

Chapter 38

The Impact of Assistive Technologies on Quality of Life and Psychosocial Well-Being

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ABSTRACT

Health-related quality of life is a comprehensive term to describe a person's experiences of health and illness. Quality of life (QOL) is a dynamic psychological construct encompassing interacting subjective and objective dimensions; thus, it is not directly observable. There is no gold standard for measuring quality of life due to the differing interests of doctors, caregivers, patients, and researchers. This chapter examines the research needs in the area of improving QoL through the proper implementation of AT. The authors also make recommendations for incorporating the needs of users and caregivers in the design, deployment, and use of AT to reduce device abandonment.

INTRODUCTION

Quality of life (QoL) is a comprehensive term to describe a person's experiences of health and illness; it is a personal, dynamic and amorphous concept. There are multiple ways to assess QoL: measuring physical health and functional ability, emotional assessment, measuring psychological well-being, and assessing social well-being. While some QoL factors can be measured objectively, there is evidence to support the utility of measuring subjective well-being (Mroczek & Kolarz, 1998). The multidimensionality of QoL presents a challenge to researchers: causal factors are interrelated and affect overall well-being. A person's subjective well-being will also change over the lifespan due to health status and life events; therefore, any QoL assessment must be considered a snapshot of well-being at that point in time and at least occasional reassessment is necessary. Quality of life is personal because needs, desires and

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priorities are different from person to person. Quality of life assessment is used to supplement objective, or clinical, measures of medical conditions. The increasing usage arises from a shift in contemporary healthcare organizations from a medical care model to a person-centered, social care model (Walsh & O'Shea, 2008). In a social care model, importance is placed on disease outcomes, satisfaction with treatment, and how patients feel. Assessing treatment, services, assistance, and outcomes is especially important for people who have a chronic medical condition, such as a disability, and is understudied. A disability occurs when a person, in an environment, cannot complete a task. For example, a wheelchair user (person) would have difficulty ascending (task) a flight of stairs (environment). Elevators and wheelchair ramps are examples of assistive devices that enable a wheelchair user to navigate not just the environment, but tasks within environments. An additional area of QoL research that needs to be further developed is the impact of assistive devices on a person's life (i.e., how a person's life is changed because of using or not using a device or service that accommodates a disability). The Technology Related Assistance for Individuals with Disabilities Act of 1988 (the United States Tech Act) defines an assistive device as "any item, piece of equipment, product, or system, whether acquired commercially off the shelf, modified or customized, that is used to increase, maintain or improve functional capabilities of individuals with disabilities". This broad definition is by design and highlights the unique needs of individuals and classifies a device as assistive whether it was originally developed to accommodate for a disability. AbleData, an online database of assistive technology resources and information, contains information on over 35,000 assistive technology devices and products. For the purposes of this chapter the terms "assistive device", "assistive technology" and "assistive technological device", all common terms in the industry and scientific literature, are referred to synonymously as "assistive technology (AT)". As important as the devices themselves is the procurement process. People cannot be satisfied or dissatisfied with a product if they cannot obtain it; therefore, researchers are also examining the QoL impact of AT services (Jutai, Fuhrer, Demers, Scherer, & DeRuyter, 2005).

BACKGROUND

Quality of life measurement is a broad field and one challenge for researchers is the lack of a scientific consensus on what constitutes quality of life. There are hundreds of QoL measures and many are manifestations of researchers' and clinicians' interests (Bowling, 2003). Patient-centered measures have been developed to investigate the gaps not addressed by questionnaires developed through the medical care model and the disparities between doctors' assessments and those of patients (Addington-Hall, & Kalra, 2001; Slevin, Plant, Lynch, Drinkwater, & Gregory, 1988). New QoL measures are frequently added to the many that already exist and choosing the correct measure for a specific clinical or research situation can be a difficult and laborious process. Validity, reliability and practicality are important; however, the choice of instrument will vary depending on the purpose and population for which it is used. Measures used as part of a population-based survey must be efficient, concise, and broadly applicable. An instrument used to detect the impact of treatment for a particular disease or condition must be responsive to the specific functional and social consequences of the condition and associated treatments. A useful measure for one situation may not be appropriate for another. For studying the impact of ATs on a person's QoL, the wide range of disabilities, devices and research purposes makes selecting an appropriate QoL measure a time-consuming process.

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