Views of Young People With Chronic Conditions on Transition From Pediatric to Adult Health Services


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ABSTRACT

Purpose: This study sought to identify and describe the views of young people with chronic conditions about the transition from pediatric to adult services.

Methods: Q methodology was used to identify young people’s views on transition. A set of 39 statements about transition was developed from an existing literature review and refined in consultation with local groups of young people. Statements were printed onto cards and a purposive sample of 44 young people with chronic health conditions was recruited, 41 remaining in the study. The young people were asked to sort the statement cards onto a Q-sort grid, according to their opinions from “strongly disagree” to “strongly agree.” Factor analysis was used to identify shared points of view (patterns of similarity between individual’s Q sorts).

Results: Four distinct views on transition were identified from young people: (1) “a laid-back view of transition;” (2) “anxiety about transition;” (3) “wanting independence and autonomy during transition;” and (4) “valuing social interaction with family, peers, and professionals to assist transition.”

Conclusions: Successful transition is likely to be influenced by how young people view the process. Discussing and understanding young people’s approaches to their transitional care and what they view as important. Much of the evidence about young

Transition is defined as “the purposeful, planned process that addresses the medical, psychosocial, educational, and vocational needs of adolescents and young adults with chronic medical and physical conditions as they move from child-centred to adult-oriented health care systems” [1]. Transfer is the event when responsibility for health care is passed from a pediatric to an adult provider. Some young people find transition difficult [2]. Suboptimal or needs-inappropriate transition are well documented nationally and internationally [3–7] and include poorer long-term health, social, and educational outcomes [8–11]. To improve services, policy-makers, and clinicians need to understand young people’s approaches to their transitional care and what they view as important. Much of the evidence about young

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people’s views on transition is specialty or condition specific [2,12–16] with some notable exceptions [17–19]. Therefore, it is unclear what are the most important generic components of clinical services that should be provided during transition and at the point of transfer.

The Transition Research Programme [20,21] aims to establish how successful transition can be facilitated in the United Kingdom to improve health and social outcomes. One component of this research seeks to elicit young people’s preferences for health care provision during transition; these are likely to depend on personal circumstances for both the health and nonhealth aspects of their lives. Thus, we expect there to be a variety of distinct views that young people have toward transition. We aimed to identify and describe these views using Q methodology.

**Methods**

Q methodology combines quantitative and qualitative methods to investigate the range of possible views about a particular subject. Watts and Stenner [22], in their guide to Q methodological work, recommend it where the answer is “particular subject. Watts and Stenner [22], in their guide to Q methodology, recommend it where the answer is “yes” to the questions “Does it really matter what people...think about this issue?” and “Can revelation of their views really make a difference?” It has been used widely with young people [23–26], including in studies on health and chronic disease management [27–29]. A Q methodology study has two key phases (1) data collection via the rank ordering of a set of statements by participants in a Q-sort and (2) by-person factor analysis of these Q-sorts to reveal shared perspectives on the topic [22].

**Q-set development**

For this study, a set of statements (Q-set) about issues that might be important to young people about transition were identified from quotes found in qualitative studies that had informed a previous review on transition [30]. These were coded into a set of emergent themes: “planning,” “staff related,” “maturity,” “parent related,” and “other.” Statements were coded to more than one theme if they contained aspects of two themes or merged if they described the same aspect of transition. All were then recategorized into a larger number of more specific themes. One representative statement from each theme was selected, creating a draft list of final statements. As it was important to have a set of statements which had balance between positive and negative statements, we adjusted the wording of a small number of cards to ensure there were not more for which there would be likely to be agreement rather than disagreement. This final list of statements was then discussed with young people who were already volunteers in two young person groups The first group, United Progression consisted of young people with chronic conditions specifically convened to advise researchers and clinicians involved in the Transition Research Programme [20,21]. The second group, the Child Health Action Team consisted of young people that a local National Health Service (NHS) Trust (health care provider organization) consults about service development and medical education. Both groups provided feedback on the clarity and suitability of language used, whether statements were easy to comprehend, and suggested additional statements. This process (summarized in Figure 1) led to the final Q-set. Each statement was then printed on a separate piece of card ready for the Q-sort, whereby cards are “sorted” onto a grid (Figure 2) depending on the respondent’s level of agreement or disagreement with each statement.

