



Original article

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



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A B S T R A C T

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 views and preferences about transition should help clinicians and young people develop personalized planning for transition as a whole, and more specifically the point of transfer, leading to effective and efficient engagement with adult care.

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IMPLICATIONS AND CONTRIBUTION

Young people exhibit a variety of distinct views on transition and may consequently have strong preferences for how their transition is managed. This research will enable clinicians to understand these preferences better when helping a young person through transition.

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 “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

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