

Moving toward a time-based and balanced quality of life

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Abstract

Current complex life conditions and changing developmental contexts draw attention to the concept of *capabilities*, the various combinations of functions a person can do or can be, and the opportunities to achieve them. A future-oriented time perspective is a dimension along which individuals express meaning-making of experiences and expectations regarding their lives, a benchmark for the well-being and satisfaction of the quality of life they experience. Findings from research studies involving adults with disabilities and family members of persons with a disability provide evidence for a time-based model, an approach tapping into both the concept and measurement of quality of life and balancing both current and expected quality of life.

KEYWORDS

capability approach, future time perspective, intellectual disability, quality of life

THE BACKGROUND

The scholarly literature on the conceptualization and measurement of quality of life has consistently highlighted its basic conceptual principles that emphasize its multidimensional nature, the attention to etic (universal) and emic (culture-bound) properties, objective and subjective components, a systemic perspective, and its dynamic nature over time (Samuel et al., 2012; Van Hecke et al., 2018). The quality of life of an individual and his/her family is, in fact, linked to possibilities and supports to reach goals, in major life areas such as education and employment.

Well-being experienced and life satisfaction for goals reached are commonly considered as measures of quality of life and, when specifically addressed, they are a means to assess the relative importance of individual quality of

life domains and indicators. The factors referred to as general and domain-specific perceptions, behaviors, or conditions that reflect a person's well-being can then be usefully analyzed and applied (Mailick Seltzer et al., 2004).

The complex ongoing circumstances that are taken into account by the Capability Approach (Sen, 2005) serve as a good guide and an applied perspective for an updated perspective on quality of life. Most important here is its attention to the possibilities of choice (Trani et al., 2011) and a vision of disability as occurring when an individual is deprived of practical opportunities as a result of an impairment (Mitra, 2006). This shifts the focus from the specifics of the disabling condition to providing possibilities and choices, as well as individual and collective agency and empowerment. This approach is in fact aimed at ensuring a space for an analysis in terms of (a) *capability for the voice* of the vulnerable individuals; (b) *conversion factors*, which are the real access to support measures; and (c) the *capability to exit* unsafe conditions

Abbreviations: CaAp, capability approach; FTP, future time perspective; ID, intellectual disability; QoL, quality of life

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a person currently experiences. These three factors contribute to providing real options that can open up individual opportunities and expand their well-being and quality of life.

A FUTURE-ORIENTED PERSPECTIVE FOR AN OPPORTUNITIES-BASED MODEL OF QUALITY OF LIFE

Quality of life is considered the result of the capabilities a person or a family influences on current life, and the options available to them and from which they currently have, or have had, opportunities to choose (Nussbaum & Sen, 1993). Time is then a dimension along which individuals express meaning-making of experiences or expectations in their lives. However, the focus is often on determinants of past and current life to identify and address challenges they meet. But complex life conditions and changing developmental contexts increasingly require considering both the present and future to support a temporal identity integration, and project experiences of well-being and satisfaction for the quality of life in the future.

Being future-oriented is also associated with a range of important outcomes across a variety of life domains, such as engagement in health behaviors and more effective planning for achieving goals (Drake et al., 2008). Limited future orientation, on the other hand, may lead to a lack of hope for a personal future (Stoddard et al., 2011), a perception of actual behaviors as disconnected from personal goals, and limited commitment. Additionally, the attainment of future goals is conceived as a benchmark for the experience of well-being and satisfaction with life (Emmons, 2003).

A quality of life paradigm should then include a future time perspective and the goals that persons with intellectual disabilities foresee in their futures. The following section provides further evidence to support this perspective.

REPRESENTATION AND ATTITUDES TOWARD FUTURE AND QUALITY OF LIFE

The voice of adults with intellectual disability

Analyzing a future-oriented time perspective means describing future goals, their breadth, and their content as well as investigating attitudes toward the future. The

experience of living with disabilities may result in struggle for individuals and make them foresee and experience a negative future trajectory in various life domains (Wood et al., 2018).

