Assessment of quality of life in young CHD children

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Outline
• background information
• aims
• methods
• results: P-PCQLI
• conclusions and future directions

Medical background
• Prevalence:
  – CHD → most common single organ malformations
  – 90-95% of pediatric cardiological patients
  – Prevalence 8/1000 – 10/1000 newborns
    (1.08% Lindinger et al.; 2010)
  – Germany: circ. 7000 to 8000/year
• improved prognosis: 80-90 % survival

Physical limitations and late effects
• limited physical capacity, fatiguability, dyspnea on exertion
• frequently infections of the bronchia and lung
• heart palpitations, extrasystole, chest pains
• growth delay and cognitive retardation/dysfunction
• “look differently” (cyanotic, postoperative scar, funnel chest)
• brain damage

Psychological Problems
• “Medical Trauma”: operations, hospitalization, separation of the family – increasing PTSD-symptoms before/after operations
  (Connolly et al. 2004)
• externalizing/internalizing behavioral symptoms (Alden et al 1998)
• social problems; negative self-worth; sense of inferiority
• feed problems and eating disorder (Lobo et al. 1992)
• overprotection
• disordered mother-child-attachment (Goldberg et al. 1991)
• troubles at everyday activities and schoolwork (Granberg et al. 2008)
• motor deficits (Heirs et al. 2007)

CHD and Quality of life
• limited agreement between parental caregivers and patients
  (Goldbeck & Melches 2005, Qual Life Res 14:1915-24)
• QoL = family affair:
  parental QoL moderates their proxy reports (low parental QoL, better agreement)
• cumulative negative effects of disease severity and social disadvantage upon parent-reported HRQoL
  (Goldbeck & Melches 2006, Cardiol Young 16:67-75)
• Lack of disease specific measures exception: PCQLI Pediatric Cardiac Quality of Life Inventory
  (Marino et al. 2006, Qual Life Res)
Quality of life

- Available Generic HrQoL questionnaires for children:
  - Child Health Questionnaire, SF-36, ILK und Kindl-R,
  - PedsQL
- absense of disease specific (proxy-) measure for preschoolers
- advantage of using disease specific measure:
  - more comprehensive for a specific disease
  - more sensitive to change in condition over time
  - better at discriminating differences between sub-groups within a disease category

Purpose of the current study

- develop a multidimensional disease-specific instrument for pre-school children, within the age range of 3 to 7 years, considering developmentally and mood adjusted indicators of HrQoL in this subpopulation
- confirm the reliability
- test its validity by evaluating its association with clinical variables: disease severity, medical prognosis, and treatment intensity,
- as well as with general behavioural and emotional symptoms

Study sample (n = 167)

- Age: 3 to 8 years M=4.8; SD=1.5

- Contact
- Gender
- Prognosis
- NYHA-classification

Methods

Phase I (Item generation and focus group methodology)
- 2 focus-groups
  - First group: parents of children aged 3-7 years with heart disease (n=15)
  - Second group: Health care professionals/specialists (n=6)
- Generation of a cumulative list of HrQoL topics and domains resulting in a total of 120 items
- Reduction to 76 HrQoL items
- Definition of five domains, based on theoretical considerations

Phase II (Pilot testing and further item reduction)
- Distribution of the preliminary questionnaire (n=21)
- Quantitative analysis of collated questionnaire data
- Item revision and reduction to 53 items, and questionnaire modification

Phase III (Psychometric testing)
- Completion of the questionnaire by parents of pre-school children with heart disease (n=167) and re-testing after 4 to 6 weeks (n=46)
- Quantitative and qualitative statistical analysis

Results

- good feasibility and acceptance
- total score excellent internal consistency:
  - Cronbach’s α = 0.95
  - test-retest correlation: r = 0.96
- external validity:
  - indicated by higher correlations with a generic pediatric QoL questionnaire (KINDL) compared to a measure of behavioral and emotional symptoms (Strengths and Difficulties Questionnaire)
- lower P-PCQLI total scores were significantly associated with
  - inpatient vs. outpatient treatment (p<.001),
  - with at least moderate disease severity,
  - NYHA classification I vs. II-IV (p<.001)
  - and with poorer prognosis as estimated by the physician (p<.001)
The Questionnaire – P-PCQLI

- 52 Items
- 5 domains:
  - physical capacity and functioning,
  - emotional well-being and behavior
  - social integration
  - treatment burden
  - functional development
- Short version (12 Items)
  - Total score

Practical example

- boy, 5 years old, inpatient
- Diagnosis: Double outlet right ventricle; loss of protein
- Treatment history: partly corrective surgery (twice) of HD with functional restriction; further surgery required
- NYHA-class IV: inability to carry out any physical activity without discomfort: symptoms of congestive cardiac failure are present even at rest. Increased discomfort with any physical activity (symptomatically 'severe' heart failure)
- prognosis infaust; complete correction of HD impossible
- medical treatment: Antarrhythmikum, Antihypertensiva, Anticoagulans, Diurethikum, and elektrolyt substitution

Case example

Outlook: Ulm Online Clinic

- Implementation of P-PCQLI
  - connecting patients, caregivers, pediatricians, and allied health professionals
  - monitoring HrQoL and indicated psychosocial interventions
- Electronic Patient & Parent reported outcomes in Pediatric clinical practice (model: CLIC-ON study, AMC, the Netherlands)
- web-based survey of HrQoL
- www.ulmer-onlineklinik.de

Summary

- P-PCQLI preschool version ready for use
- disease- and age-specific (3-7 years)
- good reliability and validity
- available in German language so far
- completes the family of PCQLI measures (schoolage children, adolescent self report, caregiver reports)
- HrQoL online in preparation

Thank you for your attention!