



Quality of Life in Children with Chronic Illness



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Objectives

To review the Quality of Life survey as a research tool

To describe assessment of quality of life in pts with chronic illness

To discuss utility of assessing QOL in chronic illness

To explore the different aspects of quality of life in patients with chronic illness, cystinosis as an example

Importance of a Quality of Life

- **Within the last decade:**
 - **Significant importance of QOL in different aspects of life has been recognized:**
 - **Social, professional and health related**
 - **Dramatic increase in the development & utilization of health-related quality of life (HRQOL) measures**
 - **To improve patient health**
 - **To determine the value of healthcare services**
- **Medline search: 34,722 publications on QOL**
 - **QOL and chronic illness – 1,696 publications**
 - **QOL and chronic illness and children – 187 publications**

Definition of a Quality of Life

- The term quality of life (QOL) refers to the perceived quality of an individual's daily life
 - In general terms: “well-being”
- This includes all aspects of the individual's life:
 - Emotional
 - Social
 - Physical

Quality of Life Definition

- **WHOQOL** (*World Health Organization Quality Of Life group*) defined QOL as the person's **perception** of:
 - Position in life (culture or value systems)
 - Physical health
 - Level of independence
 - Psychological state
 - Social relations & personal beliefs
- QOL refers to a person's **subjective judgment** of overall state within the cultural, environmental & social context
 - Most individuals share common values in relation to QOL
 - Priorities vary by socio-demographic & personal characteristics

Petersson et al. Health and Quality of Life Outcomes 2013, 11:75

Quality of Life and Chronic Conditions

- **Medical care advancements for children with chronic illness resulted in improved long-term survival, consequently patients are living with the burden of chronic illness into adult age**
- **Young people with chronic conditions face social, psychological as well as physical challenges, trying to live a normal life like their friends**

Petersson et al. Health and Quality of Life Outcomes 2013, 11:75

Quality of Life and Chronic Conditions

- **Life-long chronic therapy can be complex and may negatively impact the child's well-being**
 - **Imposes restrictions on daily life**
 - **Can significantly influence the child's development and the quality of life**
- **Children with chronic illness report lower**
 - **Physical functioning, emotional, social and school performance in comparison to healthy children**

Petersson et al. Health and Quality of Life Outcomes 2013, 11:75

Quality of Life and Chronic Conditions

- **The challenge for health care providers is to:**
 - **Identify pediatric patients with chronic health conditions at risk for poor QOL**
 - **Enroll in the high quality comprehensive healthcare services in order to mitigate the potential long-term negative consequences on patient HRQOL**
- **In clinical practice, patient-reported HRQOL should be a component of high quality comprehensive care**

Petersson et al. Health and Quality of Life Outcomes 2013, 11:75

Methods of QOL Measurement



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Health Related Quality of Life (HRQOL)

- HRQOL is a multidimensional concept that measures the subjective perception of:
 - Physical, emotional, mental and social functioning
- It focuses on the impact of health status on quality of life

Petersson et al. Health and Quality of Life Outcomes 2013, 11:75

HRQOL Instruments

- **HRQOL instruments must address the following criteria:**
 - **Brief and maintain reliability and validity**
 - **Well designed**
 - For ease of use by patients/parents
 - For quick, easy scoring and interpretation
 - **Responsive to meaningful patient change**

Varma et al. Health and Quality of Life Outcomes 2005, 3:34

Generic HRQOL Measures

- **Generic HRQOL measurement instrument**
 - Allows for screening in healthy populations
 - Enables standardized comparisons across pediatric chronic health conditions
 - Facilitates benchmarking with healthy populations
- **Generic HRQOL does not:**
 - Measure specific disease symptoms and treatment side effects of relevance to particular disease groups
 - May not be as responsive to changes in disease specific symptom as disease-specific measures

Varma et al. Health and Quality of Life Outcomes 2005, 3:34

Disease-Specific HRQOL Measures

- Disease-specific measures (e.g. ESRD, transplant) are:
 - More sensitive to specific clinical changes in patients with a particular illness than a generic measure
 - Particularly informative for pediatric chronic disease management at the individual patient level
- Disease-specific instruments **are unable to:**
 - Provide comparisons across diseases, including benchmarking with healthy population norm

