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Quality of Life Considerations in Life Care Planning

Chandylen Nightingale, Jamie Pomeranz, Giselle Carnaby, and Barbara Curbow

Quality of life is a multidimensional construct that has gained popularity in the health care field over the past four decades. Consideration of one's quality of life following disease or disability is critical when addressing psychosocial issues within a life care plan. This article identifies definitions and models of quality of life, types of instruments used to assess quality of life, and measurement challenges that have been identified in the literature, especially in a cancer context. Included in this article are examples of potential life care planning recommendations following a quality of life assessment of individuals with a chronic disease or disability.

Advancement in medical treatment has resulted in decreased disease-related mortality and an aging population living with a myriad of chronic diseases, traumatic injuries, and long-term treatment complications. Consequently, there has been a shift to focus on the *quality* of one's life as opposed to mere *longevity*. It is critical for patients, their family members, the health care team, and life care planners to consider quality of life (QOL) when making recommendations regarding medical treatment and living accommodations. Growing acknowledgment of the importance of QOL has resulted in a substantial amount of research that has increased rapidly since the 1940's. In order for this research to translate into practical applications, it is essential that health professionals and life care planners have a solid understanding of QOL and how it relates to their practice and professional aid. Moreover, although all life care plans may implicitly advocate for QOL, a greater understanding of the construct may help facilitate a stronger justification for recommended services.

This review article, presented primarily in the context of cancer, will provide a brief introduction to QOL and the implications for life care planners. Specifically, we will present examples of definitions, models, and commonly used instruments, along with a hypothetical case study for illustrative purposes. Oncologic QOL is emphasized, which may be especially beneficial for life care planners working with medical malpractice cases attributed to a missed or delayed cancer diagnosis.

Defining Quality of Life

Although the evolving analysis of QOL has led to a greater understanding of the construct, it is still defined with little consistency across the literature. QOL is highly unique to each individual, making it difficult to define universally; however, QOL is often equated to overall happiness or life satisfaction (Fayers & Machin, 2007). In contrast, health-related quality of life (HRQOL) is typically used for assessing the effects of illness and treatment on well-being (Ferrans, 2005). Originally defined as the absence of illness, the World Health Organization (WHO) later recognized that the original definition failed to capture the full spectrum of QOL. Consequently, the definition was broadened to include physical, mental, and social well-being (WHO, 1948). Today, these dimensions are commonly accepted along with spiritual/existential and sexual well-being, although variability still exists depending upon the focus of the inquiry, the population being assessed, and instrument used (Fayers & Machin, 2007). Similarly, the components within each domain may also vary.

Definitions of QOL vary in focus from narrow to broad; narrow definitions limit measurement within the domain of physicians and the health care system. Broader definitions focus on the impact of illness and treatment, with the broadest definitions also accounting for positive functioning (e.g., post-traumatic growth) (Ferrans, 2005). Although differentiated by some, the terms "QOL" and "HRQOL" are often used interchangeably. Spilker and Revicki (1996) argue that this flexibility is acceptable as many domains that are typically considered outside of traditional definitions of HRQOL are fluid and can become health-related. For the purpose of this review, we will use the term "QOL", for any health and non-health related concerns.

Conceptualizing Quality of Life

Separate from pure definitions of a concept, the use of a model that conceptualizes the interaction of multiple components may help inform a life care planner about the role of various domains/sub-domains contributing to a person's overall QOL. Several authors have proposed models for QOL. For example, Spilker (1996) proposed a simple pyramid model consisting of three levels. The highest level includes a person's overall assessment of well-being. The second level includes the physical, psychological, economic, spiritual, and social, domains, while the lowest level includes the components that comprise each of the above noted domains. Although Spilker's model (1996) is useful for conceptualizing the components of QOL, it does not identify causal relationships within QOL. Similarly, a classical framework for cancer survivors proposed by the City of Hope (Ferrell et al., 1992) includes physical, social, psychological, and spiritual domains but again, does not identify causal relationships among or within these domains.

