Development of a transition readiness scale for young adults with cystic fibrosis: face and content validity

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Abstract

Background The process of moving from a paediatric to adult health care setting is known as health care transition (HCT). The current lack of transition planning to determine and ensure readiness means patients with chronic conditions experience less than ideal outcomes. There is a lack of a widely used, validated instrument to assess readiness to transition in adolescents with cystic fibrosis (CF).

Objective To develop the *Cystic Fibrosis Health Care Transition Readiness Scale* and assess this instrument for face and content validity.

Design The study used both qualitative and quantitative methods in the design and testing of the *Cystic Fibrosis Health Care Transition Readiness Scale*.

Participants Two adolescents with CF and four parents of adolescents with CF participated voluntarily in this study.

Method Interviews were conducted in a semi-structured manner to explore the meaning of health care transition for study participants. Qualitative data were analysed using a thematic content method. These results were combined with those of a literature review of existing published measures of transition readiness for other chronic illness groups to formulate a draft *Cystic Fibrosis Health Care Transition Readiness Scale*. Expert opinion was used to assess content analysis using the content validity index.

Results Sixty-six readiness items were developed from the integration of interview findings and items from other scales. A confidence rating scale was used. After testing for face and content validity, it is proposed the 57-item *Cystic Fibrosis Health Care Transition Readiness Scale* undergo further testing.

Conclusion: The *Cystic Fibrosis Health Care Transition Readiness Scale* includes views of experts and participants undergoing the experience to strengthen its content validity. However, this study also highlighted the more general concern of adolescents' disengagement with health care found in other studies. A condition-specific readiness measure should facilitate a smooth transition to adult health care by targeting areas needing more preparation.

Keywords: adolescents, cystic fibrosis, health care transition, readiness scale.

What is known about this topic

- In order to be successful health care transition processes need to be guided by an adolescent's readiness not chronological age.
- A lack of preparation and planning of health care transition contributes to negative health outcomes for adolescents.

What this paper adds

- Details of a scientifically rigorous development of a health care transition readiness scale for adolescents with CF that has documented face and content validity.

Declarations

Conflicts of interest None.

Funding This study was funded by grants from the Government of Western Australia Department of Health and The PMH Foundation.

Ethical approval Ethics approval was obtained from the Ethics and Review Committee from Curtin University of Technology's School of Nursing and Midwifery (reference number SON&M7-2008) and also by Princess Margaret Hospital for Children's Ethics Committee (reference number 549/EP). All study participants gave informed consent.

Background

Cystic fibrosis (CF) is the most common autosomal genetic disorder that exists within the Caucasian race[1]. Due to advances in technology and health care, the life expectancy of a child with CF is 35 years, an increase in 20 years since 1960[2]. Hence, adolescents and young adults require a continuum of care that extends beyond the facilities provided within a paediatric setting. This move into adult care has been referred to as health care transition (HCT)[3].

Recommendations for HCT processes have consistently referred to three phases and not an event[3-5]. The phases included preparation, transfer and evaluation but, in particular, that the preparation stage starts early and extends over two or more years. It is during this preparation stage that health professionals work with adolescents and parents to make the change from parental control to effective self-management.

The extant literature recommends that the timing of an individual's HCT change from an age criterion to one based upon assessment of a range of criteria including the individual's physiologic status, knowledge of the condition and willingness to assume greater autonomy in self-management[3,6-8]. Collectively, these criteria have been used to describe developmental readiness for transition[5].

Current HCT processes for adolescents with CF rely on dichotomous worded checklists that are unable to facilitate judgements about an individual's stage of readiness to become more independent with their self-management. Such an assessment would judge not only when, but also what, needs to be done before the transfer phase to adult health care.

Globally, the lack of preparation and planning before the move from paediatric to adult health care has been identified as a contributing factor towards negative health outcomes for adolescents[7,9]. In addition, a smooth transition process has the potential to decrease feelings of abandonment and apprehension associated with HCT[5,10]. However, a CF-specific scale that can assess an adolescent's stage of readiness to transition has yet to be developed.

