

Preferences for health care and self-management among Dutch adolescents with chronic conditions: A Q-methodological investigation

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ARTICLE INFO

Article history:

Received 10 July 2009

Received in revised form 6 October 2009

Accepted 10 October 2009

Keywords:

Adolescents

Chronic care

Health care preferences

Health lifestyle attitude

Patient-centred Care

Q-methodology

ABSTRACT

Background: Adolescents with chronic conditions have to learn to self-manage their health in preparation for transitioning to adult care. Nurses often struggle with how to approach youth with chronic conditions successfully. Little is known about the preferences and attitudes of these young people themselves.

Objective: To uncover preferences for self-management and hospital care of adolescents with various chronic conditions.

Design and method: A Q-methodological study was conducted. Semi-structured interviews were held with adolescents who rank-ordered 37 opinion statements on preferences for care delivery and self-management. They were asked to motivate their ranking. By-person factor analysis was conducted to uncover patterns in the rankings of statements. The factors were described as preference profiles.

Participants and setting: A purposive sample of 66 adolescents (12–19 years) treated in a university children's hospital in the Netherlands was invited to participate. Thirty-one adolescents, 16 boys and 15 girls with various chronic conditions eventually participated (response 47%). Eight participants (26%) had a recently acquired chronic condition, while the rest (74%) had been diagnosed at birth or in the first 5 years of life.

Results: Four distinct preference profiles for health care delivery and self-management were identified: 'Conscious & Compliant'; 'Backseat Patient'; 'Self-confident & Autonomous'; and 'Worried & Insecure'. Profiles differ in the level of independence, involvement with self-management, adherence to therapeutic regimen, and appreciation of the parents' and health care providers' role. The desire to participate in treatment-related decisions is important to all preference profiles. The profiles are recognizable to adolescents and nurses alike. As Q-methodology allows no inferences with respect to the relative distribution of these profiles in a given population, only tentative hypotheses were formulated about associations between profiles and patient characteristics.

Conclusion: This study increases our understanding of different subjectivities of adolescents living with a chronic condition related to their treatment and health. There is no "one size fits all" approach to adolescent health care, but rather a limited number of distinct preference profiles. This study demonstrates the value of a non-disease-specific approach in that adolescents with various chronic conditions were found to have much in common. The profiles seem a promising tool for nurses to actively seek adolescents' opinion and participation in health care and will be further explored.

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What is already known about the topic?

- Adolescents with chronic disorders have to learn to manage their own condition, yet they are not often asked for their preferences.
- Actual involvement of adolescents in consultations and decision-making is limited.
- Previous research revealed majority views and attitudes, while adolescents are known to have different preferences.

What this paper adds

- This Q-methodological study reveals four preference profiles among adolescents with different chronic conditions about health care and self-management.
- Profiles differ in attitudes toward independence, self-management, treatment adherence, and in appreciation of the parents' role. All profiles share a common desire to participate in decision-making.
- The short profile descriptions are recognizable to nurses and seem a practical tool to seek adolescents' opinion and may increase young patients' participation in clinical encounters.

1. Background

Adolescents are rarely consulted as health care consumers, even though they are important users of health services whose preferences and concepts of care differ from those of adults (Cavet and Sloper, 2004; Dixon-Woods et al., 1999; Sloper and Lightfoot, 2003). Thus, little is known about priorities, desires and expectations of care from the adolescent perspective (Britto et al., 2004; Farrant and Watson, 2004; Litt, 1998) and (Oppong-Odiseng and Heycock, 1997).

As adolescence is a critical period for the establishment of health behaviours (Viner and Barker, 2005) and of a new working partnership with physicians and nurses, transition of adolescents with chronic conditions from paediatric to adult care is a major challenge for health care professionals in both settings (McDonagh and Viner, 2006; Viner, 2008). The first thing we should do is studying their perspectives and care-related attitudes (Britto et al., 2007; Woodgate, 1998a,b; Wray and Maynard, 2008). In this regard, Britto et al. (2004) asked adolescents with various chronic illnesses to rate statements on quality of care and physician–patient communication styles in order of importance. This produced a list of preferences from a majority perspective, with aspects of interpersonal care (especially honesty, attention to pain, and respect) ranking highest. However, the authors did not embed these rather specific preferences in adolescents' general views of their situation, their ideas about healthy lifestyles, coping with a chronic condition, and attitudes on compliance with treatment regimens. In addition, a majority view does not represent the variability of health care-related priorities and preferences among adolescents. Not all adolescents are alike and less dominant preferences do not emerge from such an approach, and may remain unrecognized and unattended. A recent study, for instance,

revealed variation in preferences for decision-making styles among adolescents with chronic illnesses (Knopf et al., 2008). Two other studies showed that younger and older adolescents with diabetes have differing attitudes with respect to preference for parents' involvement and responsibility in the management of their disease (Dovey-Pearce et al., 2005; Hanna et al., 2003).

Everyday health care typically applies a disorder-specific approach. Different chronic health conditions nevertheless encompass many comparable tasks, such as managing symptoms and treatment, forming relationships with care providers, maintaining a positive self-image, relating to family and friends and preparing for an uncertain future (Moos and Holahan, 2007). The importance of such adaptive tasks was established in a large study among older patients with different chronic diseases in the Netherlands (Heijmans et al., 2004), but not yet in youth with chronic conditions.

