Views of young people with chronic conditions on transition from pediatric to adult health services

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Abstract (219 words – limit=250)

Purpose

This study sought to identify and describe the views of young people with chronic conditions about the transition from paediatric 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'*, 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 personalised planning for transition as a whole, and more specifically the point of transfer, leading to effective and efficient engagement with adult care.

Implications and contribution summary statement (39 words – limit=50)

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.

Highlights (3-5 bullet points, 85 characters including spaces max per bullet point, to be submitted as separate file in online submission)

Four views on transition were identified from young people with chronic conditions.

These are: “laid-back”; “anxious”; “autonomy-seeking” and “socially-oriented”.

Recognition of these views may help clinicians personalise young people’s transition.

Main text (3500 word limit) now 3968

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 healthcare systems'.[1] Transfer is the event when responsibility for healthcare is passed from a paediatric to an adult provider. Some young people find transition difficult.[2] Sub-optimal 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 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 UK 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 non-health aspects of their lives. Thus, we expect there to be a variety of distinct views that young people have towards 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, 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?”.[22] 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 re-categorised 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 (UP) 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 (CHAT) consisted of young people that a local NHS Trust (healthcare provider organisation) 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 (summarised 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 paediatric to adult services. Those with intellectual disability that would make it difficult for them to make the trade-offs 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 ten paediatric and adult specialties from one healthcare 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 under sixteen, 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, following 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 0.01 level). PQMethod[33] was used to analyse 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

post-sort qualitative information to determine the 'factor solution': the final number of factors identified.

For each factor an idealised '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 characterise 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. 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. Following consultation with the young people, the Q-set of 39 statements was finalised (see Table 1).

Forty-four participants were recruited between March and November 2013; 23 female, 21 male; age range 14-22 years, (mean 17); 26 from paediatric, 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 specialities (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 below, 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 paediatric 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, -3 and #17, +3 and #31, +2]. As one participant noted "*You can't ensure 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- 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 following 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- 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 characterised 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 though 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 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 live independently"* [#4, +2] which might indicate they were preparing for independent living. They also agreed more strongly than the other groups that adult services need to be flexible 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 paediatrics 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- 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 socialise 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- and two post-transition young people form this factor.

Discussion

This research is amongst 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 towards 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; healthcare 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 pre- and post-transfer.

Our findings from more than 40 participants are similar to those of a Q-sort study in 31 adolescents, receiving healthcare but not necessarily with chronic conditions, of their preferences for healthcare 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 healthcare, whilst 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 healthcare.[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; mode of transfer. Amongst 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: 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 towards 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 counter-intuitive

or confusing; and Q-sorts were conducted in the presence of the researcher who could clarify the meanings of statements.

The factors, whilst useful in their own right, have also contributed to a Discrete Choice Experiment (DCE) required for a larger longitudinal study[21] to quantify strength of preference for different ways transition might be organised. 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 DCE, 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 personalised 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] Personalisation 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.

Table 1: For each factor's composite Q-sort, the list of statements by their column on the Q-sort grid

No.	Text	Position in Factor 1	Position in Factor 2	Position in Factor 3	Position in Factor 4
1	"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."	+2	+2	+1	+1
2	"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."	-2**	+2*	+1	+1
3	"Sometimes even just taking the bus is difficult, so leaving home and cooking all my meals would be a big shock"	-1	-1	-2*	-1
4	"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."	+1	+1	+2	+1
5	"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."	-1	+1	+2	-2**
6	"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."	+1	-1	-1	0
7	"My parents are too involved in medical decisions about me. They don't want to let go. They're afraid of change."	-3	0	+2**	-3
8	"If I'm struggling to get my parents to understand…if my doctor could talk to them on my behalf, explain things from my point of view; that would really help."	0	+1	-3**	+2
9	"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."	+1	0	-1	+3**
10	"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."	-3	-3	0	-3
11	"Transition doesn't matter that much to me. I'm not too interested."	+2**	-2	0	-2
12	"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."	+1	-3**	0	-1
13	"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."	+2**	-2**	+1	-1
14	"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?"	-2	-2	-1	-2
15	"There is no area of my life that my condition does not affect."	-2	+3**	-3	+2**
16	"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."	-1	-2	+2	+2
17	"It's probably important to be lectured on some things if they're going to affect your health so in some circumstances doctors should tell you what to do"	+3	0	-1	+2
18	"Sometimes you feel you know more than the staff. They don't seem to know what they're doing or they just don't get it. It's a real worry."	-2	+1	0	-1
19	"Even if you 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."	-1	+2**	-2	-1
20	"I need extra support to help me do things or I think I'll struggle more in future."	-3**	+1	-2**	+1
21	"Adult services need to be flexible. You might be working full-time and it would be difficult to get time off for appointments."	+2	0	+3	+2
22	"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."	0	-1	-1	+2**
23	"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."	0	+1	+1	+3
24	"A bit more time with the medical staff would be nice. Sometimes it's hard to process information when my appointments are so short."	-1	-1	-2	0
25	"I don't think anyone would judge me if I got extra support."	+2*	-1	0	+1
26	"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."	0	+2*	0	0
27	"You're not really attached to the doctors. It's not like you really need to say goodbye when you move."	+1	-2	+1	-2

