

A black silhouette of a person in a dynamic, almost dancing pose, set against a solid red background. The person's arms are extended outwards, and their body is slightly arched, suggesting movement and balance.

Relating Quality of Life measurement to the lived experience of persons with PWS and their families

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President WPA-WG ASD - World Psychiatric Association - Working Group on Autism Spectrum Disorder

President SIDiN - Italian Society for Neurodevelopmental Disorders

President AISQuV - Italian Association for the Study of Quality of Life



MEANING OF CARE

Normalisation

restore structural and functional entirety

VS

Quality of Life

help to be satisfied with one's own life

QoL: PRINCIPLES AND IMPLICATIONS

A dark blue background with a white silhouette of a person in a dynamic, almost dancing pose. The person's arms are extended outwards and upwards, and their legs are in a wide, balanced stance. The silhouette is centered and occupies most of the frame.

- human entitlement to a life of quality
- Universality of human characteristics
- Uniqueness of human needs, behaviours and performances (choice)
- Human attitude to self-fulfilment (self perception, self image)
- Holism in human life
- Dynamic nature of human life (growth, improvement, life-span)

HEALTH AS A WAY OF BEING

HEALTH

capacity to live in a mindful and free way, increasing the value of all one's own energies

DISEASE

incapacity to live in a mindful and free way, and to increase the value of one's own skills and energies

It is not a given status but a conquest; it is not a definitive achievement but a pursue, a task, a life-style, enriched by that ethical dimension which encompasses all other human dimensions (physical, psychic, and ecological)

QoL: A POLYSEMIC CONCEPT

Mass-Media meaning

a universal ideal of high quality of most material and most marketable areas of life (i.e. objects owned, success in career, money to spend, social environment, holidays and free-time, physical performances)_

objective

a person's life conditions as they appear to an external observer. Hetero-evaluation.

Medical meaning

the patient's perception of his own health status
(aspects of life related to wellbeing and fonctionement)

subjective

the individual perception of satisfaction with the 'being in the world'. It can be evaluated only trough the person's opinion. Auto-evaluation.



Reframing QoL assessment in persons with neurodevelopmental disorders

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Abstract

The paper reviews the international literature on quality of life (QoL) for persons with neurodevelopmental disorders (NDD) in order to define the theoretical frame for optimal assessment. The application of the QoL approach to assessment procedures should be based on three main aspects: shared QoL, personal QoL and family QoL. The first aspect refers to characteristics of individual life that are shared with other people. The second aspect proceeds from the fact that each individual has a changing set of personal attributes that determine the subjective experience of life. In the third aspect the previous two are applied to the family that includes a person with NDD. Disability impacts the whole family and the determination of appropriate conceptualization of family outcomes requires an understanding of the impact of members with a disability on family QoL. At any level, it seems best to take a comprehensive approach to assessing QoL, integrating subjective and objective aspects, self-reports and hetero-evaluations. The QoL approach is above all a way to explore the rich intricacies of personal quality of life. Such assessment may be used effectively with people with NDD, independently from the severity of their functioning impairment. Individuals with profound ID may express their inner states through consistent behavioural repertoires, which can be discerned by persons closest to them and validated by more independent others. Attention must be paid in using non-generic instruments, such as those that measure health-related QoL. Although they do focus on the individual person, they still support a theoretical perspective of QoL that has not departed significantly from the traditional medical approach. Currently available generic tools, although they have some common conceptual and evaluation characteristics, still show considerable differences in the areas to be included in "shared QoL", the dimensions used to evaluate "Individual QoL", and the role attributed to indicators of QoL. QoL assessment should not represent a classification of individuals, services or systems, but it should help provide, within service systems and organizations, a value system that is consistent with those values held by people with NDD.

Key words

- quality of life
- intellectual disability
- autism-spectrum
- assessment
- measurement

- Shared QoL
- Personal QoL
- Family QoL

SHARED Quality of Life

- Characteristics of human life and humans' environments that are common to, or shared with, other people.
- Shared QoL is relatively easy to assess, even in persons with severe ID/LF-ASD, although no consensus has been reached yet within the scientific community on exactly what aspects should be assessed.
- This assessment is appropriate for groups of people, for services and supports that address the needs of large numbers of individuals, and for making policies that affect populations.