In contrast to the classical model, a model proposed by Wilson and Cleary (1995) provides a stronger framework for the conceptualization of QOL. This model does indicate causal relationships between component domains. Their model takes into consideration how characteristics of the individual and environment contribute to a multitude of factors (i.e., biological and physiological variables, symptom and functional status, general health perceptions) that impact one's QOL. Although this model is mostly framed within a health perspective, it also considers the influence of non-medical factors on overall QOL. A model by Brenner, Curbow and Legro (1995) uses a conceptualization that distinguishes among the level of proximity of QOL domains to the health condition. In their model, the effects of a health condition flow through proximal indicators (e.g., pain) to affect distal indicators (e.g., life satisfaction). The more the proximal indicators are compromised, the more widespread the disturbance in a person's life. Similar models may be informative for a life care planner because they provides a more comprehensive explanation of the relationships that lead to overall QOL.

Quality of Life Instruments

There are numerous instruments available to measure QOL. Life care planners may use an instrument during an intake evaluation to identify potential needs as a result of a client's illness or injury. Given that there are no required credentials or training to administer QOL instruments, they can be easily utilized by life care planners or other health care professionals. Although QOL is not the major focus of the life care planner during his/her evaluation, results may at the very least help identify areas that need further evaluation, especially instruments that provide published norms or cut-off points. These results can help foster communication between the life care planners and treatment providers.

Early Instrument Development

One of the earliest instruments, the Karnofsky Scale, dates back to the late 1940's (Karnofsky & Burchenal, 1947). This scale, which is still used today, was one of the first instruments to expand beyond the traditional physiological or clinical examination by taking into consideration QOL. The instrument's score ranges from a 0 (i.e., individual is dead) to a 100 (i.e., individual is normal with no complaints or evidence of disease) and is typically completed by a treating health professional. The Karnofsky Scale differs markedly from more recently developed QOL instruments due to its limited scope and lack of self-report. Since this time, QOL instruments have evolved in sophistication with more recently developed instruments utilizing self-report and encompassing a broader assessment of well-being/ functioning (Fayers & Machin, 2007). This integration of a broader assessment of well-being is valuable for life care planners who take into consideration a person's functioning across multiple domains of their lives.

Generic and Disease Specific Instruments

Generally, QOL instruments today can be categorized as generic or disease-specific. Generic instruments can be given to any population and allow for the comparison of different groups of individuals (Fayers & Machin). For example, the Medical Outcomes Study (MOS) Short Form Health Survey (SF-36) is an example of a widely used generic QOL instrument (Ware & Sherbourne, 1992). The SF-36 assesses eight health concepts including 1) physical activity limitations due to health, 2) social activity limitations due to physical or emotional problems, 3) usual role activity limitations due to physical health problems, 4) bodily pain, 5) general mental health, 6) usual role activity limitations due to emotional problems, 7) energy and fatigue (i.e., vitality), and 8) general health perceptions. Respondents are also asked to rate their current health as well as their health in comparison to a year ago. An advantage to using the SF-36 is the ability to compare a client with norms for the patient's age and sex. If a client is a standard deviation below that norm on a domain, this may indicate services are needed. An example of the SF-36 is demonstrated in a study by Holt et al. (2011) who found that patients with lung cancer scored more poorly on vitality and mental and physical functioning than those with colorectal cancer.

Disease-specific instruments are designed to measure QOL for individuals with a particular disease. Unlike generic instruments, they cannot be directly used to

compare across disease categories. The Functional Assessment of Cancer Therapy-General (FACT-G) is one example of a commonly used disease specific instrument intended for patients undergoing cancer treatment (Cella et al., 1993). This instrument detects treatment-related side effects and impairments in QOL that generic instruments are not designed for. The FACT-G instrument assesses physical, social, emotional, and functional well-being (Cella et al., 1993). Although it can be used to assess QOL in cancer populations in general, there are also FACT instruments that are tailored to specific types of cancer. For example, the FACT-Head and Neck (FACT-H&N) is intended for patients with cancer in the head or neck and in addition to the FACT-G items, it also includes items specific to head and neck cancer (e.g., swallowing difficulty) (Cella, 1997; List et al., 1996). Some disease specific instruments are designed to measure QOL issues that commonly present after treatment has concluded (Zebrack & Cella, 2005). For example, the Quality of Life-Cancer Survivors (QOL-CS) scale is an example of a QOL instrument developed for cancer survivors who are post-oncologic treatment (Ferrell, Dow, & Grant, 1995). The QOL-CS scale assesses psychological, social, physical, and spiritual well-being. Life care planners who are interested in QOL as it relates to a specific disease, should focus on disease specific instruments as opposed to generic instruments.