Although the importance of consulting with chronically ill children and adolescents has been recognized, their views are rarely sought or acknowledged in health care settings and there is a need for strategies to facilitate and increase young patients' participation (Coyne, 2008). Most nurses will agree that there is no "one size fits all" approach when it comes to stimulating youth to take responsibility for self-management and improving health care delivery for youth with chronic conditions. On the other hand, patients are not all different and it may thus be practical to identify sizeable and meaningful sub-groups. Is this also the case for chronically ill adolescents? And do we go by age, socio-demographics, developmental milestones, or transition readiness scales? Or do we start with the viewpoint of young people themselves?

We decided on the latter. In this paper, therefore, results are presented of an exploratory study of attitudes of adolescents with chronic conditions toward health care delivery and self-management.

2. Method

Investigating a variety of accounts requires a methodology that is designed to identify the similarities and differences in attitudes from 'within'. Q-methodology (Brown, 1980; Stephenson, 1935) was chosen because it allows identifying preference profiles of adolescents with a variety of chronic conditions sharing common viewpoints and to describe similarities and differences between these profiles.

2.1. Q-methodology

Q-methodology combines elements of qualitative and quantitative research methods and provides a scientific foundation for the systematic study of subjectivity, such as people's opinions, attitudes, and preferences (Cross, 2005; Smith, 2001; van Exel and de Graaf, 2005; Watts and Stenner, 2005). While Q-methodology has had a place in science for almost 75 years (Stephenson, 1935), it is fairly new in health research (Aldrich and Eccleston, 2000; Baker, 2006; Bryant et al., 2006; Morecroft et al., 2006; Risdon et al., 2003; Stenner et al., 2003; van Exel et al., 2007). In

nursing research, Q-methodology is increasingly popular (Akhtar-Danesh et al., 2008; Barker, 2008; Kim et al., 2006). Among adolescents, Q-methodology has been applied before to investigate their attitudes toward living with end stage renal disease (Snethen et al., 2001), therapy adherence in renal transplant receivers (Tielen et al., 2008), and toward healthy lifestyle attitudes (van Exel et al., 2006).

The aim of a Q-methodological study is to reveal principal views on a certain topic. Typically, respondents rank-order a sample of statements about the topic from their individual point of view, and thus reveal their subjective viewpoints (Smith, 2001). The individual rankings, called Q-sorts, are then correlated in order to reveal similarities in viewpoint. Stephenson (1935) presented Q-methodology as an inversion of conventional factor analysis, in the sense that it correlates persons rather than statements. If individuals each should have their own specific likes and dislikes, their Q-sorts would not correlate. If, however, significant clusters of correlations exist, these can be factorized, described as common viewpoints, and individuals can be mapped to them.

Q-methodology typically focuses on the range of viewpoints shared by specific groups of people (Akhtar-Danesh et al., 2008; Watts and Stenner, 2005). Therefore, this method can be used to describe a *population of viewpoints* rather than a population of people. For this purpose, a small sample of purposively selected respondents will do (Smith, 2001). A Q-methodological study will thus *not* inform about proportions of people adhering to the viewpoints identified, or how these are associated with personal characteristics. Still, to map attitudes and subjective opinion, Q-methodology is a more robust technique than alternative methods (Cross, 2005).

This Q-methodological study was conducted in four consecutive steps. Fig. 1 presents an overview. Below we describe each of these steps.

Table 1
Major themes represented in final Q-set.

	Themes	Statements
I	Clinical 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, 30
V	Therapeutic regimen	26, 29, 33, 37
VI	Disease perception	25, 34, 36
VII	Contact with fellow patients	27, 28, 35

2.2. Step 1: statements (obtaining Q-set)

As the first step, we collected opinion statements regarding preferences for hospital care delivery. We did so through interviews with adolescents who recently transferred to adult care, by watching TV-documentaries, and by scrutinizing documentation and websites of patient organizations. All this resulted in a broad sample of 104 statements. Thematic analysis next identified seven major themes (Table 1). Each author independently assigned the statements to the seven themes and made a selection. These selections were discussed until consensus was reached on a final Q-set consisting of 37 representative statements, a number that was considered manageable for the population under study. Each of the themes was represented by at least three statements. The statements were randomly assigned a number and printed on cards (Table 2).