**Conducting the Q-sort**

Participants had to be 14–22 years old and have a chronic condition that would soon require or had already required transfer from pediatric to adult services. Those with intellectual disability that would make it difficult for them to make the tradeoffs or hypothetical choices required by the Q-sort were excluded. Participant sampling in Q methodology is purposive; seeking to identify data-rich participants. Sampling does not aim to achieve representation of the population but rather to recruit participants that may hold different views on the topic [31]. Our sample was recruited to ensure a range of gender, age, health condition, and stage in the transition process. We sought to recruit about 45 participants, aiming for data “saturation” when no new views emerge and additional participants only confirm the existing factors. Clinicians in 10 pediatric and adult specialties from one health care provider invited young people to take part.

Each Q-sort was administered by the researcher in a face-to-face setting. Consent was sought from the participant and, if aged younger than 16 years, their parent or carer. The researcher explained the process and asked each participant to sort the Q-set cards into three bundles: statements they disagreed with, agreed with, or about which they were not sure. The participant was then asked to rank order the cards onto the grid from “strongly agree” through to “strongly disagree” (see Figure 2). Then the researcher asked each participant open-ended questions about why they had placed particular cards in specific positions, particularly the extreme columns, and asked if they had any comments on transition or the Q-sort process, in accordance with best practice guidance for the conduct of Q-sorts [32]. To ensure the young people felt comfortable, recording devices were not used and participants had the option to write responses if they did not want to say them.

**Data analysis and interpretation**

Q methodology uses “by-person” factor analysis to identify underlying shared similarities between Q-sorts. Emerging from this are “Factors” (distinct views). The degree to which an individual’s Q-sort corresponds to each factor is given by their “factor loading” which is a correlation coefficient between −1 and +1; the closer to 1 the more similar an individual’s Q-sort is to the factor. Individuals are “exemplars” for a factor if they have a significant factor loading on that factor alone (at the .01 level). PQMethod software [33] was used to analyze Q-sorts using centroid factor analysis followed by varimax rotation [22]. Outputs include the number of exemplars per factor, eigenvalues and factor variance which provide information on the proportion of variance for the entire study explained by each factor. These are used alongside the postsort qualitative information to determine the “factor solution”: the final number of factors identified.

For each factor an idealized “composite” Q-sort is computed, illustrating how a person with a factor loading of 1 would have laid out their statement cards. Attention is paid to statements which characterize each factor, for example those placed in
the +3 and –3 position on the grid, and those statements which distinguish between factors.

Ethics

Ethical approval was obtained from Newcastle and North Tyneside 1 Research Ethics Committee (12/NE/0206); research and development approval was received from the Newcastle Upon Tyne Hospitals NHS Foundation Trust (Reference: 6249).

Results

Figure 1 shows the Q-set development process. A total of 200 statements were discarded because they were study context or condition specific, for example, mentioning specific medications or limitations associated with having a particular condition that may not be relevant across all chronic conditions. After consultation with the young people, the Q-set of 39 statements was finalized (see Table 1).

Forty-four participants were recruited between March 2013 and November 2013; 23 female, 21 male; age range 14–22 years (mean 17); 26 from pediatric, 18 from adult clinics. Data from three participants were excluded from analysis because they did not complete the Q-sort, leaving 41 participants from nine specialties (Table 2). Thirty-eight participants gave verbal feedback on their chosen card positions, yielding 174 comments (available from the authors on request). The remaining three participants did not want to or did not have time to comment.

Factor analysis suggested solutions of three to seven factors should be considered. Eventually, a four-factor solution was judged to be both statistically optimal and most meaningful given the comments from participants.

Table 1 shows, for each composite Q-sort factor, the list of statements by their column on the Q-sort grid (Figure 2). In the description of the factors in the following section, the statement numbers are in parentheses, along with the column for that statement i.e., (#3, +1) means statement 3 is placed in the +1 column of the Q-sort grid.

