

Distribution & Associations



- Q-methodology is a small sample method
- It gives insight into existing views or attitudes on a topic
- But it is not suited to provide information on prevalence and associations with respondent characteristics
- Only tentative hypotheses are possible
- Therefore we designed a follow-up study



Online-Survey



- All adolescents aged 12-19 years who mid-2006 were in active long-term treatment for a somatic chronic condition in the departments of Pediatrics or Pediatric Surgery in the Erasmus MC - Sophia Children's Hospital, selected from the hospital database.
- And their parents



In- & exclusion criteria



- Inclusion criteria: prior to July 1st 2006, adolescents must have been in treatment for over three years;
- They must have made outpatient visits and/or been hospitalized at least three times in these three years.
- They were excluded if transfer to adult care had already been effected or if they had a documented diagnosis of intellectual impairment.

Measures



- Socio-demographic characteristics
- Disease- and health care-related variables
- Assessed impact of the chronic condition (including quality of life)
- Preferences and competencies for care
- The questionnaire was built on findings from a literature review, extensive data-analysis of our previously conducted interviews with 31 adolescents, and pilot tests of the draft questionnaire in face-to-face interviews with 5 adolescents and 4 parents.

Outcome variable: QCP

How does this description fit you?



A

If I just do what the doctors say, I don't have to worry about my disease or health. After all, my disease permits living a normal life. I think I am pretty independent now and would like to be treated like an adult. That is why I want the doctors to talk to me and not to my parents. Health professionals should point out my own responsibility to me, for I don't want to regret it or be confronted with my disease later. For not following the rules now, I know enough about my disease, but I would like to know the consequences of a treatment for my daily life. Also, I don't need any support from the hospital in coping with my disease, I will take care of that myself, or my parents will help me.

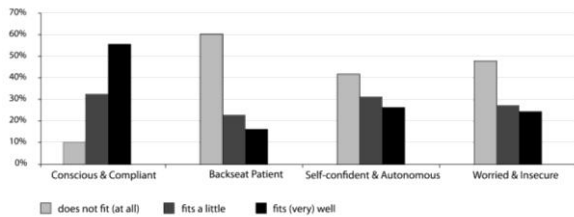
Not at all Not really A bit Well Very well

Results (adolescents)

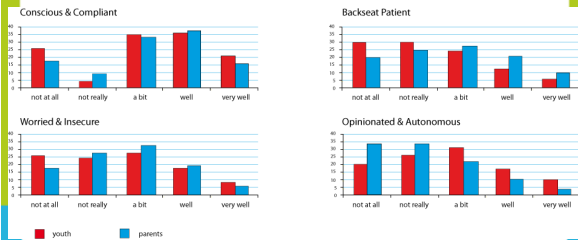


- Response 1,087 (29.8%), 990 valid concerning QCP
- 56.6% girls, 43.4% boys
- 61.4% 12-15 yrs, 38.6% 16-19 yrs
- 14% non-Dutch surname
- 55.7% lower/middle level of education
- 9.9% special education

Prevalence: fit to profile n=990



Differences between youth & parents (n=593)



Conscious & Compliant N=939



	R² = .09		95% CI	
	OR	P	Low	High
Age	1.71	<.001	1.29	2.27
Non-Dutch Surname	0.50	<.001	0.34	0.74
Educational level (high)	1.73	<.001	1.32	2.27
Hospital admission	0.70	.03	0.51	0.96
General Health score	1.31	<.001	1.14	1.50

0=No Good Fit, 1=Good Fit

Backseat Patient N=939



	R² = .15		95% CI	
	OR	P	Low	High
Age	0.34	<.001	0.22	0.53
Non-Dutch Surname	0.33	.002	0.16	0.67
Educational level (high)	0.46	<.001	0.30	0.70
Type of education (special)	3.35	<.001	2.00	5.62
Presence of physical limitations	1.57	.03	1.06	2.32

0=No Good Fit, 1=Good Fit

Self-confident & Autonomous N=939



	R² = .01		95% CI	
	OR	P	Low	High
Number of outpatient departments (>1)	0.67	.01	0.49	0.92

