

## Assessment of quality of life in young CHD children

Lutz Goldbeck & Mandy Niemitz

University Ulm Medical Centre  
Child and Adolescent Psychiatry/Psychotherapy

Working Group Psychosocial Care from Fetus to Adult  
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gefördert durch:



## 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)
- disordered mother-child-interaktion (Gardner et al. 1996); overprotection
- disordered mother-child-attachment (Goldberg et al. 1991)
- troubles at everyday activities and schollworc (Granberg et al. 2008)
- motor deficits (Holm 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 and Kindl-R, PedsQL
- absence 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

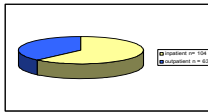
- develop a multidimensional disease-specific instrument for pre-school children, within the age range of 3 to 7 years, considering developmentally and mood adjusted indicators of HrQoL in this subpopulation
- confirm the reliability
- test its validity by evaluating its association with clinical variables: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



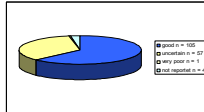
## Study sample (n = 167)

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

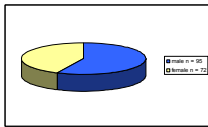
### Contact



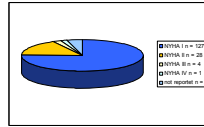
### Prognosis



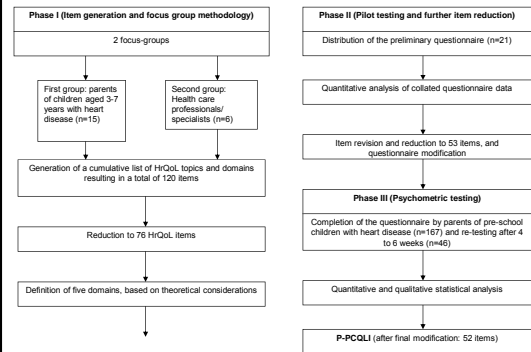
### Gender



### NYHA-classification



## Methods



## Cooperations



- Dr. Christoph Galm, Universitätsklinik für Kinder- und Jugendmedizin Ulm, Pädiatrische Kardiologie, Eyrstr. 04, 89075 Ulm
- Dr. Thomas Borth-Bruhn, Nachsorgeklinik Tannheim gGmbH, Gemeindefeldstr. 75, 78052 Wiltgen-Schwenningen
- Prof. Dr. med Michael Hofbeck, Universitätskinderklinik Tübingen, Klinik für Kinder- und Jugendmedizin, Kinderkardiologie, Pulmologie, Intensivmedizin (II), Hoppe-Seyler-Str. 1, 72076 Tübingen
- Prof. Dr. med. Hedwig H. Hövels-Gürich, Universitätsklinikum Aachen, Klinik für Kinderkardiologie, Pauwelsstraße 30, 52074 Aachen
- Prof. Dr. Ingrid Sittler, Universitätsklinikum Freiburg, Zentrum für Kinder- und Jugendmedizin, Mathäidenstraße 1, 79106 Freiburg
- Prof. Dr. med. Felix Berger, Deutsches Herzzentrum Berlin, Klinik für Angeborene Herzfehler / Kinderkardiologie, Augustenburger Platz 1, 13353 Berlin
- Prof. Dr. Dietmar Schranz, Universitätsklinikum Gießen und Marburg GmbH, Kinderkardiologie, Feußengstr. 12, 35392 Gießen
- Dr. med. Ines Konzag, Kindernachsorgeklinik Berlin-Brandenburg gemeinnützige GmbH, Bussardweg 1, 15321 Bernau-Waldesiedlung
- Dr. Balmer, Dipl.-Psych. Johanna Schelp, Kinderspital Zürich, Steinwiesstraße 75, 8032 Zürich Kreis 7 (Hottingen)



## Results

- good feasibility and acceptance
- total score excellent internal consistency:  $Cronbachs' \alpha = 0.95$
- 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

**ELTERN**  
Fragebogen für Eltern hinsichtlich Kinder (3 bis 7 Jahre)

Name des Kindes: [ ] Geb. datum Kind: [ ] Geschlecht: [ ] [ ] [ ]  
angehört von: [ ]

**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

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**Skala 1: Körperliche Belastbarkeit und Funktionslevel**

**Skala 2: Emotionale Befindlichkeit und Verhalten**

**Skala 3: Soziale Integration**

**Skala 4: Therapielastung**

**Skala 5: Funktionale Entwicklung**

**Gesamtwert Langversion**

**Gesamtwert Kurzversion**

### 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!

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Contact: [mandy.niemitz@uniklinik-ulm.de](mailto:mandy.niemitz@uniklinik-ulm.de)  
[lutz.goldbeck@uniklinik-ulm.de](mailto:lutz.goldbeck@uniklinik-ulm.de)

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