Method

The development of the *Cystic Fibrosis Health Care Transition Readiness Scale*, using qualitative enquiry and a review of the literature, was guided by the trans-theoretical model[8,11,12] and self-efficacy theory[13]. The professional literature, supplemented by solicited feedback from individuals in the field, was recommended as the most appropriate method for item generation[14].

Keywords used in the search of PsycINFO, Ovid MEDLINE® and ProQuest were 'health care transition', 'assessment of readiness', 'cystic fibrosis' and 'stages of change'. Human Research Ethics Committee approval based on the NH&MRC guidelines[15] was granted by the study hospital.

Recruitment, data collection and analysis

All out-patients who met the inclusion criteria, and their parent or guardian, were sent letters of invitation to participate. The main inclusion criterion was adolescents with CF who were within six months of actively transitioning to the adult health care sector. Inclusion of parents was not dependent on their child volunteering. Potential participants were excluded if they had cognitive impairment, or were unable to read or speak English. The 33 eligible adolescents and their parents were sent separate letters of invitation to participate. Six responses were received, two adolescents and four parents.

Two sources of data were used: interviews and extant literature. The open-ended, semi-structured interviews provided in-depth exploration of each participant's perception of readiness to transition. Participants were asked about their perceptions and beliefs as to which behaviours and knowledge were important for an adolescent's sense of autonomy prior to transitioning. Semi-structured interviews were audiotaped with consent. Notes and memos were written by the researcher to serve as memory joggers of topics as they arose during the interview process.

Thematic content analysis of the interview transcripts followed the guidelines proposed by Burnard[16] and was managed with NVivo Version 8 software. The systematic recording of general themes and issues raised in the interviews was followed by open coding that involved rereading the interview transcripts and the formation of as many headings as necessary to describe all aspects of the context, excluding issues that were unrelated to the topic. Once all data were coded, the headings were grouped together under eight higher order category codes.

The eight category codes were labelled *Maintaining a Sense of Normality, Attitude to Change, Cutting Ties with the Paediatric Hospital, Reaching Adolescent Milestones, Parents Experiencing Transition as a Loss of Control, Perceptions of Readiness, Readiness as Outgrowing Paediatric Hospital* and *Transition Communication Frustration*. Similar category codes were grouped together and divided to form two major categories that were identified and named *Negotiating the Health Care Transition Process* and *Experiencing Readiness*.

The second analysis stage matched participant narratives with the literature and pre-existing readiness scales. In particular, other disease-specific instruments from the professional literature were reviewed for item generation[17-19]. Where categories and items from the literature were similar, they were collapsed to avoid repetition. Hence, the initial *Cystic Fibrosis Health Care Transition Readiness Scale* had 66 items.

Instrument development

The 66 draft items developed from both the literature and interview data were worded as self-efficacy type statements[13]. "I can …" statements represented taking responsibility for self-management of their CF. Higher scores on the 10-point confidence scale indicated higher levels of confidence.

Face and content validity

Testing for face validity involved all participants and four field experts being asked to assess the language, grammar and readability of the initial 66-item *Cystic Fibrosis Health Care Transition Readiness Scale*. Minimal changes included rewording of items to remove any ambiguity or potential for misinterpretation.

The testing of content validity used a Content Validity Index (CVI) form[20]. A panel of four field experts was chosen to decide if the items in the measure were relevant. The number of experts was based on recommendations from the literature – any less than three would make claims of validity statistically unjustifiable[20,21]. Field experts from the study hospital included the respiratory clinical nurse consultant, respiratory liaison nurse, a paediatric respiratory physician involved with transition processes and a clinical nurse manager with experience in adolescent transitional care. The experts were presented with a copy of the draft *Cystic Fibrosis Health Care Transition Readiness Scale* and asked to assess it using the CVI, the most widely used rating tool for content validity[20,21]. The CVI is a four-point ordinal rating system that requires experts to rate the content relevance of new instrument items from one as 'irrelevant' through to four as 'extremely relevant'.