Assessing a Specific Component of Quality of Life

Although QOL is a multidimensional construct, some studies focus solely on a specific component of QOL (e.g., physical functioning). These types of instruments may provide a more in depth assessment of one dimension or component of QOL, rather than the full spectrum of QOL (Zebrack & Cella, 2005). An example of such a measure is the State Trait Anxiety Inventory (STAI) (Spielberger et al., 1983). The STAI is a self-report measure that quantifies adult anxiety levels and differentiates between state and trait anxiety. Moreover, similar to the SF-36, the STAI has national norms that can be used as a comparison to gauge level of anxiety. Another example of a unidimensional measure is the Center for Epidemiologic Studies Depression Scale (CESD) (Beeber et al., 1998). The CESD measures depression and has a cut-off score that indicates significant or mild depression. The cut-off score allows a life care planner to evaluate presence and level of depression in his/her client, which is advantageous when making a case for therapeutic services. The STAI, CESD, and many other instruments that are limited in scope, are considered generic and can be used in any adult population. These instruments may be beneficial for life care planners seeking information regarding the impact of disease or disability on a limited component of QOL. In addition, they may also be useful when taking a composite approach by using two or three different instruments, for example, that each measure a different domain. See Table 1 for examples of the different types of QOL instruments.

Challenges When Measuring Quality of Life

Application across different age groups. One of the biggest challenges in the area of QOL is knowing how to operationalize the construct for different populations at various points in the life course. For example, Nightingale et al. (2011) proposed a working model of QOL considerations for young adult survivors of childhood cancer (YASCC). Their findings indicated that YASCC experience some unique domains and sub-domains of QOL that have not been identified in other populations. For example, authors proposed that "fertility/sexual", "resilience", and "body appearance" should be included in a QOL framework for YASCC. Their findings underscore the importance of taking into consideration how a QOL framework may differ in individuals at different stages in the life course.

Measurement of pediatric QOL can also be challenging because younger children are generally not able to comprehend and complete an instrument on their own. Pediatric instruments (e.g., PedsQL) often rely on a proxy assessment from a parent or primary caregiver (Varni & Limbers, 2009). Research indicates that proxies tend to rate patients as having more symptoms and worse functioning than what truly exists (McColl & Fayers, 2005). Taking this into consideration, parent assessment may falsely yield poorer QOL in comparison to true levels.

The influence of culture. A relativist epistemological stance would argue that QOL instruments are heavily influenced by culture (Fox-Rushby & Parker, 1995). From this perspective, QOL should be considered relative to each culture rather than as a global construct that can be applied cross-culturally. In line with this philosophy, a QOL instrument needs to be carefully selected to coincide with a population's cultural background. The obvious limitation in developing separate instruments for separate groups of individuals with different cultural backgrounds, is the resulting inability to make comparisons between different cultures. One method of assessing QOL, while taking into consideration cultural background, is to conduct qualitative research in which participants respond to semi-structured interviews or focus groups. This type of evaluation allows participants to identify components of QOL that they value, rather than responding to items on an instrument that may neglect issues relevant to their cultural background. For example, Clavarino (1999) conducted qualitative interviews with ten patients with metastatic, incurable

Table 1
Examples of Different Types of Quality of Life Instruments

Type	Population	Domains/ Areas of Focus
		SF-36 (Ware & Sherbourne, 1992
Generic	No restrictions	physical activity limitations due to health
		social activity limitations due to physical or emotional problems
		usual role activity limitations due to physical health problems
		bodily pain
		general mental health
		usual role activity limitations due to emotional problems
		energy
		fatigue (i.e., vitality)
		general health perceptions
		current health
		health compared to a year ago
		FACT (Cella et al., 1993)
Disease-specific	Cancer patients in active treatment	physical
		social
		emotional
		functional
		QOL-CS (Ferrell et al., 1995)
	Cancer survivors	physical
		social
		psychological
		spiritual
		STAI (Spielberger et al., 1983)
Component-specific	No restrictions	anxiety
		CESD (Beeber et al., 1998)
Component-specific		depression

cancer and concluded that culture influenced participants' judgments regarding QOL. This suggests that life care planners should consider their clients' cultural background and how it is potentially related to their QOL. Moreover, it also suggests that when assessing multiple domains, each may be weighted differently across cultures. For example, the family unit and fulfilling family roles is more significant in Chinese culture in comparison to American culture. This discrepancy suggests that assessment of family well-being/functioning may need to be given greater weight in those with a Chinese background.

