Objectives

• History of Conceptual Development of QOL

• Why important?

• Resources and Measurement Tools
History Concept QOL

- first recorded external audit of

Aristotle (384-322 BC)- wrote of “the good life” 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.
Quality of life (QOL) is a broad multidimensional concept that requires multiple approaches from different theoretical angles. It includes subjective evaluations of both positive and negative aspects of life. Composite of physical, social and emotional facets of the well-being that the individual deems as significant and relevant. Reflects a number of subjective physical, social, and psychological aspects of health and is distinct from symptoms of the disorder.
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 **situation in life** as evidenced by their **physical, psychological, and social functioning**
• Not uniformly defined

• Subset of QOL, specific to person’s health\textsuperscript{10} influenced by health interventions\textsuperscript{1}

• 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.¹

• 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.³

• In any given year, only 20 percent of children with mental disorders are identified and receive mental health services.⁴
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. Clinically reveals areas of illness where person is most affected to help clinician make best choices to care for patient.

• Measures change in quality of life over course of treatment of how a patient’s quality of life, helping to improve practitioner-patient relationship.

• 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 **service needs 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*  

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Health Related Quality of Life

• 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
Research

Sawyer et al. (2002) used the CHQ-Parent Form 50 to assess the HRQOL of children and adolescents (6-17 years) with ADHD, major depressive disorder or conduct disorder versus children with a physical disorder or no disorder.

- Children with psychiatric disorders had consistently worse HRQL compared to children with no disorder.
- Specifically on scales of Mental Health, Physical Health, General Health Perceptions and the Pain and Discomfort.
- And had significantly worse HRQL on all scales except Physical Health and perceived interference with physical activities.
Research

• Bastiaansen, Koot, Bongers, Varni & Verhulst (2004) used the PedsQL 4.0™ 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™ than children not referred for psychiatric problems.

• They also had scores similar to children with cancer or rheumatic diseases.
Research

- **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
Research

- Dey, Landolt, & Meichun (2012) results
  - ADHD, Conduct Disorders - reduced HRQOL psychosocial and family-related 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 disorders - bipolar disorders reduced overall HRQOL and psychosocial, family related and physical
Weitkamp, Daniels, Romer & Wiegand-Grefe (2013) • used the KIDSCREEN-27 to measure the association of HRQOL to internalizing and externalizing symptoms and determine what extent child and environmental characteristics relate to poor HRQOL. Data for 120 participants ages 6 to 18 initiating outpatient psychotherapy treatment. Children 11 yrs and older and parents filled out questionnaire. • Lower HRQOL associated with internalizing more than externalizing symptoms in self and parent report in psychological well-being, social support and peers and well being with school environment with moderate to large effect sizes.
Resources


• [http://www.nami.org/Template.cfm?Section=federal_and_state_policy_legislation&template=/ContentManagement/ContentDisplay.cfm&ContentID=43804](http://www.nami.org/Template.cfm?Section=federal_and_state_policy_legislation&template=/ContentManagement/ContentDisplay.cfm&ContentID=43804)