Varma et al. Health and Quality of Life Outcomes 2005, 3:34

Child Self-Report versus Parent Proxy-report in Pediatric Practice

- A self-report is considered the standard for measuring perceived HRQOL
 - Children <5y of age are regarded as unreliable, therefore current surveys are directed to children > 5 y of age
 - Children and parents do not necessarily share similar views about the impact of illness thus there are surveys designed to compare parents view vs. children's view on QOL
- In the circumstances when the child is too young, or too ill or fatigued – a parent proxy-report is needed
- Typically parents' perceptions of their children's HRQOL mostly influences healthcare utilization

Varma et al. Health and Quality of Life Outcomes 2005, 3:34

Utility Value of HRQOL

- Utilizing HRQOL measurement in pediatric healthcare settings can
 - Facilitate patient-physician communication
 - Improve patient/parent satisfaction
 - Identify hidden morbidities
 - Assist in clinical decision-making
- HRQOL measurement is an important in
 - Clinical practice
 - Improvement strategies
 - Treatment decisions
 - Healthcare services research and evaluation

Petersson et al. Health and Quality of Life Outcomes 2013, 11:75

Importance of QOL Assessment

- **HRQOL measure is important in:**
 - **Planning treatment & interventions for chronic conditions**
 - **It enables to focus on psychological domains**
- **Patients perceive the instruments to be helpful in communicating their healthcare needs to the physicians**
- **HRQOL instruments are considered to be a patient reported outcome measure (PROM) and should be used in routine practice**

Petersson et al. Health and Quality of Life Outcomes 2013, 11:75

Significance of HRQOL Measurement in Clinical Practice

- **Facilitation of patient-physician communication**
 - Pts are willing to discuss HRQOL, but MD's are not likely to ask
- **Improvement in patient satisfaction**
 - Related to physician discussion of psychosocial topics
- **Identification of hidden morbidities in pediatric clinical care**
 - MD's underestimate psychosocial and functional disabilities in pts
- **Impact on clinical decision-making**
 - ~52% MD's make decisions (*e.g., medication changes, lab tests*) on the basis of pt-reported HRQOL
- **Improvement in patient outcomes over time**

Health & QOL Outcomes 2005, 3:34

Barriers to HRQOL Measurement in Clinical Practice

- **Concerns about resources**
 - Lack of time & resources needed to collect & interpret HRQOL data
 - Lack of support for storing and retrieving data in clinical practice
- **Attitudinal barriers**
 - Lack of understanding of the value of HRQOL

Varma et al. Health and Quality of Life Outcomes 2005, 3:34

The Future Implications of QOL in Pediatric Practice

Driving forces for incorporating HRQOL measurement in pediatric clinical practice:

1.
Demonstration of utility of pediatric HRQOL measurement
(identification of children with the greatest needs)

2.
Demonstration of the healthcare cost saving
(provision of timely, targeted interventions to address the hidden morbidities)

Paterson et al. Health and QOL Outcomes 2013, 11:75

Aspects of Quality of Life



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Discussion of

- Sleep disorders
- Anxiety and depression
- Pediatric Medical Traumatic Stress
- QOL of parents and siblings
- QOL in Palliative Care

Pediatr Nephrol (2012) 27:451–459

Sleep Disorder in CKD

- **Common in CKD pts**
 - **Adults:**
 - 50–80% dialysis
 - 30–50% renal Tx
 - **Children: 58.5%**
- **Specific signs and symptoms of:**
 - Sleep-disordered breathing & obstructive sleep apnea
 - Restless legs syndrome &/or periodic limb movements
 - Insufficient sleep
 - Excessive daytime sleepiness

Pediatr Nephrol (2012) 27:451–459

Depression and Anxiety

- Depression and anxiety are the **most common co-morbidities** in pts with ESRD
- Patients with ESRD face many challenges which increase the likelihood that they will develop depression or anxiety:
 - Disruptions in lifestyle
 - Need to comply with treatment regimens:
 - Dialysis schedules
 - Dietary restrictions
 - Hospitalizations
 - Fear of disability, morbidity and shortened lifespan

IJKD 2010;4:173-80

Anxiety in Chronic Illness

- **Anxiety is a normal reaction to life stressors**
 - Anxiety can be problematic when its intensity and duration begin to impact one's functioning and QOL
- **Anxiety disorders may develop**
 - As a response to being ill or in the hospital
 - As a result of other genetic and psychological factors
- **Prevalence rate of anxiety disorders:**
 - Children with chronic illnesses 7-40%, vs. healthy peers 2-7%
 - ESRD pts 12% to 52%

