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USING Q-METHODOLOGY TO EXPLORE PREFERENCES FOR CARE OF ADOLESCENTS WITH CHRONIC DISORDERS: FOUR PROFILES

Staa AnneLoes van^{1,3}, Jedeloo Susan^{1,2}, Latour Jos², Exel Job van³

1. Rotterdam University Expertise Center Transitions of Care, Rotterdam, The Netherlands
2. Erasmus Medical Center – Sophia Children’s Hospital, Rotterdam, The Netherlands
3. Erasmus Medical Center – Institute of Health Policy and Management, Rotterdam, The Netherlands

Introduction

Adolescents with chronic disorders are seldom asked to give opinions about their preferences for care, even though they are frequent healthcare users and soon need to take over responsibility of managing their own care.

Aim and material

Aim of the study is to investigate care-related preferences of adolescents with chronic disorders. A Q-methodological study was conducted in a random sample of 31 adolescents with various congenital and acquired disorders from the total population of Erasmus MC–Sophia (12-19 years). Adolescents rank-ordered 37 statements about preferences for care and self-care using a quasi-normal distribution. Factor analysis was applied to identify clusters in the Q-sorts, groups of adolescents with common preferences.

Results

Four profiles were distinguished: Concerned & Compliant; Backseat patient; Opinionated & Careless; Worried & Insecure. Differences between profiles are related to independence competencies, level of involvement in management of the illness, adherence to therapeutic regimes, and to appreciation of their parents’ role. All adolescents want to have an important say in treatment-related decisions. Although adolescents are used to being accompanied by their parents in the consultation room, they sometimes prefer to be on their own.

Conclusions

Four different preference profiles were uncovered. Caregivers recognize these profiles in daily practice. As the goal of Q-methodology is to establish different patterns but not their prevalence, the distribution of profiles will be explored in a large follow-up survey. Further use of these profiles in daily practice will be also explored, as rank-ordering the statements stimulated adolescents to talk about care issues.

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SLIDE 2 Background

As a result of the improved pediatric care, 90% of all children in Western countries with a chronic illness of physical disability now survive into adulthood. As a result, pediatricians now see more adolescents than ever before. These adolescents with severe chronic disorders need to prepare themselves for adult life and soon need to take over responsibility of managing their own care. At the age of 18, they are expected to leave pediatric care and transfer to adult care. Transition from pediatric care to adult care is becoming a major challenge in pediatrics. Although they are at an age to speak out for themselves, adolescents are seldom asked to give opinions about their preferences for care.

SLIDE 3 On Your Own Feet

Today I present some results of the large research project On Your Own Feet about the preferences and competencies of adolescents (12-19 years of age) with chronic disorders. I will now focus on the part of the research in which we used Q-methodology.

SLIDE 4 Aim & sample of the research

To investigate care-related preferences of adolescents with various chronic disorders using Q-methodology

We used a random sample of 31 adolescents with various congenital and acquired disorders from the total population of Erasmus MC–Sophia (12-19 years).

SLIDE 5 Q-Methodology

Q-methodology is a small sample methodology, combining qualitative and quantitative aspects. It is suited for the investigation of subjective issues and reveals patterns of inter-subjectivity. Q-methodology describes a population of viewpoints: it constructs profiles of the major views on a certain issue. In our study, the issue was preferences for self care and health care delivery in the transition period.

Participants sorted a set of 37 statements which represent a spectrum of ideas / viewpoints existing on the subject. They are printed on small cards, and then placed by the participants along a continuum of preferences in order to reveal categories of individuals who shared common viewpoints.

Factor analysis using a specific computer program called PQ-method is applied to identify clusters in the Q-sorts, these clusters being groups of adolescents with common preferences.

SLIDE 6 Example Results: Profile C

This is an example of the composite Q-sort of one factor, profile C. It represents how a hypothetical respondent with a 100% loading on that factor would have ordered all the statements of the Q-set.

The yellow blocks represent the characterizing statements of this profile: these statements are ranked at both extreme ends: the statements which the adolescents in this profile agree or disagree most with. These statements are used to produce a first description of the composite point of view represented by this factor or profile.

The statements printed in RED are the distinguishing statements: these highlight the differences with other profiles.

The statements in the middle columns concern less important issues for this profile, as compared to the issues positioned at the extremes. The program also presents consensus statements. An example is the statement *I want to have my own say in important matters*

about my health or treatment. This statement is characteristic for all four profiles (position 2), thus revealing how important it is to all adolescents that they are involved in treatment decisions.

Finally, respondents gave explanations on their preferences in a follow-up interview. These explanations are helpful in the interpretation of the factors and help to illustrate the composite profiles.

SLIDE 7 Results: Four profiles

Four profiles were distinguished: Concerned & Compliant; Backseat patient; Opinionated & Careless; Worried & Insecure. Differences between profiles are related to independence competencies, level of involvement in management of the illness, adherence to therapeutic regimes, and to appreciation of their parents' role. There are also similarities between the profiles.

A) Concerned & Compliant

"As long as I just follow doctor's orders, I don't have to worry"

B) Backseat Patient

"If my parents know what to do, it's OK"

C) Opinionated & Careless

"I take my own decisions, I will not have my illness limit me"

D) Worried & Insecure

"Just imagine that things will go wrong later.."

On the slide a characteristic quote belonging to each profile is presented. As stated before, consensus between the profiles also exists. All adolescents want to have a say in treatment decisions and they sometimes prefer to be on their own when interviewed by the doctor.

SLIDE 8 Conclusions

Four preference profiles were uncovered. Caregivers recognize these profiles in daily practice. As the goal of Q-methodology is to establish different patterns but not their prevalence, the distribution of profiles will be explored in a large follow-up survey. Over 1.000 adolescents gave their opinion on their 'fit' with each of the four profiles. Results are currently being analyzed. Preliminary results indicate significant differences with age, education and other variables between profiles.

Participating in the study was enjoyed by the adolescents. The element of play experienced during rank-ordering the statements, stimulated them to talk about care-related issues. As doctors and nurses often experience difficulties communicating with adolescents, further use of these profiles in daily practice will be also explored.

Extra information on Factor scores & difference scores:

A statement's factor score is the normalized weighted average statement score (Z-score) of respondents that define that factor. Based on their Z-scores, statements can be attributed to the original quasi-normal distribution, resulting in a composite (or idealized) Q-sort for each factor. The composite Q-sort represents how a hypothetical respondent with a 100% loading on that factor would have ordered all the statements of the Q-set. When factors are computed, one can look back at the Q sorts and see how high their loadings are on the different factors. When a respondent's factor loading exceeds a certain limit (usually: $p < 0.01$), this called a defining variate (or variable). The difference score is the magnitude of difference between a statement's score on any two factors that is required for it to be statistically significant. When a statement's score on two factors exceeds this difference score, it is called a distinguishing (or distinctive) statement.....

See: www.qmethodology.net; Van Exel & De Graaf - Q-methodology: A sneak preview (2005)