0=No Good Fit, 1=Good Fit

Worried & Insecure N=939



	R² = .11		95% CI	
	OR	P	Low	High
Gender (male)	0.67	.02	0.49	0.93
Age	0.68	.02	0.49	0.95
Non-Dutch Surname	1.60	.03	1.04	2.46
Educational level (high)	0.46	<.001	0.33	0.64
Hospital admission	0.74	.001	0.63	0.88
General Health score	1.30	.002	1.10	1.54

0=No Good Fit, 1=Good Fit

Attention & Interventions



QCP	Attention	Interventions
Conscious & Compliant	•Ideal patient: involved, independent	•Individual Transition Plan (ITP) •Independent Youth Consultations (IYC)
Backseat patient	•Parents role •16+	•Work on self-management skills •ITP for parents •Motivational interviewing (MI)
Self-confident & Autonomous	•Non-adherence •Visible due to behavior •Underestimated by parents	•Confrontation •Praise & compliments •Non-medical issues •ITP, MI, IYC
Worried & Insecure	•Most at risk? •Likely to develop depression & social isolation •Difficult to identify	•Psychological support •Contact with peers •Work on skills (security)

Use of QCP in practice

- QCP-manual for healthcare containing:
- Six steps for using QCP
 - A checklist and tips for attention per profile
 - Interventions
 - Q-Care Profile Test 1 for healthcare providers
 - Scorings can be compared



OpEigenBenen.nu

OpEigenBenen.nu website interface showing navigation menus (Opaving, Projectinformatie, Uitgang, Toelicht, Toelicht bij raamwerk) and a central diagram titled 'Interventie om het transitieproces organisatorisch te ondersteunen'. The diagram features a central circle labeled 'Jongere' surrounded by six other circles: 'Coördinatie', 'Coördinatie', 'Inzet van zorg', 'Educatieprogramma', 'Toelichting', and 'Toelichting'. Below the diagram is a list of seven principles and a search bar.

Possible follow-up studies



- Usability in daily practice (does it stimulate discussion, practical use)
- Is it feasible to use QCP as a screening instrument to identify groups at risk (readiness for transition, self-management)?
- Which interventions should be used for each profile and are they effective?
- Associations between QCP-scores and disease-specific characteristics?
- Sensitivity for change in time?

Questions



- Is this tool useful to enhance communication in the consultation room?
- How do you think that your patients and parents would react to this tool (is it feasible to use it in your practice)?
- Which interventions could/should be used for each profile?

References

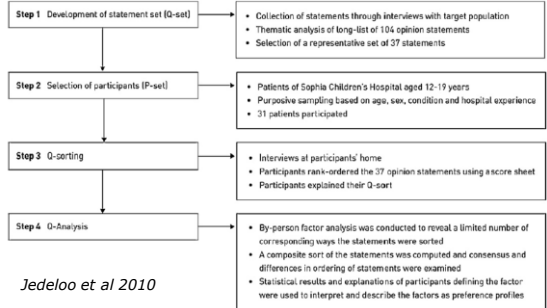


- Jedeloo, S, AL Van Staa, JM, Latour, J van Exel (2009) Preferences for Health Care and Self-Management among Dutch Adolescents with Chronic Conditions: A Q-Methodological Investigation. International Journal of Nursing Studies (2010) 47 (5):593-603.
- Jedeloo, S., van Staa, A.L., 2009. Q-methodologie, een werkelijke mix van kwalitatief en kwantitatief onderzoek? (Q-methodology: A true mix of qualitative and quantitative research?). Kwalon 14 (2), 5-15.
- In preparation: AL Van Staa, S Jedeloo, H van der Stege, J van Exel. Four Types of Chronically Ill Adolescents: Distribution of and Associations with Q Care Profiles
- www.opeigenbenen.nu (also information in English)
- s.jedeloo@hr.nl

thank you!



Developing Q-Care profiles



16. I would like to health professionals to treat me like an adult

1. Outpatient appointments should be scheduled according to my working hours/school hours

I	Physical environment/ organization of care	1, 8, 10, 13, 19, 23, 31, 32
II	Physician/patient communication	2, 4, 12, 16, 22
III	Information provision	3, 5, 11, 14, 15
IV	Self-management/Independence	6, 7, 9, 17, 18, 20, 21, 24, 25, 26, 27, 28, 29, 30
V	Therapeutic regimen	
VI	Disease perception	
VII	Contact with fellow	

20. Fortunately, my parents are there to remind me of my treatment and appointments

