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Health-related Quality of Life: Expanding a Conceptual Framework to Include Older Adults Who Receive Long-term Services and Supports

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For older adults receiving long-term services and supports (LTSS), health-related quality of life (HRQoL) has emerged as a critical construct to examine because of its focus on components of well-being, which are affected by progressive changes in health status, health care, and social support. HRQoL is a health-focused quality of life (QOL) concept that encompasses aspects of QOL that affect health such as function, physical, and emotional health. Examining existing theoretical constructs and indicators of HRQoL among LTSS recipients led us to posit a revised conceptual framework for studying HRQoL among LTSS recipients. We adapted the Wilson and Cleary HRQoL model by expanding function to specifically include cognition, adding behavior and LTSS environmental characteristics in order to create a more robust HRQoL conceptual framework for older adults receiving LTSS. This refined conceptual model allows for the measurement of a mix of structural, process, and outcome measures. Continued development of a multidimensional conceptual framework with specific HRQoL measures that account for the unique characteristics of older adults receiving LTSS will contribute significantly to LTSS research, policy, and planning efforts.

Key Words: Long-term care, Nursing homes, Homeand community-based care, Assisted living facilities

About six million older adults receive long-term services and supports (LTSS) in their own home, assisted living facilities (ALFs) and nursing homes (NHs) in the United States (Kaye, Harrington, & LaPlante, 2010). The projected growth of the elderly population, particularly those 85 years of age and older, coupled with the increased lifespan of older adults with

chronic diseases and disabilities, are expected to create a demand for LTSS that the U.S. Health Care System is inadequately prepared to meet (Vincent & Velkoff, 2010). Advances in medicine and technology combined with improvements in the management of chronic diseases continue to increase the complexity of care needs for this growing population (Institute of Medicine (U.S.), 2001a, 2001b; Vincent & Velkoff, 2010). Current conceptual models of health-related quality of life (HRQoL) using multidimensional domains (Fitzpatrick et al., 1992; Ware, 1995; Wilson & Cleary, 1995) have been designed to primarily address a general adult population, failing to take into account the unique challenges of both the LTSS population and the LTSS organizational environments. Functional decline, both physical and cognitive, combined with multiple chronic illnesses, and attributes of the LTSS organization require an expansion of existing HRQoL conceptual models to more fully explore the unique needs of this population. The purpose of this article is to present a revised conceptual model of HROoL for LTSS recipients.

Background

Defining and Measuring HRQoL

Quality of life (QOL) is a broad multidimensional concept that includes subjective evaluations of both positive and negative aspects of life (Orley, Saxena, & Herrman, 1998), including multiple life domains such as jobs, housing, and health. HRQoL is a health-focused QOL concept that encompasses aspects of health that influence QOL ratings (McHorney, 1999). At an individual level, HRQoL includes physical and mental health perceptions and their correlates—including health risks and conditions, functional status, social support, and socioeconomic status. At an environmental level, HRQoL includes resources, conditions, policies, and practices that influence a population's health perceptions and functional status (Centers for Disease Control and Prevention, 2000; Gandek, Sinclair, Kosinski, & Ware, 2004). HRQoL is an important concept consideration because it can contribute to evaluating the appropriateness and effectiveness of both individual and system level interventions and outcomes (Wodchis, Hirdes, & Feeny, 2003). Specifically, data on the multiple domains of HRQoL can inform decisions about innovative clinical practices, new technologies, and resource allocation for chronically ill and disabled

older adults. HRQoL measures provide critical data for selecting among alternative interventions and for guiding decision making when there is a trade-off between length of stay and HRQoL (Adams & Corrigan, 2003; Guyatt et al., 1993).