The mean of the experts' scores for each item was used to determine the item's content validity score and subsequent inclusion or deletion in the final list of items; that is, with four experts, the total possible score for each item was 16. The sum of the experts' scores for each item was then divided by 16. A CVI of 0.75 or greater was required for items to remain[22]. Items that received widely varying scores from the experts were retained, along with high-scoring items, for future psychometric testing to determine if the item warrants retention.

The results of the content validity testing indicated that of the 66 items, 57 met the criterion of 0.75. Of these, 20 were consistently graded highly by the field experts, with CVI scores above 0.92. These items related to the adolescent having a sound overall knowledge of CF and the adolescent's ability to independently manage their health care. Nine items received a CVI score less than 0.75 and were deleted. Although the majority of items deleted related to CF-specific dietary requirements, three dietary items remained. Subsequent factor analysis of the 57 items will be required to test their utility.

Conclusion

Development of the 57-item *Cystic Fibrosis Health Care Transition Readiness Scale* used data obtained through qualitative enquiry and the published literature on transition checklists. Though preliminary testing of face and content validity has been undertaken, it is recommended that the scale undergo further psychometric testing. A 57-item measure of transition readiness is unlikely to have clinical utility and a 'short version' should be developed. Adolescents who have not yet made the transition to the adult health setting as well as those who have recently made the transition need to be included in the next iteration of testing.

Contributors

PR, LD and SW jointly contributed to the conception and design of the study. LD collected, analysed and interpreted the qualitative data, devised the *Cystic Fibrosis Health Care Transition Readiness Scale* and co-wrote the article. PR and SW jointly contributed significantly to revisions of the article and supervised the overall project. PR, LD and SW all approved the final version of the article for submission.

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Appendix A. Scale items with individual rating scores and CVI.

Item	Instrument item	#1	#2	#3	#4	CVI
1	I can explain what CF is	4	4	4	4	1
2	I can explain what treatments I require in order to keep myself healthy	4	4	4	4	1
3	I can explain what it means to have CF	4	4	4	4	1
4	I can understand what test results (such as lung function) mean to my overall state of health	3	4	4	4	0.94
5	I can recognise situations that can make me unwell due to my CF (such as close contact with someone who has a cold or flu)	3	2	4	4	0.81
6	I can recognise environments that can make me unwell due to my CF (such as smoky confined rooms)	3	2	4	4	0.81
7	I can avoid situations that I know will probably make me unwell	3	4	4	4	0.94
8	I cannot attend clinic appointments by myself	3	4	4	4	0.94
9	I cannot recognise signs and symptoms that I am becoming unwell with my CF	4	4	4	4	1
10	I can adapt my daily treatment regime in response to a change in my health	4	4	4	4	1
11	I can organise to get medical treatment when unwell	4	4	4	4	1
12	I can describe my symptoms to health professionals in a way that makes them understand what I am feeling	3	4	4	4	0.94
13	I cannot stay the night in hospital by myself	3	4	4	4	0.94
14	I can ask my doctor questions about my health and treatment	3	4	4	4	0.94
15	I can talk with my doctor if I am unhappy about an aspect of my treatment	3	4	3	4	0.87
16	I cannot make my own decisions about my health care	3	4	4	4	0.94
17	I can answer questions about my health when asked	3	4	4	4	0.94
18	I can name each of my medications	4	2	4	4	0.87
19	I can describe the purpose of each of my medications	4	2	4	4	0.87
20	I can always remember to take the correct medication at the correct time	2	2	3	4	0.68
21	I can use equipment needed to administer my medication such as a nebuliser or pump	2	2	4	4	0.75
22	I can get my prescriptions filled before I run out of medication	3	2	3	4	0.75
23	I cannot arrange payment for my prescriptions	2	2	4	4	0.75
24	I can describe any possible side effects of my medications	2	2	3	4	0.68
25	I can get help and manage these side effects if they occur	2	2	3	4	0.68
26	I cannot calculate the correct number of enzymes to take before each meal	3	2	4	4	0.81
27	I can maintain a healthy weight	2	2	3	4	0.68
28	I can prepare meals that meet my dietary needs	2	2	4	4	0.75
29	I can accurately supplement my dietary intake with snacks or energy drinks	1	2	4	4	0.68
30	I can explain why I have different dietary requirements compared to somebody who doesn't have CF	2	2	4	4	0.75
31	I can always remember to perform my physiotherapy routine	2	3	3	4	0.75
32	I cannot perform my physiotherapy routine	3	4	4	4	0.94
33	I can participate in exercise and sports to a level that maintains my fitness	2	2	2	4	0.62
34	I can increase the intensity of my physiotherapy if I notice an increase in my secretions	3	3	4	4	0.87
35	I can perform my physiotherapy routine effectively enough to clear my secretions	2	4	4	4	0.87