Factor 1: a laid-back view of transition ("laid-back")

For the young people associated with this factor transition was not a particular worry (#11, +2). As one participant noted “[It will] not make much difference transitioning. For different people [it] might be a big issue but for me [I was] not bothered” (ID2785). They expected new doctors to provide similar care in adult and pediatric clinics (#13, +2) so that after transfer it would be the same. They were happy to take instruction from staff about how to manage their condition (#17, +3) and wanted their parents to continue being involved in their care (#7, –3 and #38, –2). They did not find it difficult living with their condition (#2, –2), “[it] isn’t that bad that I need support or help” (ID7417) and felt that their condition did not affect every aspect of their life (#15, –2). They did not think they needed extra support (#20, –3) but neither did they think that anyone would judge them if they got extra support (#25, –2). They were not worried
about facing discrimination in the future because of their condition (#32, +3). They wanted to be well informed about their condition, including receiving information in a variety of ways (#10, /C0 3 and #17, +3 and #31, +2). As one participant noted “You can’t be sure that you receive proper care and treatment if you aren’t informed of how your condition affects certain aspects of your life, even if they may be embarrassing” (ID9263). Five pre-transition and five post-transition young people form this factor.

Factor 2: anxiety about transition (“anxious”)

In this account transition is a worrying event, and as one participant noted “I don’t like change” (ID5956). Transition mattered very much to this group (#11, –2). In particular, the point of transfer was considered important; they did not want it to happen at a set age (#12, –3), and they wanted a written plan in place (#33, +3) beforehand. They thought that some planned processes (e.g., going to the adult clinic beforehand and meeting all the staff) would not make the process of transition any easier (#19, +2). They had strong feelings about their relationships with staff and thought that a new doctor after transfer would provide different care (#13, –2). One young person noted “[There’s] fewer checks at the adult clinic” (ID8515). They felt attached to their doctors, felt a need to be able to say goodbye (#27, –2), and that seeing different doctors was not conducive to building up trust (#36, +2). Such trust was clearly important to them as they disagreed with the statement “The doctors should give you suggestions and choices about treatments and services, but you should make the decisions and they should respect that and not try to change your mind” (#16, –2). However, they also indicated that they wanted to know all the things that could possibly happen with their condition in the future (#10, –3).

They agreed it was difficult living with their condition (#2, +2), one participant said “As I get older I realise how much I cannot do because of my condition. This makes me think ahead of myself, always worrying about what could go wrong” (ID 3120). They also felt that there was no area of their life that was unaffected by their condition (#15, +3) but disagreed that they already knew what kinds of support were available/going to be available to them in future (#34, –2). They wanted their parents to have input into their care (#37, –3), feeling strongly that transition should cater for those around them (e.g., friends and family) too (#39, +3) as “It affects the people around me. We’re a close family. I’m doing better than them mentally about it because they’re not catered for” (ID2919). Three pre-transition and three post-transition young people form this factor.

Factor 3: wanting independence and autonomy during transition (“autonomy-seeking”)

Young people associated with factor 3 were characterized by their desire for the withdrawal of parental involvement in their care. As one young person stated “I can manage fine on my own” (ID3216). They agreed that their parents were too involved in medical decisions about them (#7, +2), and did not want their parents’ input into their care anymore (#37, +3). They also agreed that having the doctor speak to their parents rather than the young person made them feel as although the doctor did not want to know them (#38, +3). “The doctors talk to my parents if they’re there...Mum would reply so what’s the point in [me] being there? [I] Might as well have sent my mum” (ID1584). If struggling to get their parent(s) to understand their point of view, they did not want the doctor to intervene and talk to their parents on their behalf (#8, –3); they wanted the doctor to give
“It’s not really about age. How long you’ve had your condition can make much more of a difference to your ability to handle it as you get older.”

“Sometimes it’s so difficult living with my condition. Some situations are really tough and it’s so hard to just get on with it all the time.”

“Sometimes even just taking the bus is difficult, so leaving home and cooking all my meals would be a big shock.”