2.3. Step 2: participants

A structured sample of respondents who are theoretically relevant to the problem under consideration was recruited to participate in the study (Brown, 1980). Regarding characteristics of patients, sex, age, nature of

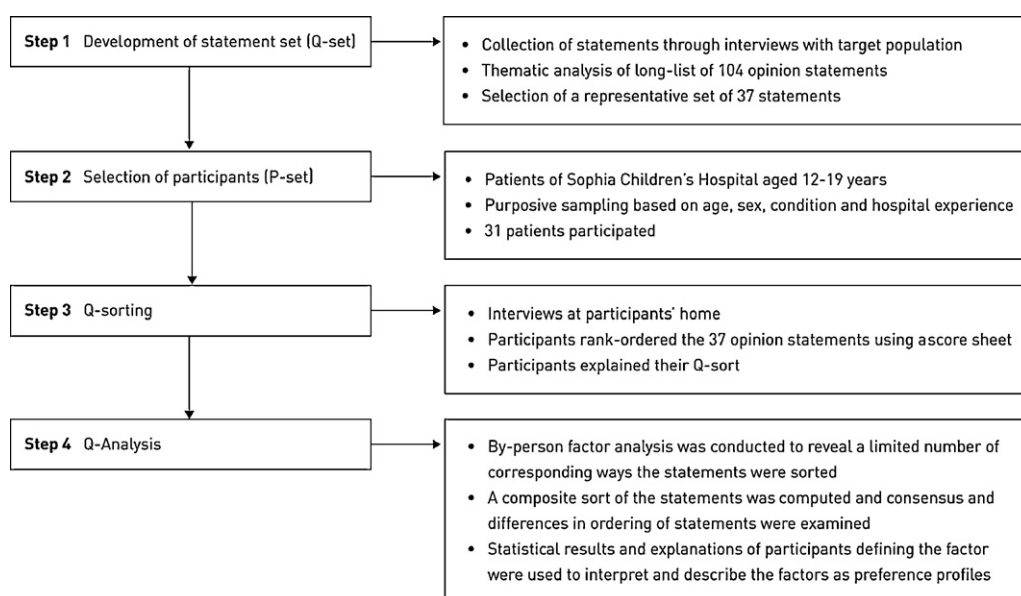


Fig. 1. Steps in this Q-methodological study.

Table 2

List of statements (Q-set) with composite factor scores.

		Factor			
		A	B	C	D
1	Outpatient appointments should be scheduled according to my working hours/school hours	0	-1	-1	-1
2	It would be nice if you could also talk to the doctor or nurse in private, without your parents being present	1	1	1	1
3	If I want to know something about my disease, I'll look it up myself (on the Internet or in books)	1	-3*	-1†	0
4	Health professionals should not ask me personal questions in front of my parents	-1	-1	-1	0
5	I don't need any detailed information from health professionals about my disease or treatment	-1	1	-2	0
6	It's important for me to have my parents present during consultations	0*	3†	-1*	1†
7	I don't need any support from health professionals in becoming independent	1†	0	0	0
8	I want to have a say in when I transfer to adult care	1	1	1	-1*
9	Health professionals do not need to ask me about school, friends or how I spend my spare time	-1	1*	0	0
10	Apart from regular appointments with my doctor, I would also like to see a personal nurse or social worker	-1†	-2	0†	-2
11	I would like to know the consequences of a treatment for my daily life	3†	-1	2†	1
12	I would like health professionals to treat me like an adult	2*	0	1	0
13	There should be an outpatient clinic, particularly for young people (up to 25 years) with combined paediatric and adult care	0	0	0	-2
14	Health professionals should talk to me about sex, relationships and hereditary matters	0	-1	0	1*
15	Taking an "exam" about your disease and treatment is a good idea	-3	-3	0*	-3
16	During consultations, I find it convenient if my parents do the talking for me	0†	2*	-2*	1†
17	Health professionals should help me to set my own goals to become (more) independent	-1	0	0	-1
18	Health professionals should discuss my wishes and future plans with me	0	0	-1	-1
19	Care at Sophia's is okay the way it is. Nothing has to be changed	2	1	0†	2
20	Fortunately, my parents are there to remind me of my treatment and appointments	1	3*	0†	1
21	Health professionals should guide my parents and teach them how to 'let me go'	-1	-1	-2†	0
22	Health professionals should not be overprotective	0	1†	-1	0
23	I would like to ask my questions to health professionals by e-mail in between appointments as well	0	-2	0	-1
24	I want to have my own say in important matters about my health or treatment	2	2	2	2
25	I'd rather pretend as if there's nothing wrong with me	2*	0*	-3†	3*
26	Living easy now is more important than being completely treatment-compliant	0	0	3	2
27	I would like to have a buddy/pal to support me	-1	1	1	-2
28	It should be possible to ask difficult questions anonymously (by e-mail or a discussion panel)	1	0	2*	0
29	It's okay if health professionals give me a good talking about the consequences of being careless about my treatment	1	-2*	1	1
30	The hospital should also support you in finding a job, applying for services or living on your own	-2	0*	-2	-3
31	I'm not looking forward to go to another hospital when I'm about 18	-2	2*	-1	-1
32	I want to arrange my own hospital appointments	0	-1	0	0
33	I'll change my own treatment if this suits me better	-2	-1	2*	-1
34	I am just like anyone else, I just have a disorder on top	3	1*	3	3
35	I like meeting fellow patients through the hospital	-2*	0	1	0
36	I am worried about my health/my disease	-3	-2	-3	2*
37	I think it's annoying to get unasked-for advice on how to live	0	0	1	-2*

Note: A = 'Conscious & Compliant', B = 'Backseat Patient', C = 'Self-confident & Autonomous' and D = 'Worried & Insecure'. "-3" indicates that the adolescents in that profile on (weighted) average disagree most with that statement; "+3" indicates adolescents in that profile on (weighted) average agree most with that statement (rank-ordered at extreme left/right in Fig. 1, respectively).

