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Original Research Article

Quality of Life in Children: A Concept Analysis

Arwa A. AL-Hamed, PhD, RN, CPNP*

Assistant professor of pediatric nursing, Head of nursing department and quality assurance unit, King Saudi Bin Abdul-Aziz University for Health Science: school of nursing, Riyadh, Saudi Arabia.

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***Corresponding author:** Arwa Abdulaziz Alhamed **Email:** hamedar@ksau-hs.edu.sa

Abstract

Background*:** The burden of living with pediatric end-stage renal disease (ESRD) impacts quality of life (QOL), a concept that has been commonly associated with adherence, morbidity, and health outcomes. There are many definitions for QOL but they rarely take the pediatric perspective into consideration and they may not apply perfectly to Muslim and Arabic societies. ***Objectives*:** The aim of this paper is to clarify the concept of QOL and identify the conceptualizations behind it and to provide some insights to QOL research in children and in the Arab world. ***Results: The defining attributes of QOL include the level of satisfaction, the individual perception of well-being, and the life domains. QOL is defined as a subjective evaluation of satisfaction of well-being across life domains based on individual perception of life in the context of culture, values, and beliefs. The antecedents of QOL include cognitive capacity, basic functioning ability, and life events. The consequences of QOL include happiness and goals accomplishment. QOL is measured using generic and disease specific measures which ask individuals to rate their satisfaction with life domains such as physical, emotional, social, and vocational. In children, QOL measures consider developmental changes, cognitive abilities, and parent-proxy reports. In the Arab world, QOL is rarely defined or measured from an Arabic and Islamic perspective. ***Conclusion*:** All attempts must be made to address QOL from a cultural, linguistic, and developmental standpoint that can reflect the complex nature of QOL in the pediatric population.

Keywords: "Quality of Life", "Concept Analysis".

INTRODUCTION

The advancing biomedical technology resulted in a better life expectancy for children with chronic health conditions but also prolonged their suffering. The burden of living with pediatric chronic conditions impacts quality of life (QOL), a concept that has been commonly associated with adherence, morbidity, and health outcomes. QOL is becoming an area of extensive research particularly for those living with chronic health conditions. However, in Saudi children with chronic diseases, the concept of QOL is rarely defined nor addressed adequately.

I used Walker and Avant (2010) method for concept analysis aiming to clarify the concept of QOL. I examined the literature to identify the conceptualizations behind the term QOL which is expected to guide my future studies on QOL of Saudi children with end-stage renal disease.

METHOD

I searched PubMed, COCRHEAN, and CIHNAL using the keywords "QOL concept analysis", "QOL in children with chronic conditions", and "QOL in children". I included 17 articles; seven articles were concept analysis papers written by nurses, and two were written by a psychologist and an epidemiologist. Three articles were qualitative research of QOL in patients and caregivers with ESRD, and the remaining five articles were quantitative studies of QOL in children with ESRD conducted by pediatric nephrologists, 3 of them were conducted in Arabic countries (Jordan, Lebanon, and Saudi Arabia).

BACKGROUND

Uses of QOL

The term QOL was first used in sociology in the 1960s after WWII. (Hass, 1999; Meeberg,1993; Moons *et al*., 2006). Lyndon Johnson was the first to use the phrase QOL in 1964. The first study on QOL was in 1957 on mental health in a sample of American adults (Taylor *et al*., 2008). QOL research started in sociology and psychology first; then health care professionals started to assess QOL in patients with chronic conditions (Moons *et al*., 2006). QOL measures started to be increasingly used in healthcare in concordance with the advancement in biomedical

technologies and therapeutic procedures. The concept of QOL has been used in health care to evaluate health care outcomes, services, patient satisfaction, reallocation of resources, policy-making. Moreover, QOL measures have been greatly used to guide treatment decisions for providers, patients, and caregivers (Taylor *et al*., 2008, Moons *et al*., 2006). Studies on QOL in children, on the other hand, did not start until the 1980s (Keenaghan & Kilroe, 2008).