PERSONAL Quality of Life

- For individuals, shared characteristics take on increased or decreased personal value in response to personal genetic makeup, individual personality, or personal environmental conditions.
- All individuals have unique characteristics and interests that are sometimes very meaningful in their lives, and thus add to their life quality, but mean little or nothing to another person.
- QoL is a personal concept in that it is, to a high degree, based on a set of personal perceptions, attitudes, values, and skills, and on the physical and social environment.
- These factors determine not only how a person's life is experienced, but also how it is interpreted.

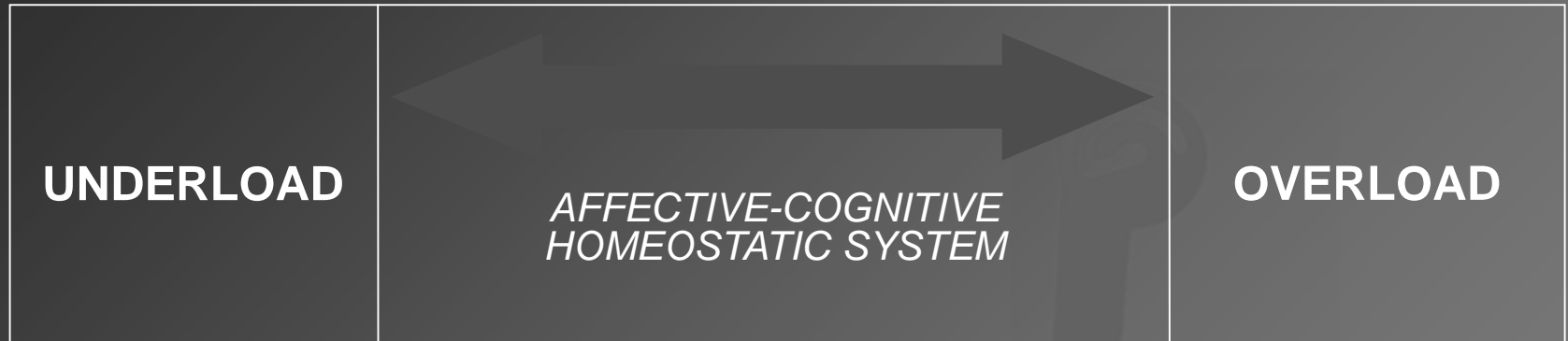
FAMILY Quality of Life

- Disability impacts the whole family and the determination of appropriate conceptualization of family outcomes requires an understanding of the impact of members with a disability on family QoL.
- This involves three main issues that research has explored in recent years:
 - stress and caregiving burden
 - impact on family functioning
 - eco-cultural adaptation.

QoL vs SUBJECTIVE WELL-BEING

- Subjective well-being concerns itself primarily with affective states, positive or negative¹
- QOL implies a broader assessment and although affect-laden, it represents a subjective evaluation of oneself and one's social and material world¹.
The exploration refers to those areas and dimensions of life that are applicable to anybody's life²

THE BALANCE OF SWB



Variables indicator of Subjective Well-Being should be considered as the least sensitive subjective measures

GENERIC QOL VS HR QOL

Generic (Whole-person): subjective modulation in those areas of life that are applicable to anybody's life

Health-Related: mixture of clinical or dysfunctioning aspects, compared to normality

EXAMPLES OF ITEM INCLUDED in HR-QoL TOOLS

CCD HRQOL-14¹

Number of days in which you felt sad or depressed ____

Number of days in which you felt worry or anxious ____

Functional Assessment of Cancer Therapy (FACT-G – 27 item)²

Physical Well-Being:

I feel lack of energy

I have nausea

I feel pain

I feel sick

I'm obliged to spend my time in bed

AIDS QoL Assessment Questionnaire – AIDS-HAQ³

Area *Item Description*

Disabilities 23/116 Measures of the level to which health status impact on 9 activities of basic autonomy (i.e. to stand up, to eat, to handle)

Symptoms 68/116 presence/absence during last week

WHO CROSS-CULTURAL CORE DOMAINS FOR QUALITY OF LIFE

1. physical (e.g. energy, fatigue)
2. psychological (e.g. positive feelings)
3. level of independence (e.g. mobility)
4. social relationships (e.g. practical social support)
5. environment (e.g. Accessibility of health care)
6. personal beliefs/spirituality (e.g. meaning in life)