Depress Anxiety. 2011 January ; 28(1): 40–49

Anxiety in Chronic Illness

- **Psychological symptoms of anxiety include:**
 - Feeling tense, worried, fearful, crying spells with no reason
- **Physical symptoms can include:**
 - Tachycardia, tachypnea, nausea, insomnia, anorexia, diaphoresis, tremor
- **Moderate to severe anxiety may affect**
 - Treatment adherence
 - Medical outcome
 - Ability of the child/adolescent to cope with illness
- **Proper identification and treatment of anxiety disorders can decrease psychiatric and physical symptoms**

Depress Anxiety. 2011 January ; 28(1): 40–49

Depression in ESRD

- Prevalence rate for major depressive disorders in the general population in the United States is:
 - 10.4% in Caucasians
 - 7.5% in African-Americans
 - 8.0% in Mexican Americans
- The prevalence rate for depression in pts with ESRD is ~ 3 times that of the general population
- Depression is an independent factor for **nonadherence** in patients on maintenance dialysis

IJKD 2010;4:173-80

Pain and Anxiety

- **Memories of painful procedures can cause**
 - Anticipatory fear and anxiety before subsequent procedures
 - Development of anxiety disorders, e.g.:
 - Fear of blood or needle phobia, making it difficult to get through the necessary medical procedure
- **Prevention of pain averts the development of anxiety symptoms**

Depress Anxiety. 2011 January ; 28(1): 40–49

Pediatric Medical Traumatic Stress

- It is a set of psychological and physiological responses of children and their families to:
 - Serious illness
 - Pain
 - Injury
 - Medical procedures
 - Invasive or frightening treatment experience
- Diagnosis:
 - ≥1 diagnostic criteria within 1mo of traumatic event
 - Avoidance of reminders of the stressor
 - Re-experiencing flashbacks
 - Hyper-arousal, e.g. persistent heightened level of anxiety

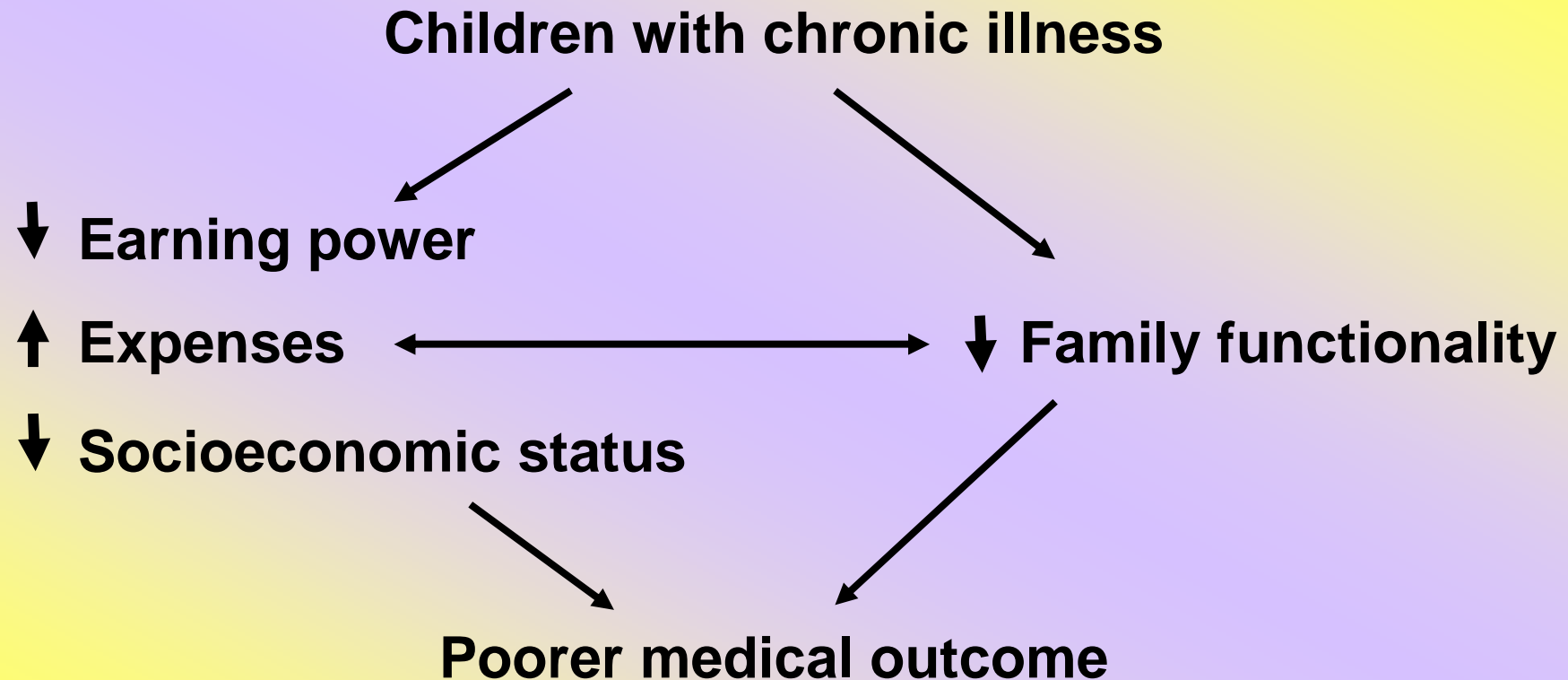
Depress Anxiety. 2011 January ; 28(1): 40–49