The 1990s was the time of the nurses' greatest contribution to QOL research. The majority of concept analysis papers were published in nursing journals. Despite this great contribution, nurses defined QOL mainly from a social perspective; which did not add to the body of knowledge of the nursing discipline (Plummer & Molzahn, 2009).

Definitions of QOL

There is no consensus among researchers from all disciplines on how QOL is conceptualized, defined, and measured. QOL is defined as a noun meaning "the degree of emotional, intellectual, or cultural satisfaction in a person's everyday life." (The American Heritage Dictionary, 1992). The word quality is of a Latin origin, it comes from the world quails, meaning "of what kind." QOL has been defined also as a degree of excellence, and a character (Webster, 1986).

QOL has been defined differently across disciplines. Philosophers defined QOL based on the nature of human existence and good life. Ethicists defined QOL based on the concept of the sanctity of life. Psychologist defined it in terms of fulfillment of human needs and goals accomplishments. Economists conceptualize QOL in a way that it could inform reallocation of healthcare resources. In sociology, the person was conceptualized within a system where QOL is a result of its subsystems. Clinicians viewed QOL in relation to health and disease and referred it to as HRQOL (Mollaoglu, 2013).

The WHOQOL (1995) group defined QOL as an individual's perception of self within the context of their culture and value system in relation to their goals, expectation, standards, and concerns of daily life. This definition applies to adults as well as children and adolescents with the consideration that children and adolescents value some domains differently based on their developmental age.

In children, QOL is defined as the view of the child and his parents about the impact of disease and treatment, not related to the disease itself (Eiser, 1997). Researchers have defined QOL in children in term of functional abilities or in term of the gap between expectations and experiences. This conceptualization includes the individual child's view about his/her QOL in relation to the impact of their medical condition as well as the view of his/her parents. It is essential to take the parents' view in consideration not only because their opinion is needed for proxy assessment, but also because their perception of life, health, and illness influence the way children construct their own.

Conceptualizations of QOL

QOL is seen as an abstract concept that could include all aspects of life (Moons *et al*., 2006). QOL is conceptualized in terms normal life which is defined as living with maximum functional capabilities to fulfill basic needs (Ferrans, 1999). QOL is also viewed in terms of social utility, where the person can contribute to the society by means of maintaining a career and a role in the family. Satisfaction with life was also a common conceptualization of QOL (Ferrans, 1999; Meeberg, 1993; Campbell, 1981). Satisfaction with life needs the person to evaluate his/her satisfaction in different life aspects such as physical, emotional, vocational, and social. Happiness was identified as a conceptualization of QOL which indicate the emotional aspect of the person's QOL (Ferrans, 1999). The person's perception about QOL in terms of happiness is not static, subjective, and keeps fluctuating based on development and life circumstances.

In nursing theories, Peplau, Rogers, King, and Parse viewed QOL as an abstract, multidimensional, subjective, and dynamic concept. Peplau (1994) added that QOL must be viewed as a product of interpersonal relationships within the person's life. Rogers (1994) used the term life satisfaction to refer to QOL. Based on her theory of unitary human beings, Rogers (1994) viewed QOL as a product of the person's life. King's system theory conceptualized QOL in term of satisfaction with life and goals achievement (Plummer & Molzahn, 2009). Leininger (1978) believed that people from one culture share the same value and beliefs about QOL. Parse (1998) whose work contributed a lot to the conceptualization of QOL in the nursing discipline; viewed QOL to be greatly influenced by culture and determined by goals achievement.

In the Arab world, the few studies that addressed QOL in Arabic speaking countries did not include any definitions or conceptualizations of QOL from an Arabic or an Islamic perspective (Al-Tuwijiri *et al*., 2007). Those studies were mainly quantitative and used QOL measures that have been translated from countries in North America and Europe. However, the underpinning conceptualization of QOL is derived from Western cultures that are certainly different than Arabic/Islamic cultures (Al Sayah *et al*., 2012).