The domains of *health* and quality of life are complementary and overlapping

THE RIGHTS MODEL FOR QoL (UN)

Domain	Details
Life	Not dying prematurely or before one's life is so reduced as to be not worth living
Health and Wellbeing	When we talk about health we mean complete physical, mental and social well-being - not just the absence of disease or illness
Bodily Integrity	Being in charge and control of your own body. Being safe from harm and abuse. For people with physical disabilities, having the necessary supports, adaptations, equipment to be able to participate in an active personal and social life.
Individual, family and social life	This domain concerns people's relationships with family, friends, intimate partners and professionals.
Legal security	How is the individual supported in a way that ensures that their human rights are promoted and protected?
Adequate standard of living	Does the person enjoy a standard of living that people would recognise as being appropriate to their choice, wishes, preferences and social cultural background?
Participation, influence and voice	Being able to participate in the choices that govern one's life Does the person have a sense of community and with whom?
Identity, self-expression and self-respect	"Who am I as a person, my culture and what I believe"
Education and learning	Is the person supported to engage in life-long learning activities?
Productive and valued activities	What does the person do throughout the day on a regular basis that are consistent with their interests, preferences and needs?

THE QOL-Q DOMAINS

QoL Factor	QoL Domain ²	QoL indicators
Independence	Personal Development	personal Skills (e.g. adaptive behaviour)
	Self-Determination	choices/decisions autonomy/control
Social Participation	Interpersonal Relations	social networks friendships social activities
	Social Inclusion	involvement in community community role
	Rights	equal opportunities legal access
Well-Being	Emotional Well-Being	safety and security protection from abuse positive experiences
	Physical Well-Being	health status nutritional status physical exertion
	Material Well-Being	income possessions

THE 9 AREAS OF LIFE OF THE QOL-IP

BEING (who the patient is as a person)

- PHYSICAL BEING
- PSYCHOLOGICAL BEING
- SPIRITUAL BEING

BELONGING (relates to connections with one's environments)

- PHYSICAL BELONGING
- SOCIAL BELONGING
- COMMUNITY BELONGING

BECOMING (relates to achieving personal goals, hopes and aspirations)

- PRACTICAL BECOMING
- LEISURE BECOMING
- GROWTH BECOMING

QoL: DIMENSIONS AND INDICATORS

- Importance
- Satisfaction
- Opportunities
- Choises

indicators

Person with NDD

proxies

external assessors

QoL: ARTICULATION OF THE ASSESSMENT

- Direct interview *person herself*
- Proxy Questionnaire *other person*
- External Assessor Questionnaire *other person*

COMPREHENSIVE QoL MODEL FOR PwPWS

- Integrating qualitative and quantitative aspects
- Integrating subjective and objective positions
- Including areas of life with proved transcultural value
- Including dimensions, to assess individual grading of quality
- Including indicators to support self and proxy quantitative grading (score attribution)

FAMILY QOL: DOMAINS

SIQF

STRUMENTO DI INDAGINE DELLA
QUALITÀ DI VITA DELLA FAMIGLIA

Per i fornitori di assistenza e cura più vicini alla persona con disabilità intellettiva
Firenze - 2006

'Family Quality of Life Survey' di
Ivan Brown
Roy I. Brown
Nehama T. Baum
Barry J. Isaacs
Ted Myerscough
Shimshon Neikrug
Dana Roth
Jo Shearer
and Mian Wang

Adattamento italiano a cura di

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1. FAMILY HEALTH
2. FINANCIAL WELLBEING
3. FAMILY RELATIONSHIPS
4. SUPPORT FROM OTHER PEOPLE
5. SUPPORT FROM D-R SERVICES
6. INFLUENCE OF VALUES
7. CAREERS AND PREPARING FOR CAREERS
8. LEISURE AND RECREATION
9. COMMUNITY INTERACTION
10. OVERALL FAMILY QoL

FAMILY QOL: DIMENSIONS

- Importance
- Satisfaction
- Attainment
- Initiative
- Stability
- Opportunity



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