* Distinguishing statements for a factor are indicated ($p < .01$).

† Distinguishing statements for a factor are indicated ($p < .05$).

the chronic condition (congenital or acquired in past 5 years), and hospital experience (number of outpatient and inpatients visits in the past 2 years) were considered most relevant to preferences for hospital care delivery.

The Erasmus MC Medical Informatics Department identified all patients between twelve and nineteen years of age ($n = 2202$) who had visited Sophia Children's Hospital at least once in the past 6 months and had been under continuous treatment for at least the past 2 years. Two thirds had been under treatment for over 10 years. We did not select specific disorders or conditions because the study aimed to obtain a general understanding of adolescents' attitudes toward health care and self-management, and to research common adaptive tasks faced by all adolescents coping with a chronic somatic disorder. Adolescents with psychiatric diagnoses, a history of life-threatening illnesses, such as cancer, and known learning disabilities were excluded.

We distinguished into two groups: younger adolescents (12–15-year-olds, $n = 1191$) and older adolescents (16–19-year-olds, $n = 1011$). To facilitate the purposive sampling process, equal numbers of random cases were drawn from both groups. We aimed at equal numbers of participants from both age groups, and even distributions of sex, nature of the condition (congenital or acquired in past 5 years) and hospital experience within groups. Eligible adolescents and their parents received an invitation letter, a study information leaflet and a reply form from the research team. Upon written consent of both adolescent and parents, the primary researcher (SJ) arranged an interview.

2.4. Step 3: Q-sorting

The Q-set was administered during the interview at the participants' homes. Participants were first asked

Table 3
Characteristics of 31 study participants.

Variable	N = 31 (100%)
Male	16 (52%)
Age (years)	Range 12–19 Mean 15.3 (SD 2.1)
Congenital chronic condition or acquired in early life	23 (74%)
Over 7 outpatient visits in past 2 years	19 (61%)
No hospital admissions in past 2 years	22 (71%)

analysis based on the determinants used for the sample selection revealed no significant differences between participants and non-participants.

Twenty-seven interviews were conducted by pairs of purpose-trained nursing and paramedical students and four by the primary researcher (SJ). Seventeen adolescents were aged 12–15; 14 aged 16–19 (Table 3). Mean age for the total group is 15.3 (SD 2.1), 16 (52%) were male. Most had visited the outpatient department over three times a year and only a minority had been hospitalized over the past 2 years. Twenty-three (74%) suffered from a lifelong chronic condition (e.g., congenital or diagnosed before 6 years of age); 8 (26%) were diagnosed in the past 5 years. Seven (23%) showed co-morbidity. Five (20%) presented with surgical conditions: scoliosis, kyphosis, benign intracranial hypertension, congenital bladder disorder, ventricular septum defect and facial schisis. Internal conditions included rheumatoid arthritis, haemophilia, diabetes mellitus, epilepsy, inflammatory bowel disease, cystic fibrosis, various metabolic disorders, HIV, nephrotic syndrome, immune and hormone deficiencies, lung insufficiency, progressive kidney failure, congenital skin diseases, asthma, and neuromuscular diseases such as Duchenne muscular dystrophy, hereditary motor and sensory neuropathy and spasticity.

3.2. Q-analysis

By-person factor analysis of the 31 Q-sorts resulted in four distinct preference profiles (factors with Eigen value >1 were retained). Adjacent factor solutions were also explored with respect to their content, but the four factor solution was also the most clear and comprehensible one. Based on a Q-set of 37 statements and $p < .01$, the factor loading of a Q-sort must be equal to or higher than .42 to be a defining variable for that factor (Brown, 1980; van Exel and de Graaf, 2005). The four factors were defined by between three and eleven Q-sorts (21 in total). They explained from 7 to 19% of the variance, 42% in total. Correlation between factors B/C; and C/D is low ($r = .03$ and $r = .01$, respectively), while factor B correlates moderately with D ($r = .32$). Factor A has rather strong correlations with factor C ($r = .41$) and D ($r = .54$); and correlates to a lesser extent with B ($r = .27$), indicating that not only discrete viewpoints were identified, but also consensus.

Hereafter, we describe the four preference profiles, referring to the statement numbers shown in Table 2 [figures in parentheses]. The motivations by adolescents loading on a factor are given “between quotation marks”. Then we discuss similarities and differences between the profiles.

3.3. Preference profile A: ‘Conscious & Compliant’

Most characteristic of this profile is the high level of involvement with disease management. These adolescents want to know the consequences of a treatment [11] “because simply I think it is very important to me, when something would have negative consequences I would rather not have it”. Taking an exam about their disease and treatment [15] is seen, however, as “nonsense” and “overdone”. They “already know most there is to know”.

These adolescents prefer to pretend nothing is wrong with them [25]. They are not so much opposed to disclosure; it is rather felt not necessary: “When it’s not necessary for someone to know, I won’t tell”. They see themselves as being like anyone else, just with a disorder on top [34]: “I try to be as normal as possible and this disease permits me to be”. This may be related to the fact that these adolescents are not too worried about their health or disease [36]. Everything is going fine now, so “I don’t worry, it is not that bad”, “it’s not life threatening or something”.