No.	Text	Position in Factor 1	Position in Factor 2	Position in Factor 3	Position in Factor 4
28	"At the paediatric 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."	0	+1	-2**	0
29	"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."	+3	+2	+2	+3
30	"If the doctor 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."	0	0	+1	-2**
31	"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."	+2*	-1	-2	0
32	"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."	+3**	0	-3**	+1
33	"You should have a written plan about moving to adult services, to help you to know what's going to happen and when."	-1	+3**	0	0
34	"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."	+1	-2	-1	0
35	"There's probably no point in trying to get support – you'll either not be eligible for it, or it won't be suitable for you, or you'll get caught up in the bureaucracy and never get it anyway."	-1	-1	-1	-2*
36	"If you see different doctors all the time, you can't develop trust. How can you tell them personal things about your life if you don't trust them?"	+1	+2	+2	-1
37	"I don't want my parents to have any input in my care. I don't need them to be there to hold my hand when I go to the clinic anymore, and so I don't think I need their advice about it from now on."	-2	-3	+3**	-3
38	"It's not my parents that have my condition. I'm the one that the doctors should be talking to so when they just talk to my parents it's like they don't want to know me as a person."	-2**	0	+3**	-1
39	"Transition services should not only cater for me, but those around me – how my condition affects them"	0	+3**	+1	+1

Grey boxes indicate statement card was placed on the grid in a column of moderate agreement (+2), strong agreement (+3) or moderate disagreement (-2) or strong disagreement (-3)
*Statement was distinguishing for this factor at the 0.05 level
**Statement was distinguishing for this factor at the 0.01 level

Table 2: Factor loadings for each participant

Participant ID	Gender	Pre/Post point of transfer	Specialty	Loading on Factor 1	Loading on Factor 2	Loading on Factor 3	Loading on Factor 4
3414	F	Pre	Rheumatology	**0.7477***	-0.1695	0.0107	-0.0172
1569	M	Pre	Respiratory	**0.7099***	0.3131	-0.0698	-0.0626
2785	M	Post	Rheumatology	**0.7051***	-0.1827	0.1018	0.2039
7417	F	Post	Rheumatology	**0.6978***	-0.0206	0.2545	-0.005
9263	M	Post	Diabetes	**0.5917***	0.1363	0.1559	0.3963
6379	F	Pre	Renal	**0.5811***	0.0737	-0.0821	0.3451
8478	F	Post	Urology	**0.5778***	-0.0595	-0.0923	0.1419
8636	M	Post	Gastroenterology	**0.5178***	0.1525	0.2449	0.3364
3551	M	Pre	Gastroenterology	**0.4266***	-0.3247	0.0512	0.0064
7893	M	Pre	Cardiology	**0.3681***	0.0451	-0.1146	0.2459
8643	F	Post	Diabetes	0.3291	-0.0967	0.2806	0.239
2919	F	Pre	Surgery	-0.0165	**0.7927***	-0.1904	0.1273
8515	F	Post	Rheumatology	0.1599	**0.6154***	-0.1528	0.2152
2168	F	Pre	Neuro-rehab	-0.0215	**0.5483***	0.1405	0.159
3120	F	Post	Rheumatology	-0.2806	**0.4417***	0.2878	0.1726
8106	M	Pre	Neurology	0.0046	**0.3297***	0.048	-0.115
5286	F	Pre	Gastroenterology	-0.2601	**0.4911**	**0.4323**	0.2496
5956	M	Pre	Gastroenterology	0.4269	**0.4910**	0.0209	0.2858
7842	M	Pre	Rheumatology	0.2885	**-0.4378**	0.4045	0.1642
1584	F	Post	Urology	-0.1486	-0.0233	**0.6827***	-0.1899
9451	M	Pre	Neurology	-0.2045	0.0422	**0.5957***	0.1057
1682	M	Pre	Renal	0.2737	-0.0655	**0.5177***	0.0617
8283	F	Post	Diabetes	0.4946	0.0509	**0.5075**	**0.4726**
3216	M	Post	Endocrinology	0.2887	-0.1628	0.3824	0.2616
4773	F	Post	Diabetes	0.2685	0.0693	0.1157	**0.7770***
6978	F	Pre	Rheumatology	0.0553	0.3557	-0.1378	**0.7707***
4381	F	Pre	Surgery	0.3133	0.3483	-0.2534	**0.6223***
4098	M	Pre	Respiratory	-0.101	0.0905	-0.053	**0.6171***
8090	F	Pre	Gastroenterology	0.3237	0.0865	0.1879	**0.5751***
9084	F	Pre	Renal	0.4332	0.2471	0.0927	**0.5677***
4432	F	Post	Endocrinology	0.171	0.3875	0.2601	**0.5137***
2320	M	Pre	Renal	0.192	-0.1302	-0.1087	**0.4929***
7202	M	Pre	Neuro-rehab	0.3902	-0.138	0.3052	**0.5027**
8382	F	Pre	Respiratory	**0.4286**	0.0255	0.2904	**0.5017**
9859	M	Pre	Rheumatology	**0.4451**	-0.1872	0.1126	**0.4737**
1052	F	Pre	Rheumatology	0.4028	0.1602	-0.0375	**0.4236**
4507	F	Post	Diabetes	0.0479	0.2528	0.3531	**0.4201**
2002	M	Post	Renal	0.1872	-0.2223	0.283	**0.4028**
3616	M	Pre	Surgery	-0.1277	0.1479	0.1879	0.3011
6928	M	Post	Urology	0.0608	0.034	0.2609	-0.1763
2638	M	Post	Urology	0.2369	0.1319	0.3047	0.0882