“You need to be organised with money to live independently. You have to know about insurance and stuff and make sure you have enough money to pay the bills.”

“It can be difficult if the doctor asks if students can be there at your appointment. You feel awkward. You don’t want some young, fit, student doctor there when you’re having a bad day and feeling really self-conscious.”

“I don’t get intimidated if there are lots of people in the room, so I wouldn’t find it hard to ask for more privacy in front of everyone if I felt I needed it.”

“My parents are too involved in medical decisions about me. They don’t want to let go. They’re afraid of change.”

“If I’m struggling to get my parents to understand…if my doctor could talk to them on my behalf, explaining things from my point of view; that would really help.”

“It’s important that doctors at least mention things like smoking, sex, and drugs because these topics may be going to affect your life and your health so you need to know about them.”

“It’s my body, but I actually don’t want the doctor to tell me absolutely everything. I don’t think it’s better to be told about all the things that could possibly happen with my condition in the future.”

“Transition doesn’t matter that much to me. I’m not too interested.”

“Transition should just happen at a set age. The doctors and nurses can’t just wait because you don’t feel ready for it yet.”

“Even if your doctor changes, the new ones are still going to give you the same care, they’ll still want you to be doing the same things. It’ll be just the same really.”

“When you come to the clinic, you get completely sick of listening to the staff always saying ‘do this and do that’. And then you think ‘What’s the point in even coming to the clinic?’”

“There is no area of my life that my condition does not affect.”

“The doctors should give you suggestions and choices about treatments and services, but you should make the decisions and they should respect that not try to change your mind.”

“Transition doesn’t matter that much to me. I’m not too interested.”

“Almost every time I go to the adult clinic beforehand and meet the adult clinic staff and talk to them, I don’t think that kind of planning really makes transition that much easier.”

“I need extra support to help me do things or I think I’ll struggle more in the future.”

“Adult services need to be flexible. You might be working full time and it would be difficult to get time off for appointments.”

“It would be good if there was always a particular person at the clinic who could help me plan the practical side of managing my condition, like making the appointments.”

“You feel relaxed, more confident when you’re regularly around people who are the same age and who have the same or a similar condition. You kind of bond with them. It’s a relief to know other people understand.”

“A bit more time with the medical staff would be nice. Sometimes it’s hard to process information when my appointments are so short.”

“I don’t think anyone would judge me if I got extra support.”

“I hate when the clinic is running late. If you turn up on time for your appointment you shouldn’t be waiting around the clinic for ages.”

“You’re not really attached to the doctors. It’s not like you really need to say goodbye when you move.”

“At the pediatric clinic, you’re sitting on a little miniature kids chair surrounded by teddies and dolls, but I’d still prefer going there than to the adult clinic.”

“Different people need different strategies. Each person is unique. You want to be listened to and treated as an individual. We’re not the same just because we’re the same age or because we have the same condition.”

“If he or she doesn’t care about the other aspects of my life like my social life, education or my plans for the future, it doesn’t really matter.”

“It would be better if sometimes you could get information about your condition in a variety of ways, like books or video clips, rather than always just from listening to the doctor.”

“I’m not worried about things like discrimination. I don’t think people will refuse to give me a job or something because of my condition.”

“You should have a written plan about moving to adult services, to help you to know what’s going to happen and when.”

“I already know what kinds of support are available out there for me now, and what will be available to me when I get older.”

“Sometimes it’s so difficult just getting to and from the clinic. Sometimes waiting around the clinic for ages.”

“Different people need different strategies. Each person is unique. You want to be listened to and treated as an individual. We’re not the same just because we’re the same age or because we have the same condition.”
them suggestions and choices, and strongly agreed that staff should let the young person make the decisions (#16, +2).

This group also indicated they were developmentally ready for the final stages of transition, disagreeing that leaving home and cooking meals would be a “big shock” (#3, −2); they agreed most strongly of all the groups that “You need to be organised to accommodate young people who might be working full time and unable to get time off for appointments (#21, +3). One participant at college argued “My studies are important...I don’t want to miss them to come to the hospital” (ID1584). There was also a preference for leaving pediatrics and its environment surrounded by “teddies and dolls” (#28, −2) as “You can manage a lot better than little kids” (ID 8283). They did not feel that the length of their appointments was too short to process information properly (#24, −2).