Impact of Chronic Illness on Parents QOL

- **Children with chronic diseases increase the stress on families**
 - Increased responsibility of caring for the ill
 - Fear of more serious illness or death
- **Impact of illness on the family:**
 - Poor sense of coherence & reduced family's functionality
 - Increased incidence of psychiatric symptoms

Kidney International (2006) 70, 1893–1894

Chronic Illness and Family QOL



Modified from KI (2006) 70, 1893–1894

Impact of Chronic Illness on Siblings QOL

- **The healthy siblings of ill children are vulnerable to emotional stress**
 - Overwhelmed and overburdened parents may overlook the symptoms and the need for the emotional support
- **Helpful strategies that can be implemented by parents:**
 - Dedication of a specific time for the healthy sibling
 - Involvement of the sibling in the care of the ill child
 - Appreciation of help and sacrifice in the care for the ill sibling

Eur J Pediatr (2013) 172:139–150

QOL in Palliative Care

- Palliative care an approach to care of chronic conditions, from the point of diagnosis or recognition, throughout the child's life, death and beyond
- It embraces physical, emotional, social and spiritual elements and focuses on enhancement of QOL for the sick and support for the family
- It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement

Eur J Pediatr (2013) 172:139–150

QOL in Palliative Care

- Despite great advances in medicine, children with chronic illness may be confronted with the shortened lifespan
- Pediatric palliative care (PPC):
 - Eases suffering (pain therapy)
 - Enhances quality of remaining life by focusing on QOL goals defined by the child & parents
 - Addresses physical, psychosocial and spiritual needs
 - Provides care through death
- PPC provides short breaks for parents and helps with bereavement

Eur J Pediatr (2013) 172:139–150

QOL in Cystinosis



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Cystinosis

- A very rare and chronic genetic disease
- Patients take multiple medications
 - Every 1 to 6 hrs, lifetime
- Although the lifespan of cystinosis patients has increased into 5th decade of life, some won't live beyond their 20s
- Parents are overwhelmed with around the clock medication delivery as well witnessing children feeling sick most of time
- Many parents live with a constant feeling of guilt, seeing their children struggle on days when they do not feel well

Cystinosis

- **The effect of chronic illness on the family life and on other, non affected children is tremendous**
 - It poses a daily living challenge
 - It teaches understanding, affection, forgiveness

Cystinosis

- **Studies in children with chronic conditions suggest that**
 - **Children can adapt better than expected**
 - **The QOL survey response provided by the parents is not equivalent to that reported by the patients**
- **Parents seem to worry more than children**

Cystinosis

- **Chronic, progressive nature of the illness and fishy breath odor may preclude pts from very active social life**
- **While struggling with their health limitations, children strive for acceptance in peer social groups**
- **The role of parents in building self-esteem and enjoying any moment of feeling well cannot be undermined**

New Cystinosis Challenge

- Despite many problems related to chronic illness, many cystinosis patients have happy childhood
- Due to tremendous medical advances in care for cystinosis patients, children grow to a very fulfilling adulthood
 - Cystinosis, previously thought to be a childhood disease, became a disease of adults
- In the past the focus was to help children to survive to adult age, now the focus has shifted, to help them have a fulfilling professional and personal adult life

Professional Life

- University graduates
- Active in the work force
- Have passion for life

In Summary



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Lessons we Learned

- QOL is an important part of life and it's assessment should not be ignored
- Medical professionals should invest time and energy in assessment of QOL in chronically ill patients in order to address the ongoing concerns/problems and to give a proper counseling
- The role of medical team should be viewed as not only addressing current medical needs, but serving as a model and guide to the future adulthood life

THANK YOU



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