The significance level for factor loadings is taken as 2.58 (SE). SE represents standard error that is defined as $1/\sqrt{N}$ where N is the number of statements in the Q set. In this case then, 2.58 (SE) = 2.58 ($1/\sqrt{49}$) = 0.41. Significant loadings are shown in bold type.

The automatic flagging procedure in PQ method software was used to identify defining sorts (*) that flags according to the following rule: Flag loading *a*: *if* (1) $a^2 > h^2/2$ (factor 'explains' more than half of the common variance) and (2) $a > 1.96/\sqrt{(N \text{ items})}$ (loading 'significant at p>.05').

Figure 1: Q-set development process

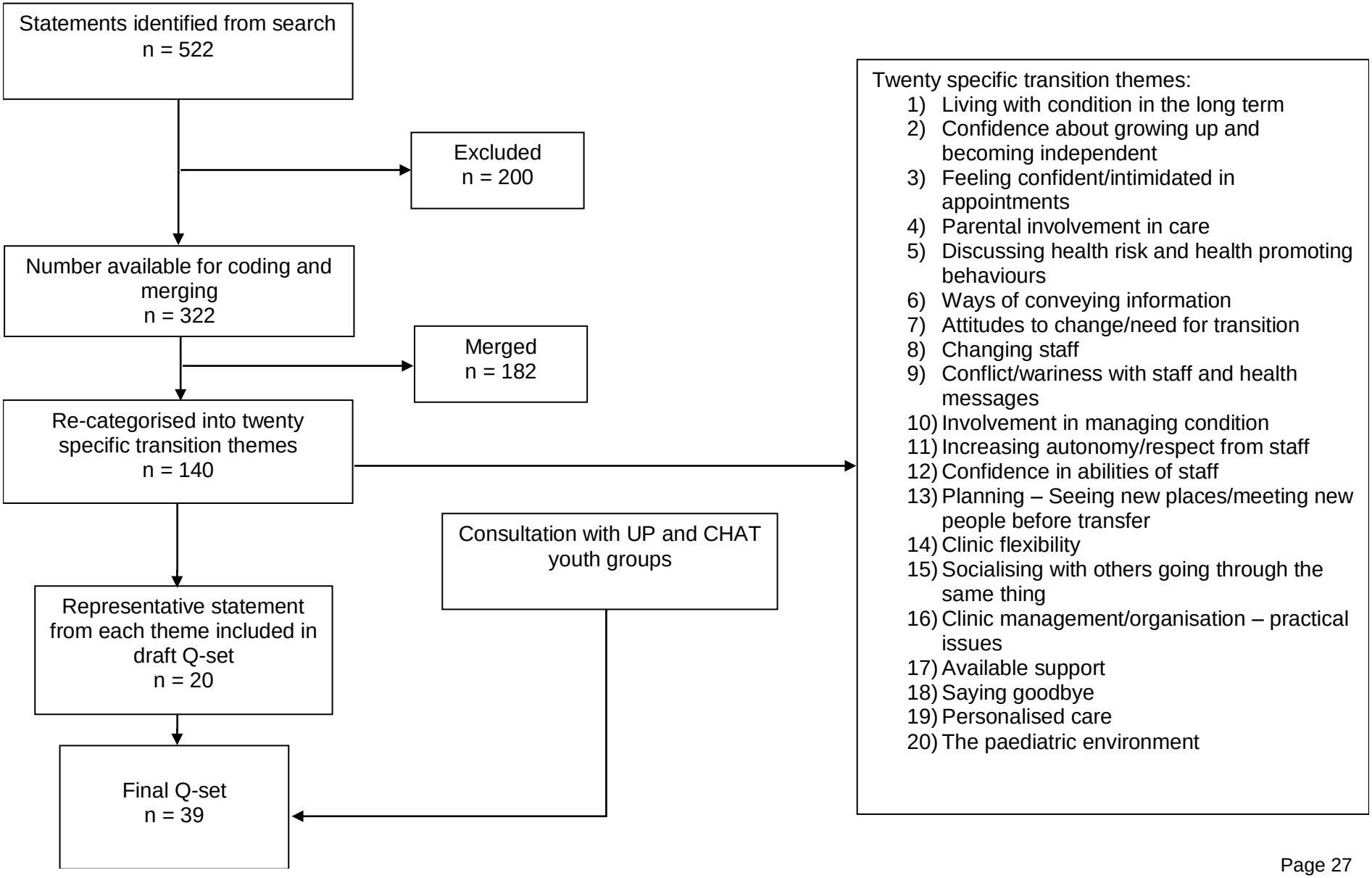

Figure 2: Q-sort grid

← Strongly disagree						Strongly agree →
-3	-2	-1	0	1	2	3

References

1. Blum RW, Garell D, Hodgman, et al. Transition from child-centred to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. J Adolesc Health. 1993;**14**:570-6
2. Lugasi T, Achille M, Stevenson M. Patients' perspective on factors that facilitate transition from child-centered to adult-centered health care: a theory integrated metasummary of quantitative and qualitative studies. J Adolesc Health. 2011;48(5):429-40
3. Care Quality Commission. From the pond into the sea. Children's transition to adult health services. 2014 [accessed March 2015]. URL: www.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf
4. Kennedy I. Getting it right for children and young people. Overcoming cultural barriers in the NHS so as to meet their needs. London. HMSO; 2010
5. Davies SC. Annual Report of the Chief Medical Officer 2012. Our children deserve better: prevention pays. London. Department of Health; 2013
6. Kaufman M, Pinzon J. Transition to adult care for youth with special health care needs. Paediatr Child Health. 2007;12(9):785-93.
7. Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. Pediatrics. 2011;128(1):182-200
8. Stam H, Hartman EE, Deurloo JA, et al. Young adult patients with a history of pediatric disease: impact on course of life and transition into adulthood. J Adolesc Health. 2006;39(1):4-13.