These adolescents, more than those fitting in the other preference profiles, want to be treated as adults by health professionals [12]: “I don’t feel like a child anymore”. “A doctor should come to the point immediately and not beat around the bush with nice stories”. They are equally firmly pronounced about not needing professional support in becoming more independent [7]: “I think I am quite independent already and I don’t really need help with it”. Nor do they feel the need to meet fellow patients through the hospital [35]: “If I would feel that need, then I’d go and surf on the Internet”.

These adolescents least of all appreciate a role for their parents and strongly prefer being at the centre of the medical encounter [6; 16]: “It is convenient when my parents do the talking, but on the other hand it is nice when they are not present because they interrupt me all the time, and that’s quite annoying”; “I am the patient; he (the doctor) should talk to me and not to my parents”. They do not see leaving paediatric care as problematic [31]. Adhering to treatment, they are not inclined to change treatment on their own initiative [33]. They wish to avoid problems and appreciate doctors’ knowledge and medical advice: “Essentially, they do everything they can to make you healthy, so I think you have to put in some effort yourself”; “If you just do what the doctors tell you to, then you don’t have to worry about your health”.

The eleven adolescents comprising this profile were seven boys and four girls with a mean age of 16 years (range 13–19 years). Six of them had been diagnosed in the past 5 years; most did not have extensive hospital experience.

3.4. Preference profile B: ‘Backseat Patient’

The adolescents in this profile are less mature and lean more on their parents. They find it important to bring their parents to the hospital [6] and feel it is convenient the parents do the talking [16] because “I don’t like to talk, this is a little difficult”, “because they take care of everything for me... it seems difficult to me”. They feel “not capable of remembering everything very well”. Therefore, they appreci-

ate parents reminding them of their treatment regimens [20]. When careless about their treatment [29], they do not like “*other people confronting me with the consequences. I know the consequences, but I don’t care*”. They count on their parents to do so: “*I prefer that they tell me, better twice too often than one too few*”.

Health professionals should not be overprotective [22]: “*My parents do this for me*”. They do not see the need for professional support in issues related to school, friends or leisure activities [9], in finding a job [30], or in becoming more independent [17]: “*That’s what I have my mother for!*” The opinions of professionals are not questioned: “*If the doctor says so, I believe him*”.

Searching for information about the disease or treatment [3] is not something these adolescents would do: “*I surely wouldn’t look it up myself*”, “*I just don’t want to know too much about it*”. Accordingly, they are not in favour of taking an exam about their disease [15]: “*One surely wouldn’t take an exam about one’s disease! If you don’t know, you can ask your doctor*”.

These adolescents are also not very involved with their health. They consider themselves to be just like others, only with a disease on top [34]: “*Mentally I’m okay, but physically things are a bit less*”. Still, they do not pretend nothing is wrong [25]: “*Because, actually there is something and if you try and pretend there is not, they will find out anyway. But I’m not upfront about it. If people ask, I tell.*” They are also not particularly engaged with transition to adult care, but they are not looking forward to leaving paediatric care [31]: “*I really appreciate Sophia Children’s Hospital, it is familiar*”. Still, thinking about the future and discussing future plans with health professionals “*does not interest me at all*” [18].

All four adolescents comprising this profile were girls, with a mean age of 15 years (range 12–17). They had serious congenital disorders with a considerable impact on daily life. They regularly visited the outpatient department and had been hospitalized as well.

3.5. Preference profile C: ‘Self-confident & Autonomous’

These adolescents strongly feel the need to be upfront about their chronic condition [25]; they do not hide behind their disease, they live with it: “*If you suffer from something, you just have to come forward; otherwise you’ll pay the price*”. The chronic disorder does not make them different from healthy peers [34]: “*It is a fact that I take medicines and sometimes have to stay in the hospital, but for the rest I am just the same and like to be treated as such*”. They strongly feel that enjoying life now is more important than being fully adherent to treatment [26]: “*Everyone sometimes skips their treatment. That should be possible! I don’t think there is anyone who’s always compliant with the rules. One should not give up things because of an illness. . .*”

In the same vein, they do not seem to worry much about their disease or health [36] and do not need help from health professionals in managing their care and independence [3; 17; 21] or from parents [6; 16; 20]: “*I can stand up for myself!*” They feel confident about their knowledge of their condition, but like to know the consequences of their treatment and of non-adherence [5; 11]. Compared to

other profiles, they are the only ones who will change treatment if felt necessary [33], sometimes after consulting their doctor or parents, but not as a general rule: “*Well, if I should have to call the doctor for every little detail, he would go mad*”. Self-confidence and a strong desire to being autonomous in decision-making characterize these adolescents.

The four adolescents comprising this profile were two boys and two girls from the older age group (mean age 17, range 16–19 years). All were diagnosed early in life and two of them were frequent hospital visitors.