Prospective assessment. Prospective assessment of QOL can also be complicated due to the inability of some measures to be applied at any time point. For example, oncologic QOL instruments are typically intended for patients in active treatment (e.g., FACT-G) or survivors post-treatment (QOL-CS) (Cella et al., 1993; Ferrell, Dow, & Grant, 1995). There is clinical value, however, in ascertaining the typical trajectory of QOL for patients with cancer transitioning from active treatment into survivorship post-treatment. The use of two distinct measures fails to provide a comparison at the different time points. In such cases, a generic instrument that can be utilized at any time point can be used either alone or as a supplement to the oncologic QOL instruments.

Prospective assessment can also be complicated by a change in how a person evaluates an item on a questionnaire over time. One hypothesis for this finding pertains to the idea of response shift. When applied in a cancer context, response shift states that over time, survivors alter their definition and evaluation of QOL due to their cancer experience (Breetvelt & Van Dam, 1991). In other words, living through the cancer experience results in a shift in the "anchor point" which one compares their current quality of life. Consider the example of a person who shows no change in physical functioning scores, yet behavioral physical functioning indicates impairment in comparison to prior scores. This lack of change in subjective physical functioning scores may reflect a shift in the person's initial expectation of physical functioning levels. In contrast, another hypothesis is that survivors engage in self-deception response bias in which survivors unconsciously deny or minimize their stress (O'Leary, Diller, & Recklitis, 2007). This is not surprising since many cancer survivors report social pressure to feel grateful and optimistic for surviving their disease (e.g., Cantrell & Conte, 2009). In addition to these two aforementioned explanations, it is also possible that survivors have simply accepted their level of functioning/ well-being.

Example: Quality of Life Considerations in a Life Care Plan

See Table 2 for an example of how a life care planner might consider QOL in a life care plan for a cancer patient. Results from a QOL instrument such as the SF-36 may indicate poor functioning compared to norms for the patient's age and sex. For example, a client may report significant fatigue and a lack of energy. Consequently, a life care planner may recommend a consult with a nutritionist for assistance with developing a nutrition and physical activity plan. Within the social well-being domain, results may indicate that a client's marriage is suffering as a result of his/her illness. In such cases, martial counseling may be recommended. Additional recommended services may include vocational counseling to address employment difficulties (as measured by the "functional" domain), a therapy dog to manage high levels of anxiety (as measured by the "emotional" domain), and psychotherapy to address spiritual or existential concerns (as measured by the "spiritual/existential" domain). Although QOL instruments help facilitate an open dialogue regarding impairment or poor functioning for a client, these instruments should be used to supplement the intake evaluation, rather than serve as the sole resource utilized for making recommendations.

Conclusion

Exploration of QOL has evolved over the years, providing insight into the construct, definitions, models, and instruments for various populations. Although this review emphasized cancer, it is important to note that QOL can be applied to any population. For example, Renwick and colleagues (2003) developed a QOL tool specific to people with disabilities. Life care planners should be familiar with the classical domains of QOL (physical, social, emotional, and spiritual well-being) and how each of these could be applied to a client with a particular disease or disability when developing a life care plan. They should also be cognizant of additional domains that apply to specific groups. A clearer understanding of a client's current QOL and projected long-term QOL issues (as identified in the literature), will allow the life care planner to provide a more holistic plan to address the client's multidimensional needs.

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Table 2
Quality of Life Considerations for Life Care Planning

Quality of Life Domain		Potential LCP Recommendations
Physical		
	Energy	Nutritional & physical activity support
	Fatigue	Medication
	Nausea	Psychotherapy
	Pain	Physical therapy
		Integrative therapy techniques (e.g., massage therapy, yoga)
Social		
	Family acceptance	Family counseling
	Family communication	Marital counseling
	Marital adjustment	Support group
	Sex life	
	Isolation	
Functional		
	Ability to work	Vocational counseling
	Impact on recreational activities	Work space accommodations
	Educational achievement	Physical therapy
	Mobility in home	College/technical school
		Home accommodations
Emotional		
	Fear of recurrence	Psychotherapy
	Anxiety	Therapy dog
	Depression	
	Poor body image	
Spiritual/Existential		Psychotherapy

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Author Notes

The lead author, Chandylen Nightingale, may be reached via mail at 1225 Center Drive, PO Box 100175 HSC, Gainesville, Fl 32610. Her email is Chandy83@phhp.ufl.edu. Her phone number is (352) 262-4450.