

QUALITY OF LIFE OF ADOLESCENTS WITH CHRONIC CONDITIONS: AN OPTIMISTIC VIEW

Susan Jedeloo, PhD, MSc ¹
 AnneLoes van Staa ^{1,2}
 Heleen van der Stege ¹

¹Rotterdam University - Expertise Center Transitions of Care
²Erasmus MC University Medical Center Rotterdam - Institute of Health Policy and Management
 The Netherlands



Feel good: Quality of life

- Quality of Life (QoL) is a complex, multi-dimensional concept
- Has become an important item on the agenda for chronic illness research
- Children and adolescents may view their QoL differently from adults / parents
- **Aim: To investigate how adolescents with various chronic disorders rate their QoL compared with healthy peers and parents**



Method

- Web based survey into competencies and preferences for care of adolescents
- All adolescents with somatic chronic disorders (12-19 years) treated in the Sophia Children's Hospital and their parents
- Excluded: recently diagnosed adolescents, those with mental retardation
- Total population invited: n=3.861



KIDSCREEN-10

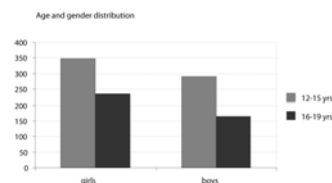
- Health Related Quality of Life Questionnaire for Children and Young People and their Parents
- Covering physical, emotional, mental, social and behavioral components of well-being and functioning
- Measures for **use in both healthy and chronically ill populations**



DISABKIDS -12

- The DISABKIDS Core Instruments measure general quality of life **and the level of distress caused by a chronic disease**
- It provides a possibility of assessing health-related quality of life (HRQoL) **in children and adolescents with different chronic health conditions**
- Covering mental, social and physical components
- Several chronic disease specific DISABKIDS disease modules available

Response Adolescents n= 1039



- Mean age 15,4 years
- Secondary school (70%) or follow-up education (15%) of which almost 50% in higher education
- 10% special education
- 90% born in the Netherlands

Response Parents n=779

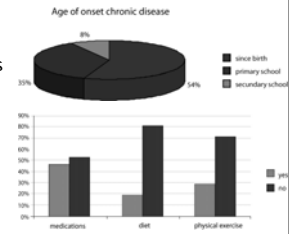
- Mostly mothers
- Mostly about daughters (except in cases the adolescent did not respond)
- 40% finished higher education, 17% only finished secondary school
- 94% born in the Netherlands

In 593 cases information on both adolescent and parent available

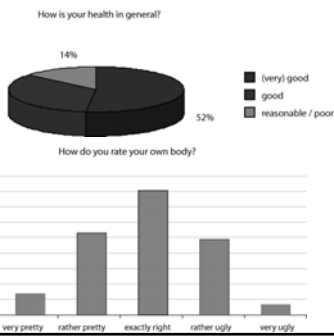


Health related variables 1

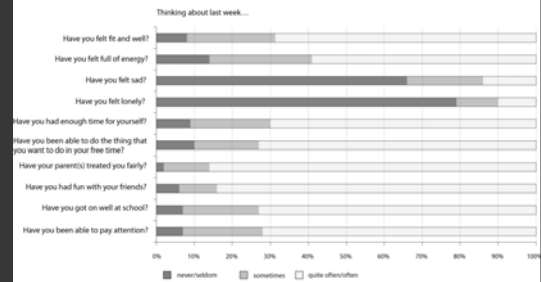
- Variation in chronic conditions
- Variation hospital visits
- Mobility limitations (30%)
- Therapeutic regime (60%)
- Visibility and notice ability of chronic condition (60%)
- Discomfort with visibility (50%)



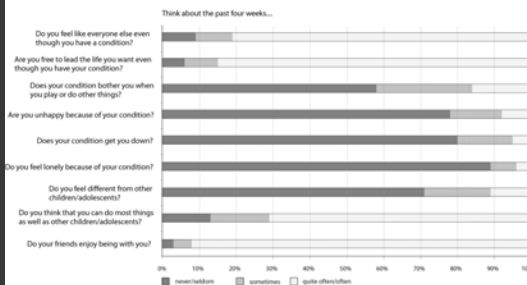
Health related variables 2



Results KIDSCREEN-10



Results DISABKIDS-12



Comparison with peers KIDSCREEN

- The KIDSCREEN Group Europe 2006
- 12-18 years
- Transformed sum scores: 0 to 100, ↑score = ↑QoL
- Dutch reference group higher quality of life than European, On Your Own Feet highest

	N	Mean	Sd	Perc 10	Perc 25	Perc 50	Perc 75	Perc 90
Europe	14932	71.93	14.95	52.5	62.5	72.5	82.5	90.0
Dutch group	1159	-	-	62.3	68.7	77.0	85.1	92.0
On Your own Feet	1028	76.89	16.34	55.0	67.5	80.0	90.0	97.5

Comparison with peers DISABKIDS



- The DISABKIDS Group Europe 2006
- 13-16 years
- Transformed sum scores: 0 to 100, ↑score = ↑QoL

European Data DISABKIDS: disease severity		
	Mean	Sd
Mild	81.3	15.8
Moderate	75.9	15.7
Severe	66.6	17.9
Overall	77.7	16.6

On Your Own Feet	N	Mean	Sd	Perc 10	Perc 25	Perc 50	Perc 75	Perc 90
DISABKIDS	1016	80.1	16.2	55.5	72.2	83.3	91.7	100
KIDSCREEN	1028	76.9	16.3	55.0	67.5	80.0	90.0	97.5

Comparison with parents n=593


On Your Own Feet	Mean	Sd
DISABKIDS •Adolescents •Parents	78.2 76.8	15.6 15.9
KIDSCREEN •Adolescents •Parents	80.2 76.4	16.3 17.5

Related factors QoL


	KIDSCREEN-10	DISABKIDS-12
Female	--	--
Age	--	-
Educational Level	x	--
Presence of functional limitations	--	--
Age of onset chronic disease	-	x
Number of hospital visits	x	--
Visibility of condition	?	?
Experiencing discomfort with visibility condition	--	--
Low body image	--	--
Therapeutic regime	--	--
Experienced health status	--	--
Readiness for transition	++	++
Total Self-efficacy score	++	++


++ positive relationship (p < 0.01), -- negative relationship (p < 0.01)
 - negative relationship (p < 0.05), ? relation unclear
 x no relationship



Adolescents at Risk for ↓ QoL


- ↑ functional limitations
- Girls
- Elder adolescents (16+)
- Experiencing discomfort with visibility condition
- ↓ body image or experienced health status
- Not feeling ready for transition
- ↓ Total self-efficacy score





Remarks & conclusions

- Having a lower QoL-score does not say everything about how well adolescents feel
- 1 in 3 adolescents experience a lower QoL
- Regression analysis will be executed
- Disabkids or Kidscreen?
- Parents and health care professionals be aware!
- Parents and health care professionals be aware!





More Information

- www.opeigenbenen.nu
- www.transitiesinzorg.nl
- <http://kidscreen.diehauptstadt.de>
- s.jedeloo@hro.nl



thank you!