9. Lyon ME, Kuehl K, McCarter R. Transition to adulthood in congenital heart disease: missed adolescent milestones. J Adolesc Health. 2006;39(1):121-4
10. McConachie H, Jaffa T. Psychology of adolescent development. In: Kurtz Z, Hopkins A, eds. Services for Young People with Chronic Disorders in their transition from Childhood to Adult Life. London: Royal College of Physicians. 1996:9-12

11. Department for Education. Support and aspiration. A new approach to special educational needs and disability: A Consultation. London; 2011. [accessed March 2015.] Available from: www.gov.uk/government/uploads/system/uploads/attachment_data/file/198141/Support_and_Aspiration_Green-Paper-SEN.pdf
12. Bolton-Maggs PH. Transition of care from paediatric to adult services in haematology. Arch Dis Child. 2007;92(9):797-801
13. Dovey-Pearce G, Hurrell R, May C, et al. Young adults' (16-25 years) suggestions for providing developmentally appropriate diabetes services: a qualitative study. Health Soc Care Community. 2005 ;13(5):409-19.
14. Tuffrey C, Pearce A. Transition from paediatric to adult medical services for young people with chronic neurological problems. J Neurol Neurosurg Psychiatry. 2003;74(8):1011-13.
15. Ko B, McEnery G. The needs of physically disabled young people during transition to adult services. Child Care Health Dev. 2004;30(4):317-23
16. Jordan A, McDonagh JE. Recognition of emerging adulthood in UK rheumatology: the case for young adult rheumatology service developments. Rheumatology (Oxford). 2007;46(2):188-91
17. van Staa A, Sattoe JN. Young adults' experiences and satisfaction with the transfer of care. J Adolesc Health. 2014;55(6):796-803.
18. Tuchman LK, Slap GB, Britto MT. Transition to adult care: experiences and expectations of adolescents with a chronic illness. Child Care Health Dev. 2008;34:557–63
19. Soanes C, Timmons S. Improving transition: a qualitative study examining the attitudes of young people with chronic illness transferring to adult care. J Child Health Care. 2004; 8(2):102-12
20. Transition Research Programme [page on the Internet]. Cited 2015. Available from: http://research.ncl.ac.uk/transition/index.html