In addition, individual outcome measures (e.g., physical health status), commonly used to assess patient populations for whom cure is the goal, often correlate poorly with self-reported health ratings, health status, and other dimensions of HRQoL that more closely reflect the health care goals for the growing population of older adults for whom progressive health change, not cure, is the health trajectory (Gold, Siegel, Russell, & Weinstein, 1996; Guyatt et al., 1993; Kane et al., 2003). The ability to cope with health limitations and personal views about the meaning and value of life are prominent factors that can significantly affect older adults' perceptions of their health status (Wilson & Cleary, 1995). Those perceptions can also be influenced by the quality of health services (Gold et al., 1996; Kane et al., 2003; Wilson & Cleary, 1995). Thus, HROoL has evolved as a more relevant and appropriate construct to use for older adults who receive LTSS, because of its focus on multiple aspects of well-being that are affected by both progressive health status changes and the health care provided to address complex and changing needs (Gold et al., 1996). Unlike measures that reflect health professionals' opinions, HRQoL emphasizes the older adults' perspectives of health and well-being. This construct is consistent with the current emphasis on "patient centered care" (health care responsive to the person's wants, needs, and preferences), a principle stressed in the Institute of Medicine reports on quality (Guyatt et al., 1993; Institute of Medicine (U.S.), 2001a, 2001b).

We sought to expand a conceptual HRQoL framework that would integrate existing HRQoL models and include older adult-identified priorities for outcomes. Unidirectional models have proven inadequate in explaining causality; most experts strongly advocate the use of a multidimensional conceptual model to guide assessment of HRQoL. Mathisen and colleagues (2007), for example, argue that overall QOL can causally influence as well as be an outcome of health status after coronary artery bypass surgery. Furthermore, most proposed models do not specify the linkages between measures and very few have been empirically tested. While a number of models have been proposed (Bergner, 1985; Johnson & Wolinsky, 1993;

Patrick & Bergner, 1990; Read, Quinn, & Hoefer, 1987; Verbrugge, 1991), few include the range of variables that need to be included in assessments of older adults receiving LTSS.

We selected the Wilson and Cleary (1995) model because it offered the most comprehensive view of pathways linking traditional clinical variables and concepts we found in the literature to be most relevant to the HRQoL construct. The model specifies an outcome-derived taxonomy associated with relevant health concepts and hypothesizes bidirectional causal relationships between and among these concepts. Additionally, the model considers health concepts as existing on a continuum of increasing complexity, a hallmark of older adults' health trajectories. Specifically, the original framework's five core domains include biological and physiological factors, symptom status, functional status, general health perceptions, and perceived QOL. Emotional and social constructs are hypothesized to have potential causal relationships with each of the five domains; for example, individuals with depression have a worse OOL than those with common diseases such as hypertension, arthritis, diabetes, and heart disease (Ormel et al., 1993; Wells et al., 1989). Distinguishing traits of individuals as well as the structural and process features of the environments, including organizations that affect the individual, also influence these core domains. Use of Wilson and Cleary's unique conceptual orientation for older adults receiving LTSS resolves the challenge of having cure as the optimum outcome. Instead, changes in multiple domains associated with aging, frailty, and coping with the effects of multiple chronic conditions are the focus for measuring change and outcomes.

Importantly, this model has been demonstrated to enhance knowledge about the HRQoL of a range of diverse populations coping with long-term health issues (Ferrans, 2007; Sousa & Kwok, 2006; Wyrwich et al., 2009). In their application of the Wilson and Cleary model to patients with generalized anxiety disorder, for example, Wyrwich and colleagues (2009) concluded that this model improved understanding and usefulness of health status for this population. Ferrans (2007), who employed this model to examine symptom management of patients in cancer trials, concluded that use of such a multidimensional orientation yielded valuable information about patients' treatment experience and outcomes that would not have been captured with a more narrowly focused approach. Sousa and Kwok (2006) used structural equation modeling to validate the Wilson and Cleary model with patients living with HIV/AIDS. These investigators concluded that the HRQoL model fit the data and, further, that the relationships between constructs were all statistically significant.