Defining attributes

The defining attributes of QOL are level of satisfaction, individual perception of well-being, and life domains. Quality of life is attributed to the level of satisfaction as evaluated by the person (Oleson, 1990; Meeberg, 1993). Satisfaction is the individual

evaluation of owns life (Moons *et al*., 2006). This attribute indicates that satisfaction has different levels as it is affected by life circumstances, growth, and development. As a result, satisfaction is not static, and people adjust their evaluation regularly. It is also important to consider life circumstances, culture, and values that can influence the subjective level of satisfaction. In children particularly, the level of satisfaction is greatly affected by age, developmental changes, family factors, and peer pressures.

The other defining attribute of QOL is the individual perception of well-being. QOL is predominantly a reflection of how individuals perceive well-being. Individuals perceive well-being across life domains differently. What constitutes as QOL varies based on individual perception. Accordingly, individuals give different weight to different life domains. Some people perceive mental well-being as QOL, others value physical well-being as indication of QOL. Age, gender, culture, and values all contribute to shaping individual perceptions of well-being.

The last defining attribute of QOL is that the concept covers multiple and essential life domains. Such life domains include physical, emotional, social, vocational or academic functioning. Although persons can give different priorities to different life domains, these four domains are the commonly reported QOL domains across all disciplines.

Definition of QOL

Subjective evaluation of satisfaction of well-being across life domains based on individual perception of life in the context of culture, values, and beliefs (WHOQOL, 1995).

Model case

T.H. is a 12-year-old Saudi girl, was diagnosed with ESRD three years ago that required her to be on hemodialysis four days a week. She continued on hemodialysis for one year until she was started on peritoneal dialysis for another two years until her brother donated one of his kidneys to her. T.H. had kidney transplant when she was ten years old and developed diabetes mellitus due to long term use of steroids for immunosuppression. T.H. keeps on getting hospitalized due to recurrent viral infections. T.H. is very active, cheerful, social, and doing good at school. T.H. has a great support system where her mom and dad and all her siblings involved in her care. The school is aware of her condition, and they provide the required accommodation in the school environment as he needed. Her friends in school call her every day when she is absent. She has plans for the future to be a doctor. She is involved in her care, and she keeps track of her medications. She is also participating in educating other patients how to administer insulin. T.H. states that her condition made it hard for her to catch up in school but she thinks that she is not different from her healthy peers.

Contrary Case

N.R. is 7-year-old Saudi boy, lost his mom and dad in a car accident. N.R. was diagnosed with ESRD 2 years ago and was kept on hemodialysis three days per week. N.R. lives with his uncle and his wife. The uncle has his own kids and the family is of a low socioeconomic status. Thus, they asked the hospital to keep N in a long-term care facility. N. also has speech delay and didn't receive any form of education. He also developed bone dystrophy and sometimes he gets too tired to eat or walk. In the unit, he is sometimes active and playful with the staff. He family rarely visits him. And when they take him out on the weekend he comes back tired and hungry. He receives physical therapy three times a week; he goes to the playroom during the days when he is feeling good, and on other days, he is just not in the mood for anything.

Antecedents

As indicated by the attributes, QOL is subjective evaluation shaped by the individual perception of well-being. Thus, having the cognitive capacity and the ability to judge life circumstance to provide an evaluation of satisfaction is considered as an essential antecedent to QOL (Cooley, 1998; Hass, 1999). Persons with cognitive impairment or unconscious are unable to provide a subjective evaluation of satisfaction.

Basic functioning ability is also an antecedent to QOL in which persons have the potentials to grow and experience life (Oleson, 1990). Survival alone is not enough; persons can experience QOL if they can maintain a basic level of functioning that enables them to perform their activities of daily living and to fulfill their basic needs independently.

Life events are also considered as antecedents to QOL as persons can evaluate their life satisfaction based on life events (McDaniel & Bach, 1994). Marriage, loss, employment, graduation, and illness are all kinds of life events that allows persons to experience certain levels of satisfaction QOL. Such life events affect on life domains changing the individuals' perception leading to different evaluation of life satisfaction.