This group showed some apprehension about transfer; they did not agree that meeting adult staff beforehand would make it less easy (#19, −2); this may indicate they value all available options to help them prepare. They also agreed that if they did not see the same doctors they could not develop trust (#36, −2). However, they disagreed that they needed extra support (#20, −2) and were not worried about discrimination (#32, −3); but they did think they would feel self-conscious (#5, +2) if the doctor asked whether students could sit in on appointments. Two pre-transition and one post-transition young people form this factor.

Factor 4: valuing social interaction with family, peers, and professionals to assist transition (“socially oriented”)

For the young people associated with this factor, it is important to interact and socialize with those involved in their care. They also strongly agreed they would feel happier around other young people with the same or similar conditions (#23, +3). One noted “we would have a lot in common” (ID4432) and another mentioned “When you...see how they’re coping, it’s reassuring” (ID9859). They felt more strongly than any other group that it was important for doctors to mention things like smoking, drugs, and sex (#9, +3). As one participant stated “Doctors need to mention things like drinking because you want to do it, but safely” (ID8090).

They continued to want parents involved in their care (#37, −3) and in medical decisions about them (#7, −3) and showed a willingness to have their doctor intervene on their behalf if they were struggling to get their parents to understand (#8, +2). One participant justified this by saying “I love my parents being involved. It means I’m not alone. I want them to know what’s going on, it means you have someone there for you” (ID9084).

They also felt that it was important for the doctor to care about other aspects of their life (e.g., social life, education, and plans for the future) (#30, −2). They did not find it difficult if the doctor asked whether students could be there during their appointments (#5, −2). They disagreed with the statement about not being attached to the doctors and not needing a chance to say goodbye before transfer (#27, −2); one participant noted “I’ve always been friendly with the doctors. Close and comfortable with them. It wouldn’t be appropriate not to say goodbye” (ID8382). They also expressed a preference for having a particular person at the clinic to help them plan the practical side of managing their condition (#22, +2). They felt there was no area of their life unaffected by their condition (#15, +2) and did not believe that attempting to get extra support to help them manage this was pointless (#35, −2).

Six pre-transition and two post-transition young people form this factor.

Discussion

This research is among the first to use Q methodology with young people from across a broad range of chronic health conditions to identify their views about transition. We identified four clearly distinct views toward transition: a relaxed view of the process (F1: “A laid-back view of transition”); an anxious attitude (F2: “anxiety about transition”); a desire for greater responsibility within and outside health (F3: “Wanting independence and autonomy during transition”); and a focus on social aspects of care (F4: Valuing social interaction with family, peers, and professionals to assist transition).

A key finding from this study is that young people do not have one view on transition. This is important information as it indicates that a “one size fits all” approach to transition is not appropriate. Indeed one of the few consensus statements was statement 29 (“Different people need different strategies. Each person is unique....”) which was strongly agreed with in all four
factors. It is important for clinicians to appreciate better that young people take different approaches to transition; health care staff should work within these varied parameters, rather than expecting every young person to conform to a view of what is the “sensible,” “logical,” or “mature” view to hold or approach to adopt.

As with all Q methodology studies the purpose was not to estimate from the findings how many people with chronic health needs undergoing transition may hold each point of view and nor is it possible because participants were purposively sampled. Therefore, this study cannot say how many of the wider population in transition hold each view or identify relative proportions in subgroups such as by age, sex, or pretransfer and post-transfer.

Our findings from more than 40 participants are similar to those of a Q-sort study in 31 adolescents, receiving health care but not necessarily with chronic conditions, of their preferences for health care and self-management [27] which also identified four factors; the “back-seat patient,” “worried and insecure,” “self-confident and autonomous,” and “conscious and compliant.” These first three factors have many similarities to our first three. We would have been unlikely to identify their fourth “conscious and compliant” group because their study examined preferences for self-management and health care, while our study examined the broader concept of transition. However the similarities are striking, adding weight to the validity of the findings and suggesting that young people’s views about transition are essentially similar to views about adolescent health care [34].