For example, an analysis of narratives on future goals by adults with Down syndrome who have mild to moderate intellectual disability frequently showed a limited number of self-determined future goals in diverse life domains, such as family, work, and social life. This is, however, not the case for affective goals that were very similar to those produced by their peers (Sgaramella, 2011). Regarding attitudes toward the future, it is worth mentioning a recent study involving 37 adults, 27 men and 10 women, aged between 27 and 52 (mean age 45.4 years) with mild to moderate intellectual disabilities of diverse origins (Sgaramella & Indrio, 2018). Participants were interviewed on their future goals in diverse life domains: health, family, friends, free time, personal growth, and work-related goals. After listing the goals, they were asked to choose across the diverse domains, the three most important goals for them, and their priorities. Besides confirming previous research that found a more limited number and diversity of goals in this population, the study provided evidence for the relevance of the attitudes toward the future. Participants who listed and described a higher number of goals also showed a more positive attitude toward the future as evidenced by higher commitment and confidence in their ability to pursue at least some future goals. Additionally, using a multimodal version of the *Satisfaction with Life Scale* (Diener et al., 1985) significant positive relationships emerged between attitudes toward future goals and life satisfaction reported. Considered from a person-centered perspective, about half of the participants who showed a limited number of self-determined future goals also reported limited global life satisfaction, thus suggesting a vulnerability in their quality of life.

The voice of family members

Recent studies give more attention to the quality of life of all members of a family with a person experiencing an intellectual disability. In one study, Marzocco (2020) provided some core elements in quality of life experienced by family members that are relevant to our analysis. Seventy-six fathers aged between 30 and 62 years (mean age 42.5, standard deviation 6.7 years) participated. Half of the parents had a son diagnosed with autism spectrum disorder, whereas the other half had a child with typical development. The researchers collected narratives about future goals as well as the degree of resilience and future

time orientation they experienced. They also analyzed psychological well-being according to a eudaimonic model along the six dimensions addressed by the Italian version of the Ryff scale (Zani & Cicognani, 1999), namely Autonomy, Environmental mastery, Personal Growth, Positive relations with others, Purpose in Life, and Self-acceptance. These dimensions are also at the core of the attention in current models of quality of life (Schalock et al., 2016).

The main findings of the study for our analysis are the following:

- a. *Taking care of a family member with a disability impacts the representation of the future.* Health and family are by far the strongest priorities—sometimes the only goals families are concerned with—and future goals related to work and free time are often in the background.
- b. *Well-being and future orientation show patterns of vulnerability.* A higher proportion of fathers reported limited well-being (23% vs. 5% of age-matched fathers) and more limited future orientation (23% vs. 3%), thus suggesting a more frequent experience that makes their well-being more vulnerable to discomfort.
- c. *A relationship between future orientation and well-being experienced by adults being fathers of persons with intellectual disabilities.* Regression analyses highlighted significant predictive relationships between dimensions of well-being and future orientation, namely, that fathers of individuals with intellectual disabilities reporting higher levels of positive future orientation also experienced higher levels of well-being.

THE CONTRIBUTION TO THE DEVELOPMENT OF AN UPDATED FRAMEWORK

This paper underlines the need to develop a “time-based, dynamic, and balanced model of quality of life,” which at the level of conceptualization and measurement considers dimensions and determinants of *current and expected future quality of life*, processes (*attitudes and resources*), and outcomes (*goals*) in a future-oriented perspective.

Time perspective, and future orientation, in particular, can act as guiding principles in developing new intervention strategies for families with a member with ID. Services and professionals should aim at promoting the awareness and reflexivity of their clients by giving voice to them and their families, increasing their ability to think about themselves in relation to the present and the future, identifying, setting, and implementing

personal future goals, and thus increasing the experience of well-being and quality of life.

A quality of life model embedding a balanced time perspective that is built on the capability approach principle of *giving voice and providing future opportunities* may provide a strong potential for identifying risk and protective factors for individuals and families. It also opens to the impact of *conversion factors* and *capability to exit* current challenging conditions (Sen, 2005), thus promoting active and satisfying participation.

A model of quality of life at the level of concept and measures should consider:

- *Both resources and determinants of current and expected quality of life.*
- Processes (*attitudes and resources*) and outcomes (*future goals*) in a future-oriented perspective.

Actions promoted in light of a time-based and balanced quality of life should then aim at:

- Giving voice to people and enhancing their subjective experience of resources.
- Promoting the ability to think about themselves in relation to the present and the future.
- Support the implementation of their personal future goals.

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CONFLICT OF INTEREST STATEMENT

The author declares no conflicts of interest.

ETHICS STATEMENT

The paper described results of studies conducted by the author and the research team. They took the appropriate steps with regard to access, informed consent, confidentiality and anonymity in publishing the research results mentioned in this paper.

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