3.6. Preference profile D: ‘Worried & Insecure’

These adolescents are most of all worried about their disease [36]: “*there are so many consequences when things go wrong*”, “*one just doesn’t know how things become later on, what you’re still be able to do*”, “*for example, I might get a heart disease or die earlier*”. They prefer to pretend nothing is wrong with them [25] and to be like anyone else [34], mainly because it prevents them from worrying: “*That way I feel better. . . pretending I belong with the others*”. They think that living an easy life now is to be preferred over full therapy compliance [26].

Being insecure, they do not feel bothered by unsolicited health advice [37]. They feel they need more information about difficult and sensitive issues such as sex and procreation [14]. They are not opposed to welcoming professional support in learning how to manage their disease [7] as “*that makes becoming independent easier, if you don’t have to do everything on your own*”. But they do not want support from health professionals in other areas, like job finding, applying for services or living independently [17; 30]; thinking about the future confronts them with the possible unpleasant consequences of their disease [18]. Unlike others, these adolescents do not want to have a say in when to transfer to adult care [8].

Adolescents in this profile appreciate their parents’ support during consultations [6], i.e., reminding them of therapy adherence and appointments [20].

Three girls comprised this profile (mean age 16 years; range 13–16). Two had recently acquired conditions with considerable impact on daily life. All had visited the outpatient department over six times in the past 2 years.

3.7. Differences and similarities between profiles

The four preference profiles differ particularly on five of the seven themes contained in the Q-set of statements (Table 1): (adherence to) therapeutic regimens; self-efficacy with relation to independent health behaviours; information provision; type of physician–patient communication and disease perception (being worried/feeling different). Differences are less pronounced with respect to adolescents’ preferences for the organization of care and contact with fellow patients.

Adolescents in profiles A and C feel more independent and display a higher degree of self-efficacy than those in the other two. However, these profiles are characterized by different attitudes toward treatment adherence. While ‘Conscious & Compliant’ adolescents prefer to adhere to

treatment to avoid future health problems, 'Self-confident & Autonomous' adolescents consciously decide to be non-adherent, preferring an easy life to continuous awareness of disease. The profiles B and D share a common feeling of dependency and lack of self-confidence, but for different reasons. 'Backseat Patient' adolescents lean on their parents because they feel uninvolved and incompetent. Leaving responsibility to their parents and having parents do the talking is easier for them. 'Worried & Insecure' adolescents lack confidence because they worry about their future health. They need their parents to support them in coping with insecurities.

With respect to information provision, adolescents in profiles A and C want to know about the consequences of their condition for daily life [11]. On the other hand, 'Worried and Insecure' adolescents would rather not know – so as to avoid anxiety. 'Backseat Patients' do not see the need of being informed, their parents ought to know.

Adolescents are positive about current care in the Sophia Children's Hospital. All but 'Worried & Insecure' adolescents want to have a say in when to transfer to adult care [8]. Only the 'Backseat Patients' agree that they are not looking forward to go to another hospital when they turn 18 [31]; the others do not seem to mind. Contact with fellow patients is desirable for 'Self-confident & Autonomous' adolescents only [28], preferably through the hospital [31]. This is in contrast to adolescents constituting the 'Conscious & Compliant' profile.

Apart from differences, adolescents' preferences also show similarities. Consensus among profiles was found on five statements (i.e., no statistically significant difference in ranking of statements between any pair of profiles; $p < .05$). All adolescents want to have a say in important treatment-related issues [24]. Adolescents do not expect professionals to play a major role in supporting their independence [7] or discussing future plans [18]. They are *not* opposed to doctors asking personal questions in front of their parents [4], probably because they are used to having their parents present during consultations. Nevertheless, when sensitive issues such as sexuality and heredity are raised, parental presence "*may be sometimes inconvenient*". All types of adolescents would like to have the opportunity to talk to doctors and nurses alone [2], even 'Backseat Patients' for who it is strongly important to have parents present during consultations [6].

4. Discussion

This study demonstrates that not all adolescents with chronic conditions share common ideas about their illness and treatment: some are care-free, others worry about their health. With respect to self-management and adherence to treatment regimens it appears that one group favours 'a good life' and autonomy over following a strict regimen; whereas another group is concerned about future consequences of sloppy adherence. A Q-methodological study among young adult renal transplant recipients (Tielen et al., 2008) found two profiles associated with non-adherent behaviour; while in a third one, young adults ran a higher risk of depression. Unlike in the present study, preferences on the parents' role did

not play a decisive role in differentiating between the profiles, possibly because the transplant recipients were older.

Preferences for information provision also vary, indicating that the desire to be fully informed is not a common trait, in contrast to what was suggested in a study of young cancer patients (Zwaanswijk et al., 2007). Other studies have stressed the importance of concrete, practical advice (Woodgate, 1998a,b) and of using understandable, jargon-free language (Beresford and Sloper, 2000). The fact that most adolescents in our group desire to know the consequences of a treatment for their daily life [11] confirms this. Still, young people report they cannot always rely on professional advice, because it does not conform to their life situation (Karlsson et al., 2008). Wanting to be informed does not imply, however, that adolescents will actively seek information themselves. 'Self-confident & Autonomous' and 'Backseat' adolescents indicate that they have no intention of doing so [3].