21. Colver AF, Merrick H, Deverill M, et al. Study protocol: longitudinal study of the transition of young people with complex health needs from child to adult health services. BMC Public Health. 2013;13:675
22. Watts S, Stenner P. Doing Q Methodological Research. Theory, Method and Interpretation. London: SAGE Publications Ltd, 2012
23. Scott S, Baker R, Shucksmith J, et al. Autonomy, special offers and routines: a Q methodological study of industry-driven marketing influences on young people's drinking behaviour. Addiction. 2014;109(11):1833-44
24. Wood RT, Griffiths MD, Derevensky JL, et al. Adolescent accounts of the UK National Lottery and scratchcards: an analysis using Q-sorts. J Gambling Studies. 2002;18(2):161-83
25. Richards J, Papworth M, Corbett S, et al. Adolescent motherhood: a Q-methodological re-evaluation of psychological and social outcomes. J Community Appl Soc Psychol 2007;17:347-62
26. Cheung AH, Levitt AJ, Szalai JP. Impact of antidepressant side effects on adolescent quality of life. Can J Psychiatry. 2003;48(11):727-33
27. Jedeloo S, van Staa A, Latour JM, et al. Preferences for health care and self-management among Dutch adolescents with chronic conditions: a Q-methodological investigation. Int J Nurs Stud. 2010;47(5):593-603
28. Tielen M, van Staa AL, Jedeloo S, et al. Q-methodology to identify young adult renal transplant recipients at risk for nonadherence. Transplantation. 2008;85(5):700-6
29. Lai JS, Kupst MJ, Cella D, et al. Using Q-methodology to understand perceived fatigue reported by adolescents with cancer. Psychooncology. 2007;16(5):437-47
30. Watson R, Parr JR, Joyce C, et al. Models of transitional care for young people with complex health needs: a scoping review. Child Care Health Dev. 2011;37(6):780-91
31. Brown, Steven R. Political subjectivity. New Haven, CT: Yale University Press, 1980
32. Gallagher K, Porock D. The use of interviews in Q methodology: card content analysis. Nurs Res. 2010;59(4):295-300

33. Schmolck P. PQ Method (Version 2.11) Computer Software: Neubiberg: University of the Bundeswehr Munich. 2002. URL: http://schmolck.userweb.mwn.de/qmethod/downpqwin.htm (accessed March 2015).
34. Kennedy A, Sawyer S. Transition from pediatric to adult services: are we getting it right? Curr Opin Pediatr. 2008;**20:**403-9
35. Fegran L1, Hall EO, Uhrenfeldt L, Aagaard H, Ludvigsen MS. Adolescents' and young adults' transition experiences when transferring from paediatric to adult care: a qualitative metasynthesis. Int J Nurs Stud. 2014 Jan;51(1):123-35.
36. Ellingsen IT, Arstad Thorsen A, Storksen I. Revealing Children's Experiences and Emotions through Q Methodology. Child Dev Res. 2014. URL: http://dx.doi.org/10.1155/2014/910529
37. Maxwell JP. Managing conflict at the county level: the use of Q-methodology in dispute resolution and strategic planning. Public Administration Quarterly. 2000;24:338-54
38. McDonagh JE, Kelly D. The challenges and opportunities for transitional care research. Paediatr Transplant. 2010;14:688-700
39. Farre A, Wood V, Rapley T, Parr JR, Reape D, McDonagh JE. Developmentally appropriate healthcare for young people: a scoping study. Arch Dis Child. 2015 Feb;100(2):144-51.
40. Farre A, Wood V, McDonagh JE, Parr JR, Reape D, Rapley T; Transition Collaborative Group. Health professionals' and managers' definitions of developmentally appropriate healthcare for young people: conceptual dimensions and embedded controversies. Arch Dis Child. 2016 Mar 4. [Epub ahead of print].