An Expanded Conceptual HRQoL Model for Older Adults Receiving LTSS

We expanded the Wilson and Cleary (1995) model to incorporate individual characteristics of cognitive and behavioral status as well as aspects of LTSS organizations as environmental characteristics (Figure 1). Individual characteristics important to HRQoL include social support, satisfaction, sociodemographic factors, functioning, psychological functioning (Wilson & Cleary, 1995), emotional status, and religiosity (Drageset et al., 2009; Fry, 2000; Keyes & Reitzes, 2007; Soh, Morris, & McGinley, 2011; Yoon & Lee, 2006). These factors are also often associated with better physical and mental health (Fry, 2000; Keyes & Reitzes, 2007; Yoon & Lee, 2006).

Our adaptation to the individual characteristics occurred in two core domains. First, we expanded the function domain to recognize the importance of cognitive ability as a factor influencing QoL, based upon the work of Brod, Stewart, Sands, and Walton (1999). Cognitively impaired individuals represent the majority of older adults receiving LTSS (Scholzel-Dorenbos et al., 2007; Sloan, Trogdon, Curtis, & Schulman, 2004; Wetzels, Zuidema, de Jonghe, Verhey, & Koopmans, 2010; Zuidema, de Jonghe, Verhey, & Koopmans, 2010). In the past, HRQoL measurement among older adults has been limited to persons who are cognitively intact because of concerns about the reliability of reports from individuals with cognitive impairment and the commensurate reliability of proxy reports (Logsdon, Gibbons, McCurry, & Teri, 2002). Kane and colleagues (2004) have challenged this notion by citing evidence from studies with cognitively impaired older adults living in NHs that support reliable HRQoL measurement using appropriate self-report instrumentation (Brod et al., 1999; Mozley et al., 1999). Our expansion to include persons with impaired cognitive ability will significantly increase our knowledge base of HRQoL for LTSS recipients.

Second, we included behaviors and mood states traditionally associated with dementia

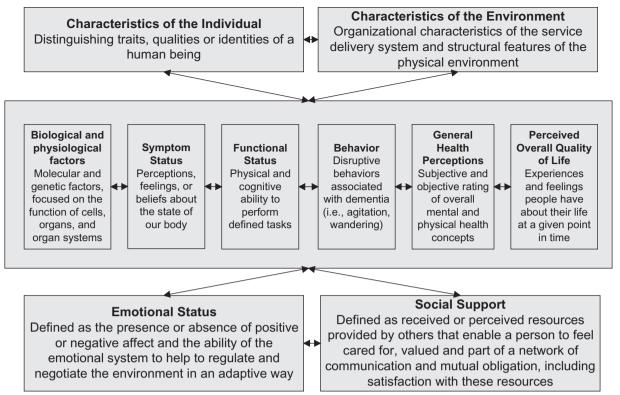


Figure 1. The long-term services and supports health-related quality of life conceptual model. As developed by Wilson and Cleary (1995) and adapted by Brod and colleagues (1999); with Patrick (1997).

as a new domain. Behaviors of persons with cognitive impairment are important to include in the conceptual model because 83% of older adults with a cognitive disorder also experience behavioral symptoms (Cummings, often exhibited through modified mood states. Common behaviors and mood states exhibited by individuals with cognitive impairment include apathy and withdrawal, anxiety, irritability, dysphoria, disinhibition, delusions, hallucinations and paranoia, agitation and aggression, and activities such as wandering, purposeless behavior, and socially improper behaviors, disturbed diurnal or circadian rhythms that cause sleep changes, loss of the ability to feed oneself, and resistance to care (Mahoney, Volicer, & Hurley, 2000). These behaviors and mood states often impact overall QOL negatively (McCall, Cohen, Reboussin, & Lawton, 1999) and increase the difficulty of caring for older adults with cognitive impairment. This increased difficulty for caregivers may be a critical predictor of transitions to LTSS settings such ALFs and NHs due to caregiver burden.