Several studies indicated that adolescents with chronic conditions give highest priority to a physician's honesty and expertise (Britto et al., 2004; Farrant and Watson, 2004; Klostermann et al., 2005). Honesty was not included in the present study, but the fact that most adolescents (except the 'Backseat Patient') do not mind it if health professionals give them a good talking about the consequences of suboptimal adherence to treatment [29] seems to corroborate this finding. Issues of confidentiality, familiarity and privacy have also been reported to be of importance (Beresford and Sloper, 2003; Freake et al., 2007; Klostermann et al., 2005), but are not so prominent in our Q-set. Most adolescents do not worry about physicians asking private questions in front of their parents [4]. For that matter, adolescents with chronic illnesses are more comfortable involving parents in their care than are healthy adolescents (Klostermann et al., 2005). Parental encouragement increases teenagers' certainty in performing self-management tasks (Karlsson et al., 2008).

Yet, adolescents in profile 'Conscious & Compliant' and 'Self-confident & Autonomous' prefer to be treated as adults [12] and to have communication directed to them rather than to their parents, as was reported before (Beresford and Sloper, 2003; Britto et al., 2004). Still, adolescents have different preferences with regard to communication, being treated as an adult (Freake et al., 2007; Wray and Maynard, 2008), level of involvement in decision-making (Dovey-Pearce et al., 2005; Wray and Maynard, 2008; Zwaanswijk et al., 2007) and parental presence during consultations (Beresford and Sloper, 2003; Britto et al., 2004). Our study confirms this: 'Backseat Patients' do not mind their parents doing the talking for them, whereas 'Self-confident & Autonomous' adolescents insist on doing it themselves [16].

Knopf et al. (2008) found that half of the adolescents studied favoured a passive decision-making style followed by one third preferring shared decision-making. Our study confirms these differences in preferred level of involvement, yet all adolescents appreciate being able to have their own say in important matters about their health or treatment [24]. This is related to adolescents' feeling that

they are the very experts in self-management and decision-making (Karlsson et al., 2008).

Several studies indicated that adolescents expect emotional support and encouragement from health professionals (Freake et al., 2007; Woodgate, 1998a,b; Zwaanswijk et al., 2007). Trust is a core concept in the relation between adolescents and health professionals (Britto et al., 2004; Klostermann et al., 2005). Our data suggest that young people appreciate health care staff 'being there' for them while at the same time they are reluctant to involve them in becoming independent young adults.

Finally, most adolescents empathically try to see themselves as normal individuals [34], an important aspect of growing up with chronic illness (Taylor et al., 2008). Only the 'Backseat Patient' is less pronounced regarding disease perception. Except for the 'Worried and Insecure' adolescents, worries about health do not figure prominently, like in the general adolescent population (van Exel et al., 2006).

4.1. Strengths and limitations of the study

A key element for interpretation of the results is combining the statistical results with the motivations by participants, marking the hybrid character of Q-methodology. Although this involves extensive interpretative work, it is firmly based on results from common statistical procedures (Jedeloo and van Staa, 2009). Compared to conventional factor analysis, a strong point of Q-methodology is its use of the language of the population under study. Q-analysis does not only reveal scores on individual items but also links these to motivations provided in individual interviews.

Careful design of the Q-set is pivotal, as the opinion statements should be representative for the study topic (Akhtar-Danesh et al., 2008). We feel our Q-set to be broadly representative, but do not claim that all subjective constructions relevant to this field have been exhaustively identified.

Participants were sampled on age, sex, nature of the condition and recent hospital experience. Other potentially relevant characteristics, such as severity of the condition and impact on daily life could not be assessed beforehand.

The non-response in this study was fairly high (53%), but because there were no significant differences between participants and non-participants on selected variables, we do not expect that the non-participating individuals would have comprised a separate profile. We do not think that the single-centre recruitment strategy has influenced the findings of this study. The Erasmus MC - Sophia Children's Hospital is the largest university children's hospital in the Netherlands, servicing a wide area and involving all paediatric subspecialties.

Q-methodology clusters respondents according to their ranking of the statements presented, whereas conventional factor analysis clusters statements according to respondents' ratings. The focus on similarities and differences elicits the diversity of viewpoints and helps avoid the tendency to concentrate on commonalities between participants (Akhtar-Danesh et al., 2008). But the results of a Q-methodological study can only be

generalized to the study topic, not to the wider population of respondents. Therefore, based on this study, it is not possible to make inferences about the relative distribution of the profiles or their associations with personal characteristics of participants. This form of representativeness plays no role in Q-methodology (Watts and Stenner, 2005). Some tentative hypotheses about associations between profiles and patient characteristics can however be made. For example, younger teenagers and girls are more likely to be 'Backseat Patient' or 'Worried & Insecure', older teenagers more likely 'Self-confident & Autonomous'. Adolescents with a congenital disorder and a considerable burden of disease are more likely to be 'Backseat Patient' or 'Self-confident & Autonomous', while those with a more recently acquired disorder will tend to be 'Conscious & Compliant' or 'Worried & Insecure'. Finally, the 'Worried & Insecure' might be prone to depression and experience a lower quality of life.

