "...the disciplines of rehabilitation, clinical medicine, psychology, and other related health and social science professions have laid the groundwork for assessing the quality of an individual's life." There are some models which can be examined and which may form the basis for examining the QOL issues in each client or consumer's life.

The most widely cited definition for QOL appears to be that developed by the World Health Organization Quality of Life Group (1994, p. 3; WHO, 1998, p. 3) which defines quality of life as "a broad ranging concept incorporating in a complex way the person's physical health,

psychological state, level of independence, social relationships and their relationship to salient features of their environment."

The World Health Organization discusses quality of life within a framework of domains, or areas of life, to be considered. These domains are the Physical, Psychological, Level of Independence, Social, Environmental, and Spiritual (WHOQOL Group, 1999; WHO, 1998). In 2000 the World Health Organization re-defined the Social domain as "Participation," referring to participation of the individual in society as a whole (WHO, 2000). In addition, they redefined the domain entitled Environmental Factors in order to address things in the environment which either impede or facilitate the lives of people with disabilities. The domains sometimes overlap, as they do in life.

**The Physical Domain**

The Physical domain includes pain and discomfort, energy and fatigue, and sexual activity, and sleep and rest. Medical care, physical therapies, and medications may be part of this domain. Work, recreation and leisure may impact or be impacted by this domain. The individual must be given the opportunity to weigh expected levels of pain, discomfort, and fatigue against potential outcomes prior to making choices about care.

**The Psychological Domain**

Measuring the subjective psychological quality of life is difficult at best. It has been described as "more than a mood . . . but not so enduring as to be a personality trait"(McCauley & Bremer, 1991, p. 386). It does not necessarily mirror the life challenge nor does it remain constant over time. This domain is not limited to the presence or absence of a DSM IV diagnosis but includes one's overall mental state insofar as it influences QOL. The facets identified by the WHOQOL Group include positive affect; sensory functions; thinking, learning, memory, and concentration; self-esteem; body image and appearance; and negative affect. Work has long been recognized as an important part of this domain (Allport, 1961; Fromm, 1955; and Tait, Padgett & Bremer, 1989). Additionally, Lucas, Diener & Suh. (1996) found that in Western cultures, high self-esteem is a strong predictor of "subjective well-being."

**Level of Independence**

The extent to which an individual is able to achieve independence controls many aspects of life. Feasel (1995) found that "self-efficacy" predicts life satisfaction. The setting in which one lives, the ability to be mobile in the community, and the ability to communicate thoughts, needs, and feelings must be addressed within the bounds of individual choice as well as individual capacity. The WHOQOL Group identified facets of this domain include mobility; activities of daily living; dependence on substances; communication capacity; and work capacity. This domain also includes nursing care at levels sufficient to ensure health and safety.

**Participation**

The Participation Domain involves one's relationships with his/her family, spouse or significant other, friends and community. In order to achieve an acceptable quality of life in the social arena, the physical and psychological domains must also be addressed. Facets of this domain

include intimacy/loving relationships; practical social support; and activities as provider/supporter. Recreation and interaction with one's peers is an important part of life that can be overshadowed by the more immediate care needs. Again, work is an important part of this domain.

**The Environmental Domain**

The environmental domain includes such factors as physical safety, security, the home environment; work satisfaction; financial resources, health and social care: accessibility and quality; opportunities for acquiring new information and skills; participation in and opportunities for recreation/leisure activities; and transport. It also encompasses factors such as leisure and transportation that have been discussed as they relate to other domains. A safe, secure, accessible home to provide the individual with a base of operations from which to pursue her or his goals and activities is an important aspect of this domain. The home environment can stimulate or relieve stress, provide rest and relaxation or require great expenditures of energy.

Finances are a part of the environmental domain. One must consider both income and the existence of finances sufficient to meet one's needs for a healthy lifestyle, as well as the ability to work and produce wealth. It is important to remember that work is a construct separate from the income it may produce. Bolton (1982) said that "...work means self -respect because it establishes the mechanism through which individuals demonstrate their worth."