In addition to expanding the functional domain to specifically include cognition and adding a behavioral domain, we also expanded the environmental domain to include the most common LTSS organizational delivery systems (home- and community-based services [H&CBS] and assisted living and NHs). We found that Patrick's (1997) model argued persuasively for assessing the environment by including both organizational factors of the service system (e.g., staff composition and hours of care) and the physical environment (e.g., size and structure) in which the services are received, to fully explain variation across settings.

Organizational characteristics, including the physical environment and service delivery models, are major factors that influence the life of the individual (Wilson & Cleary, 1995). Studies exploring the determinants of high-quality LTSS have sought to define key organizational characteristics of the service delivery system—structure and process features of care—that play a significant role in the variation in outcomes (Kane et al., 2004; Unruh & Wan, 2004; Zinn & Mor, 1998). The outcomes that dominate these studies are health status and health service use (e.g., morbidity, mortality, and hospitalization) or adverse events (e.g., pressure ulcers). In NH organization studies, three key organizational characteristics

that have been linked broadly with quality outcomes include nurse staffing (e.g., hours of nursing care; Institute of Medicine [U.S.], 2001a, 2001b), ownership type (for profit; not-for profit; Institute of Medicine [U.S.], 2001a, 2001b; Kane et al., 2004), and availability of hospice care (Baer & Hanson, 2000; Mezey, Dubler, Mitty, & Brody, 2002; Miller, Mor, & Teno, 2003; Petrisek & Mor, 1999; Wilson, Kovach, & Stearns, 1996).

We found few studies linking organizational characteristics and HRQoL among ALF and H&CBS settings. Higher levels of resident satisfaction were associated with smaller facility size, a moderate level of physical amenities, greater availability of personal space, fewer socio-recreational activities, and nonprofit ownership (Sikorska, 1999). Studies exploring organizational characteristics in H&CBS found that organizational characteristics related to the local economy and ownership status (for-profit vs. nonprofit) were significant predictors of quality of care (Alkema, Reyes, & Wilber, 2006; Dill & Cagle, 2010). Additionally, organizational indicators associated with higher staff job satisfaction and more positive staff views included organizational cultures in which there was greater teamwork and participation in decision making (Sikorska-Simmons, 2006). Organizational process features, such as the assessment and management of symptoms also play an influential role in the perception of and satisfaction with services (Rantz et al., 2004).

Finally, including both subjective (older adult) and objective (medical chart) data is paramount to further refinement of HROoL. Testa and Simonson (1996) argue that each domain of health can be measured in both objective and subjective dimensions. The objective dimension (traditional clinical health measures) defines a patient's degree of health; the subjective dimension (patient reported health) translates health status into the QoL experienced (Testa & Simonson, 1996). Thus, two patients with identical health status may have very different OoL, depending on their subjective experiences, expectations, and perceptions regarding health. It is specifically these subjective evaluations that we were interested in capturing across multiple domains. Clinically important differences also often differ across groups of patients as influenced by their living conditions, levels of disease severity, socioeconomic status, and nationality (Bowling, Banister, Sutton, Evans, & Windsor, 2002).

Conclusion

Gaps in knowledge of the linkages and intersections across and among HROoL domains remain undefined. As the empirical basis for relationships between domains strengthens, the relationships between interventions and domains and the multiple dimensions reflecting HROoL, a complex multidimensional outcome, should be tested. These relationships will be instrumental in understanding HROoL among older adults receiving LTSS. Research agendas focused on HRQoL in LTSS can take many forms. Our team's approach includes an emphasis on capturing the older adults' perspectives (voice) of their health and well-being, interviewing older adults as they transition to LTSS and following them over time using instruments that measure the HRQoL domains (specifically every three months until death), and including persons with cognitive impairment as a key component of the HRQoL conceptual design. Many comparisons and subset analyses will result, such as examining changes in cognition, depression, or functioning over time; examining those changes by site of care (assisted living vs. NH); or how they interact to determine opportunities for interventions (i.e., how treating depression impacts function and how processes of care by setting impacts function or cognition).

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