Two reviews of qualitative studies on the issue of transition identify themes common to that literature. The first [2] identifies four main areas of inquiry: patients’ feelings and concerns; patients’ recommendations about components of transition services; outcomes after transfer; and mode of transfer. Among the feelings and concerns, views about trust, anxiety, dependency, uncertainty, and independence were revealed and these are included in our Q-set. The second review [35] examined the point of transfer and identified four major themes:

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The significance level for factor loadings is taken as 2.58 (SE). SE represents standard error that is defined as 1/√N where N is the number of statements in the Q-set. In this case then, 2.58 (SE) = 2.58 (1/40) = 41. Significant loadings are shown in bold type.

The automatic flagging procedure in PQMethod software was used to identify defining sorts (*) that flags according to the following rule: Flag loading: if (1) a ≥ b²/2 (factor “explains” more than half of the common variance) and (2) a > 1.96/√(N items); loading “significant at p > .05”).
facing changes in significant relationships; moving from a familiar to an unknown ward culture; being prepared for transfer; achieving responsibility. Again these are themes included in our Q-set. However, the themes from these two reviews do not reveal how individuals approach these dilemmas. We think our results add a fundamental new dimension, revealing four views on how young people engage with the transition process. Recognition of these approaches should help health care providers explore with young people how they approach their transition, rather than cataloguing potential problematic issues.

Q methodology elicits young people’s opinions without requiring them to be expressed verbally. This is a well-known advantage of Q methodology [36,37] where respondents may have strong views about a subject but find it difficult or embarrassing to articulate them.

The selection of statements that respondents are asked to sort is of key importance when using Q methodology. Statements must be broadly representative of opinions which exist on the topic and should be balanced so they are not biased toward one particular view [22]. In developing statements, one area of potential inaccuracy is the inconsistent way the words “transfer” and “transition” are used in the literature and by health professionals [2,38], and the general public. It was also sometimes necessary to alter the phrasing of statements so that there were a roughly equal number of positive and negative statements. We assumed that if a young person agreed with a positive statement they would disagree with its opposite. Although we are not able to be certain that all statements will have been understood correctly and consistently by all participants, care was taken to try to ensure statements were not counterintuitive or confusing; and Q sorts were conducted in the presence of the researcher who could clarify the meanings of statements.

The factors, while useful in their own right, have also contributed to a Discrete Choice Experiment required for a larger longitudinal study [21] to quantify strength of preference for different ways transition might be organized. By doing so, we hope to determine whether having services configured in ways that are preferable to young people can improve the extent to which their transition is viewed as a “success.” From the factors identified in the Q-sort, for the Discrete Choice Experiment, six aspects of transition that had provoked strongly held beliefs were included.

The views of some young people on transition may relate to underlying personality characteristics and therefore may not change substantially over time. However, the preferences of many young people are likely to change somewhat as they move through adolescence and young adulthood due to factors such as developmental maturation or changes in their health status. We would not propose that every young person be formally assessed, with the risk that such assessment might assume a permanence in clinical notes that was not justified. Rather, clinicians need to have awareness of a young person’s style of engagement with transition and consider how changes over time may affect their likely preferences about how their transitional care is provided. This may be assessed through some direct questions which could elicit a young person’s preference for parental involvement, how much written information they wanted to receive, or how much they wanted to be directed rather than being given options from which to choose.

Our results should encourage health care providers to elicit from a young person how he or she is approaching their transition. This immediately shows that the provider is engaging with the patient as a distinct person, rather than using a “one size fits all” approach. Such personalized approaches are desirable in all health care but especially for adolescents in transition where “therapeutic” relationships, rapport, and trust are important as part of Developmentally Appropriate Healthcare [39,40]. Personalization should hopefully lead to more engagement and satisfaction with services, greater compliance with treatment and in turn, improved service use and health outcomes in adulthood.

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