G.4 Transition

Review question: What parts of the transition from children's to adult services are most important for young people with cystic fibrosis and their family members and carers?

Study details	Participants	Methods	Findings	Comments
Full citation Al-Yateem, N., Child to adult: transitional care for young adults with	Sample size 15 young adults with CF	Setting Two major children and adult hospital in Ireland.	Themes/categories Main Theme: Preparing for transition Sub-themes	Limitations The methodological limitations of the study were assessed using an adapted Critical Appraisal Skills Programme (CASP 2006)

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cystic fibrosis, British Journal of Nursing, 21, 850-4, 2012 Ref Id 366753 Study type Qualitative study Aim of the study To explore and understand the experience of young people before and after their transitional care, and the factors that both contribute to and hinder that experience Country/ies where the study was carried out Ireland Study dates Not reported Source of funding Not reported	Characteristics Not reported Inclusion criteria Young adults with CF who were listed for transfer in the child setting, or who had been transferred to the adult setting within the last 2 years Exclusion Criteria Not reported	Sample selection Health professionals working in hospitals identified possible candidates and contacted through postal letters. Data collection In-depth interviews were carried out in the two hospitals during the data collection process, and followed the interview guide to ensure coverage of all the transition areas. Data analysis The phenomenological descriptions of experiences given by research participants, were carried out using the thematic analytical process.	Preparing for transition: sharing knowledge Participants noted a lack of adequate information about the transition process, especially about the different aspects of this process. One participant noticed a lack of detail "Ah, very little, almost nothing. I mean all they do is to tell you that you are transferring." Another participant was not aware of the hospital or CF service to which he would be referred. He said: "I don't really know, it might be either X hospital or Y hospital. I don't know we have to go and see. I don't know how they will be like?" One participant said that information is sometimes provided in a distracted environment and based on the judgment of health professionals which might not be relevant to CF patients. "Everyone [health professionals] will rush in the room and start doing their stuff and start talking … you are kind of distracted ... I don't really get much … after a while I kind of didn't even listen to what they are saying…" Lack of sharing knowledge led to unmet information need for CF patient.	Aim(s): Aim of the study clearly reported, research method was appropriate for answering the research question Sample selection: The sample selection process was not clearly reported. The relationship between the researcher and the respondents clearly reported. The participants were appropriate to address the topic. Age of participants not reported, however, the criteria for inclusion was transition in the last 2 years from child to adult services. Data collection: Data collection relied on the in-depth interviews. Description of data collection method was vaguely described. Data analysis: The analytical process was reported vaguely. Thematic analysis reported, but description of how emerging and overarching themes was constructed and unclear on whether data saturation was reached. Findings/results: Results were presented clearly and was applicable to the aim. (e.g., citation/data and the researchers' own input distinguished)

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			"Well the thing that they don't talk with us enough about CF, how it will be ... you know, and what it will be like in the future." Participants also stated that information should be provided at timely interval. "Actually, we haven't been told about the transfer yet, nobody talked to us about it…" "Yes, I know about transition…last month the CF nurse told me that I will be going to another hospital next year when I turn 18…" Preparing for transition: easing the process Transition from children to adult healthcare setting has created anxiety in the CF patients. "I am worried about the cutbacks in health and all when we move there (the new hospital), you know that with CF there are some cuts that you don't know when it's going to knock off…" The difference in quality of care was also raised as a major concern of CF patients. "We used to do it (sputum test) every month in x hospital, but they just do it	Overall quality: Low Other information: Ethical process reported. Study conducted by lone researcher as a part of PhD study and may lack some of the formal research vigour.

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			every 3 months in here, so you kind of stay anxious for a long time ... you don't know when the infection is going to hit … it will be late…" One participant recommended visiting the adult hospital before transition to reduce anxiety: "They are going to take us over to the other hospitals, and talk to the other staff there, that would help, you will know them and they will know you…" Main Theme: Amorphous service Sub-themes No structured transition service CF patient stated that service provided were amorphous and appeared to lack a comprehensive and coherent structure to transitional programming. "There was no real discussion … it was just the CF nurse who told us last year that it would be when I finish the leaving cert. It would not be straight away when I turned 18, so it would be after." This lack of structure created anxiety and negative feeling "I don't really like to come here…like, they don't do much for me…if they just listen I would have told them what I want to know…or how they can help…this is very annoying…"	