Consequences

Happiness and goals accomplishment results from QOL. Good QOL as indicated by higher rates of satisfaction evaluated by the individual results in a significant sense of happiness (Meemberg, 1993). People with high QOL can cope with life circumstance, adapt to changes, able to produce which contribute to feelings of fulfillment and happiness. It is important to consider that happiness focuses on the emotional aspect of QOL rather than the functional (Moons *et al*., 2006).

Therefore, happiness is defined differently among people.

Children with ESRD in some studies rated their QOL comparably similar to their healthy peers (Hooper *et al*., 2009). In another study, children with ESRD developed effective coping strategies to adapt to their symptoms (Snethen, 2008). Children viewed their condition to be interfering with their academic performance, and they reported that their illness made it harder for them to catch up with their healthy schoolmates (Taylor *et al*., 2008).

Goals achievement is also considered as a consequence of QOL. Having high QOL allows individuals to accomplish their goals. Such goals are also shaped based on culture, peers, values, and experiences. The gap between the expectations and actual accomplishment is an indicator of QOL. The larger is this gap, the negatively impacted is the QO (Moons *et al*., 2006). Also, Children who viewed their quality of life as good were able to focus on achieving their personal goals. Children viewed their condition to be interfering with their academic performance, and they reported that their illness made it harder for them to catch up with their healthy schoolmates (Taylor *et al*., 2008).

Empirical measures

Empirical measures are defined as measures of attributes, events where the concept exist. In the 1970s and contemporary with the positivist approach to science, it was believed that QOL should be measured using objective measures (Shaw, 1977; Hollandsworth, 1988). Then researchers realized that objective measures constitute only 15% of QOL indicators (Hass, 1999). Thus, psychological and subjective indicators were added to QOL (Campbell *et al*., 1976). In the 1980s, gap theories were used to explain QOL by measuring the gap between the individual's actual life with the standard, expected, or desired life. However, gap theories did not use consistent measurement for comparison (Hass, 1999).

Today, there are no standardized measures or approaches to QOL. There are various QOL measurement tools that are to some extents consistent. QOL is commonly measured using two main approaches. One approach is called Generic which asks individuals to subjectively rate their overall satisfaction with life domains such as physical, emotional, social, and vocational. The other approach is called disease-specific which measures individual satisfaction with life domains in relation to a specific disease condition. Some researchers tend to add objective indicators such as income and vocational productivity to supplement the subjective indicators of QOL. QOL is commonly indicated by self-reported ratings of functioning status across multiple life domains such as physical, emotional, social, and vocational (work) or academic.

In children, QOL measures consider developmental changes and cognitive abilities of children. Pediatric QOL scales always consider parent-proxy reports. Parents contribute greatly to their children's evaluation of satisfaction and their individual perception of well-being.

There are many measurement issues involved in using self-reports. Some issues involve using a limited range of Likert scale that doesn't give individuals enough freedom to rate their satisfaction (Gonzales *et al*., 2010). Self- report is also affected by external and emotional factors. Moreover, people might value things differently based on life situations and time. Therefore, it might be ideal to include qualitative questions or widen the range of the Likert scales. Such addition can serve to reflect a more accurate individual reports. They can also offer new insights for future QOL research.

Furthermore, there is no measurement tool that is specifically designed to measure QOL from an Arabic or Muslim perspective (Al Sayah *et al*., 2012). Given the significantly different culture, language, and religion. It might be ideal to develop cultural and language specific QOL tools.

CONCLUSION

QOL is an abstract, multidimensional, and dynamic concept. Therefore, definitions of QOL can vary according to the contexts in which it is being analyzed which makes standardizations of QOL definitions, conceptualizations, as well as its empirical measures challenging. However, this lack of standardization, unfortunately, hindered QOL research. QOL research, particularly in patients with chronic conditions, can yield tremendous insights to patients, providers, and policy makers. Studies have shown that QOL is a strong indicator of general health outcome and mortality among those with chronic health conditions. Therefore, all attempts must be maid to find standardized QOL definitions and measures that reflect the complex nature of QOL. Addressing QOL using an integrated approach that includes subjective as well as objective indicators might be ideal.

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