# Quality of Life of Children with Mental Illness

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- History of Conceptual Development of QOL
- Why important?

Resources and Measurement Tools

## History Concept QOL

#### quality of care

#### - first recorded external audit of

Aristotle (384-322 BC)- wrote of "the good life" and and can help foster it.

1980s -present Health-related quality of life (HRQOL) has evolved to include aspects of overall quality of life that can be clearly —either physical or mental.

#### Definition Quality of life (QOL)

that requires multiple approaches from different theoretical angles<sup>3</sup> **Broad multidimensional concept** including **subjective** evaluations of both **positive** and **negative** aspects of life<sup>2</sup>

Composite of physical, social and emotional facets of the well-being that the individual deems as significant and relevant<sup>1</sup>.

Reflects a number of **subjective physical, social, and psychological** aspects of health and is **distinct** from **symptoms of the disorder** and

# Definitions QOL

- Include both objective and subjective perspectives
- Three Dimensions- physical, psychological, social Social further divided into public and private domains
- QOL describes individual's of their situation in life as evidenced by their physical, psychological, and social functioning <sup>9</sup>

## Definition Health Related Quality of Life

- Not uniformly defined
- Subset of QOL, specific to person's health <sup>10</sup> influenced by health interventions <sup>1</sup>
- HRQOL closely depends on the subjectively perceived impact of the disorder (and of the respective treatment) on the level of physical, psychological and social functioning

## Why Important?

Prevalence of Child and Adolescent Mental Disorders (Nami)

- Four million children & adolescents suffer from a serious mental disorder resulting in significant functional impairments at home, at school and with peers.
- Of children ages 9 to 17, 21 percent have a diagnosable mental or addictive disorder that causes at least minimal impairment.<sup>1</sup>
- Half of all lifetime cases of mental disorders begin by age 14.
- Long delays, sometimes decades, between the first onset of symptoms and when people seek and receive treatment, despite available effective treatments.
- An untreated mental disorder can lead to a more severe, more difficult to treat illness and to the development of co-occurring mental illnesses.<sup>3</sup>
- In any given year, only 20 percent of children with mental disorders are identified and receive mental health services.<sup>4</sup>

Why Important? How does HRQoL Help Children & Adolescents with Mental Illness?

 Clinically reveals where person is most affected to help clinician make best choices to care for patient<sup>4</sup>

*in quality of life* over *course* of treatment

of how a patient's quality of life, helping to improve practitioner-patient relationship

and patient perception

• Research by assessing how disease impairs the patients' subjective well being

and different benefits of different treatments

and monitoring of policy changes

• Increasingly important measure of outcome in child and adolescent mental health research and clinical practice Why Important? How does HRQoL Help Children & Adolescents with Mental Illness?

- HRQOL is an important component of health surveillance and generally considered valid indicators of and intervention outcomes.
- Self-assessed health status proved to be more powerful predictor of mortality and morbidity than many objective measures of health.9-10
- HRQOL measures make it possible to scientifically demonstrate impact of health on quality of life, going well beyond the old paradigm that was limited to what can be seen under a microscope.

#### HRQOL Tools for Children and Adolescents

- Child Health Questionnaire (CHQ)
- Pediatric Quality of Life Inventory (PedsQL 4.0) proven success in measuring the QOL across different diseases in children and is well validated in different languages.
- Child Health and Illness Profile
- KIDSCREEN-27
- International Classification of Functioning, Disease and Health by WHO assess degree of disability caused by disease or disorder
- International Classification of Functioning, Disease, and Health <sup>6</sup>

#### Research Health Related Quality of Llfe

- HRQOL research in children with mental illness is in early stages and limited
- Limitations of current studies:
  - No identification if children on meds or not
  - No self measures, only parental input
  - Overlap of certain questions
  - Diagnoses are not verified

physical activities

- Bastiaansen, Koot, Bongers, Varni & Verhulst (2004) used the *PedsQL 4.0<sup>™</sup> parent and child forms* for ages 5-7, 8-12 and 13-18, in children referred for *psychiatric problems* to assess its effectiveness in assessing the QOL of this population.
- Children *referred for psychiatric problems* had *significantly lower mean PedsQL 4.0<sup>TM</sup>* than children not referred for psychiatric problems.
- They also had scores *similar to children with cancer or rheumatic diseases.*

#### • Dey, Landolt, & Meichun (2012)

- Systematically reviewed studies about the quality of life (QOL) of children with various mental disorders vs healthy controls described limitations in these studies.
- QOL of children with various mental disorders is compromised across multiple domains.
- The largest effect sizes were found for psychosocial and family-related domains and for the total QOL score, whereas physical domains generally were less affected.

#### **Limitations** in the existing literature

- lack of study samples drawn from the general population,
- the failure to use self-ratings
- not determining whether the children were receiving medication for their mental disorder

- Dey, Landolt, & Meichun (2012) results
- ADHD, Conduct Disorders- reduced HRQOL psychosocial and familyrelated subscales whereas no reduction in physical subscales
- Autism -parent rated social subscale most compromised and physical health least compromised while children perceived their physical health the most compromised and school least affected
- Schizophrenia/schizoaffective disorder-largest ES for psychosocial and family related subscales

**Mood diso**rders-bipolar disorders reduced overall HRQOL and psychosocial, family related and physical



Weitkamp, Daniels, Romer & Wiegand-Grefe (2013)

### Resources

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