Myers, Sweeney & Witmer (2000) postulate a different though similar model which can be utilized for examining QOL. The "Wheel of Wellness" is a holistic model of wellness and prevention over the lifespan. Although primarily designed for counseling, the model appears to the authors to have promise in the field of life care planning. Myers, et al. (2000, p. 252) define "...*wellness* as a way of life oriented toward optimal health and well-being in which body, mind, and spirit are integrated by the individual to live more fully within the human and natural community. Ideally it is the optimum state of health and well-being that each individual is capable of achieving". The model has roots in medicine, ecology, psychology and sociology. The "Wheel of Wellness" model includes five "Life tasks": Spirituality, Self-Direction, Work and Leisure, Friendship, and Love.

Spirituality refers not to the practice of a religion, although it does not preclude that, but to a broad concept representing an individuals beliefs and values. There is also a component of emotional support involved in this task.

Self-Direction refers to mindfulness and direction in daily activities and in pursuit of goals. Self-direction includes sense of worth; sense of control; realistic beliefs; emotional awareness and coping; problem solving and creativity; sense of humor; nutrition; exercise; self-care; stress management; gender identity; and cultural identity.

Work and Leisure encompass the many sides of the concept of work,economic, psychological and social. Leisure includes physical, social, intellectual, volunteer and creative activities. Friendship as a life task includes all "...social relationships that involve a connection with others, either individually or in community, but do not have a marital, sexual, or familial commitment." (Myers, et al., 2000, p. 256).Veenhoven et al. (1994) found that happiness was correlated with leisure satisfaction and level of leisure activities at about a .20 correlation overall.

Love refers to relationships that are formed on the basis of a "sustained, long-term, mutual commitment and involve intimacy" (Myers, et al., 2000, p. 257).

A third model which presents itself as a way of empowering the individual for whom a

life care plan is prepared is the "Perceived Enactment of Autonomy" model developed by Hertz & Anschutz (2002. p. 171). PEA, which was originally presented as a model for autonomy in health care in an older adults, represents the "potential for self-care action".

Hertz & Anschutz describe three attributes of PEA:

1. Voluntariness, sensing an ability to freely choose a course of action and having access to information and resources
2. Individuality, recognizing personal needs and goals; and
3. Self-direction, having a sense of being in control and guiding one's own destiny.

PEA is conceptualized as being able to freely choose to meet personal needs for dependence as well as independence. Chase, Cornille, & English (2000, p. 17) found that "Perceived control was the single largest predictor of life satisfaction...and was significant at the .01 level" in their exploratory study of life satisfaction of persons with traumatic spinal cord injuries. Feasel (1995) found that feeling high self-efficacy toward more important goals was a stronger predictor of well-being than feeling high self-efficacy toward less important goals.

A fourth model for examining quality of life is presented by the work being done around the concept of "subjective well-being" (SWB). Subjective well-being as a concept involves a number of components: Global life satisfaction, contentment with specific life domains, the presence of frequent positive affect, and a relative absence of negative affect (Continuing Psychological Education, 2003). Domains involved in SWB include work, family, leisure, finances, self, and one's group. According to Diener (1994), SWB has several cardinal characteristics. First, it is concerned with well-being from the perspective of the respondent. Second, it is measured in terms of long-term satisfaction and affect. Third, healthy personality variables are measured rather than just negative states.

The World Health Organization (1998, p. 3) has defined quality of life as...an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns...quality of life cannot be equated with the terms "health status, "life satisfaction", "mental state", or "well-being." Rather it is a multidimensional concept incorporating the individual's perception of these and other aspects of life.

Murphy and Williams (1998 p. 31) indicate that the World Health Organization has defined health as a state of complete mental, physical, and social well-being rather than as merely the absence of disease or infirmity. They also state that "the efficacy of the rehabilitation process and the professional credibility of the rehabilitationist should not rest solely on selected areas or domains of human function, but on a collective assessment of life function as a whole." Neulicht, Riddick-Grisham, Hinton, Costantani, Thomas, & Goodrich (2002, p. 118) point out the need for "...further analysis of the critical thinking, decision-making models, theoretical processes and methodologies utilized by life care planners."

The future direction of Life Care Planning must, in the authors' view, go beyond the assessment and recommendations necessary to provide for an absence of illness or preservation of life. As life care planners, we must closely examine issues such as wellness, autonomy, and quality of life for each individual with whom we work. It is imperative to understand the concepts involved in these constructs and develop a theoretical framework that allows the life care planner to fully incorporate them into his or her work product.

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