Item	Instrument item	#1	#2	#3	#4	CVI
36	I can explain why smoking is worse for my health because of my CF than it is for my friends who don't have CF	3	1	4	4	0.75
37	I can explain how alcohol affects the body and decision-making ability	1	4	4	4	0.81
38	I can explain how alcohol will interact with my current medications	1	4	4	4	0.81
39	I cannot explain how illicit drugs (marijuana, cocaine etc.) affect the body	1	4	4	4	0.81
40	I can say "no" when offered cigarettes, alcohol or illicit drugs	1	3	4	2	0.62
41	I can get help if I react badly to using cigarettes, alcohol or illicit drugs	1	4	4	4	0.81
42	I can talk with my friends about having CF if I chose	3	4	3	4	0.87
43	I can balance keeping myself healthy with having fun and socialising with friends	3	4	4	4	0.94
44	I can explain how sexually transmitted infections get passed from person to person	3	4	4	4	0.94
45	I can access contraception	3	2	4	4	0.81
46	I cannot explain how CF can affect fertility	3	4	4	4	0.94
47	I can explain how CF is genetically acquired	3	4	4	4	0.94
48	I cannot attend clinic appointments without my parents	4	4	4	4	1.00
49	I can make decisions about my health care without my parents	4	4	4	4	1.00
50	I can choose what information I share with my parents about my health care and treatment decisions	3	4	4	4	0.94
51	I can ask for support from my parents if I need it	1	4	4	4	0.81
52	I can explain to teachers/lecturers/employers why I may need to miss some time from school/university/work because of my CF	3	4	4	4	0.94
53	I can motivate myself to complete homework/study to keep up with my education when I miss school because of my CF	1	4	1	4	0.63
54	I cannot discuss with my school/university any special requirements I may have due to my CF	3	1	4	4	0.75
55	I can arrange a doctor's certificate if I need to miss school/university/work at any time due to illness	3	4	4	4	0.94
56	I can balance my school/university/work commitments with my health commitments such as clinic appointments and physiotherapy routine	3	4	4	4	0.94
57	I cannot complete all administrative paperwork when arriving to clinic appointments	4	4	4	4	1
58	I can complete all admission paperwork when being admitted to the ward	4	4	4	4	1
59	I cannot complete Medicare forms and submit them	4	4	4	4	1
60	I can always remember appointment times and dates	3	4	4	4	0.94
61	I can book appointments for a time suitable for me	4	4	1	3	0.75
62	I can organise and keep a file of my medical records including lung function results, medical history and list of treatments	2	1	3	4	0.63
63	I can arrange my own transport to get to and from hospital appointments	4	4	4	4	1
64	I can arrange my own transport to get to hospital appointments on time	4	4	4	4	1
65	I can organise payment for public transport, taxi or parking costs	2	4	4	4	0.87
66	I cannot ask questions and read signs to find my way around the hospital	2	4	4	4	0.87

#1 – #4 = item scores given by independent scorers; CVI = Content Validity Index.

Shaded areas = items removed.