Because the study sample included adolescents with a wide range of chronic conditions, nothing can be said about possible relations between profiles and specific chronic conditions. A survey study which presents the four profiles to a representative sample of adolescents could reveal this type of information and is intended.

As demonstrated earlier (Tielen et al., 2008; van Exel et al., 2006), applying Q-methodology among adolescents is quite successful in triggering adolescents to speak freely and extensively about their own views and preferences. In the course of the study we learned that health care professionals valued this specific characteristic of the method, making Q-methodology potentially useful for clinical practice.

4.2. Clinical implications

This study demonstrates that there is no "one size fits all" approach to adolescent health care, but that irrespective of individual differences between patients, a limited number of distinct preference profiles can be identified. There are also aspects that all adolescents share an interest in; they value the opportunity to have both voice and choice in decisions regarding their care. Knowing this, nurses and other health care professionals would do well to strive for a personalized approach and a more adolescent-centred health care system. Therefore, a priority for further research is developing more differentiated strategies, related to each of the four profiles, to stimulate adolescents' self-management competencies.

Most nurses and other health professionals involved in adolescent health care would welcome a simple screening instrument that helps identify potentially risky situations in clinical practice, such as over-dependence, lack of self-confidence and non-adherence, sooner and better. Motivated by this interest, we used abbreviated factor descriptions (Appendix A) as a first test of such an instrument. To avoid undesired response effects, names of the profiles were not to parents or adolescents. Although the profile descriptions refer to general attitudes and preferences for self-management and hospital care and do not address disease-specific tasks or skills, they still seem potentially useful in a range of clinical settings. Nurse

specialists working with youth with different chronic conditions recognized the typologies and saw the descriptions as helpful in stimulating discussion with patients. Also, adolescents could easily recognize and identify themselves with the profiles.

Furthermore, adolescents' attitudes and preferences may develop over time. These abbreviated profile descriptions may therefore also be useful as part of a clinical assessment tool to measure changes in autonomy and preferences in adolescents with chronic conditions. These are issues of particular importance for future studies.

5. Conclusion

Q-methodology enabled us to identify four general clusters of adolescents with chronic conditions in terms of their priorities and preferences for health care provision, self-management and adherence. Irrespective of individual differences between adolescents, a limited number of distinct preference profiles could be identified. This study demonstrates the value of a non-disease-specific approach, as the preference profiles are recognizable to adolescents with various chronic conditions. There are also aspects that all adolescents share an interest in; they value the opportunity to have both voice and choice in decisions regarding their care. Knowing this, nurses and other health care professionals would do well to strive for a personalized approach and a more adolescent-centred health care system.

Use of these profiles in clinical practice could stimulate a much needed conversation between adolescent patients and their providers and needs to be further explored. Further research should also reveal the relative distribution of these four profiles in the broad population of adolescents with chronic conditions and the associations with personal characteristics such as sex, age and educational level and disease-related characteristics, such as type of chronic condition, severity of illness, and disease duration.

Acknowledgements

We thank all young people who participated in the study and appreciate the contribution of students from Rotterdam University. Margo Trappenburg and Ko Hagoort are thanked for their thoughtful comments on earlier drafts of this paper.

Conflict of interest

The authors have no conflict of interest to declare.

Funding

This work was funded by ZonMw, the Netherlands organization for Health Research and Development (Grant number 32560005). The sponsor was not involved in the project planning, data collection and analysis, the paper and the decision to submit the paper for publication.

Ethical approval

The study protocol was approved by the Medical Ethics Review Board of Erasmus MC, University Medical Center Rotterdam (MEC-2004-343).

Appendix A. Abbreviated descriptions of preference profiles

How well does this profile fit you?

A = Conscious & Compliant

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.

B = Backseat Patient

I am not too bothered about my disease; my parents will take care of this. They are helping me with my treatment and see to it that everything is in control. I think it will be pretty difficult to take care of this myself. I don't need to know everything in detail, if my parents do, it's okay. When I'm at the doctor's, it's convenient to have my parents with me; they can do the talking for me. I find this difficult and actually, I'm not too interested. But the doctors shouldn't treat me like a child, nor tell me what I'm doing wrong. That's my parents' job. I'm not ready yet to leave the children's hospital and go to adult care.

C = Self-confident & Autonomous

Living easy now is more important to me than being completely compliant. It's me who decides how to live; I won't have my disease limit me in daily life. I'll change my own treatment if this suits me better. I am capable of doing this myself, for I know enough about it. I do want to be treated like an adult and do my own talking. I don't need my parents for that. No one needs to hold my hand, but I do find it convenient to get information. Though this does not mean I will always use it.

D = Worried & Insecure

I'm pretty worried about my disease. Suppose things will turn for the worse later. Sometimes, through my illness, I don't feel at ease with myself, but I try not to think about it too much. I'd rather pretend there's nothing wrong with me. I do not always take advice too seriously, that way I don't have to think about my disease. But I do need my parents and health professionals to help me discuss difficult subjects that are important for my future. I feel more secure about myself if they tell me how to live best. *Note:* Profile names are not provided when the descriptions are presented to adolescents or parents.

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