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			Focusing on the young adult The focus of some health professionals on clinic activities, rather than focusing on the actual individual needs of the young adult, was source of frustration in CF patients. "People need to be looked at and listened to …and then you make your diagnosis from there, but sometimes they are over reliant on paperwork that is obsolete and doesn't give any function. It doesn't solve problems..."	
Full citation Al-Yateem, N., Guidelines for the transition from child to adult cystic fibrosis care, Nursing Children and Young People, 25, 29-34, 2013 Ref Id 473328 Study type Qualitative survey with focus group interview Aim of the study	Sample size Not reported Characteristics Healthcare professionals working with young adults. Inclusion criteria Healthcare professionals working with young adults with CF during their transition from	Setting CF centre Sample selection All health care professionals in the environments where the group interviews took place were invited to participate by postal letter Data collection The focus group interviews were held in conference rooms in both settings and were audio recorded. Each	Themes/categories An individualised comprehensive approach: Participants in the group suggested a systematic approach that considered every adolescent as an individual case. As one participant stated: "Absolutely, we should have an individualised comprehensive approach that cares about each individual separately and meets their needs" Assessment and care	Limitations The methodological limitations of the study were assessed using an adapted Critical Appraisal Skills Programme (CASP 2006) Aim(s): Aim of the study clearly reported, research method was appropriate for answering the research question. Sample selection: Sample selection was vague in detail. No actual number of interviewee in the focus group reported. The relationship between the

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To develop relevant and feasible guidelines for transition care, based on perspectives of stakeholders. Country/ies where the study was carried out Ireland Study dates 2012 Source of funding Self funded by researcher.	child to adult health care, covering more than two years. Exclusion Criteria Not reported	meeting lasted approximately 60 minutes. The transitional needs of adolescents with CF were discussed, contributions were analysed and proposed interventions were extracted. Data analysis The analysis of transcribed group interview data followed systematic approach based on literature. Relevant statements in the transcripts were highlighted. Similar statements were gathered and combined into categories and merged under one heading or theme	Planning of individual patient for transition was considered important by the group. One participant in the group: "The assessment will highlight to us what the adolescents actually need, and what might affect his or her transition in terms of information, family, or any other issues" Planning of care Care planning should include specific interventions targeted at the specific needs of the individual. As one participant suggested: "It will be good for everyone [planning] adolescent, parents, and even us… everybody will know what to do" Provision of information It should be appropriate to the person's age and developmental stage and supplemented with extra printed or digital material. "Anyway, providing information should be given extra attention, and possibly information sessions could solve this problem." Continuous evaluation and follow up mechanisms This according to group allows them to monitor and improve the care during transition One participant said: "Based on the transition plan you can later on evaluate whether the child has	researchers and the respondents not clearly reported. Data collection: Data collection relied on the focus group interview interviews for CF. No information on structure of interview or whether topic guide reported. Description of how "themes" were arrived at was discussed but information was not sufficient to conclude if data collection process was robust. No information on data saturation and full exploration of theme. Data analysis: The analytical process was described with description of themes and categories but lacks detail in data processing, checking validity or robustness of the data. No critical review of the researchers' role in the process. Findings/results: Results were presented in a confusing way with themes and categories overlapped. Themes were supported by quotes. Researchers' role and potential influences in the analytical process not critically reviewed. Overall quality: Low Other information Ethical approval obtained for this study.

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			made any progress, or any further intervention might be needed" An approach that promotes independence One participant suggested that young adult should be more involved in decision making process "I think it is important to keep them involved … and take part in all decisions and activities during clinic and so on" Gradual handover to the adult service Group suggested that handover should be staggered overtime to make transition easier for young adults. "I think staff from the ... hospital can come over here and do their first few clinics with adolescents…this might help… and we can give them better information about our patients" Creating a suitable environment It was suggested that transition care should be provided taking account of developmental stage of young adults and their needs. One participant said: "Here, the adolescents do not feel attracted to the place… they sometimes tell us they feel like kids here… they are waiting to get out of here" Continuous training for health care	Study conducted by lone researcher and may lack some of the formal research vigour involving multiple researchers.

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			Group advocated the continuous training and knowledge sharing among professional regarding transition care "I think we are used to dealing with kids more, and indeed adolescents, being in a different and unique developmental stage, may need another type of communication style, that we are not used to"	
Full citation Begley, T., Transition to adult care for young people with long-term conditions, British Journal of Nursing, 22, 506, 508-11, 2013 Ref Id 329512 Study type Qualitative study Aim of the study To evaluate how the transition from child to adult healthcare is managed in young people with CF or diabetes in Ireland. Country/ies where the study was carried out Ireland Study dates Not reported Source of funding Not reported	Sample size N=132 healthcare professionals Characteristics Not reported Inclusion criteria All known consultants, clinical nurse specialists, advanced nurse practitioners caring for young people with CF and insulin dependent diabetes mellitus. Exclusion Criteria Not reported	Setting Healthcare centres across Ireland. Sample selection The study aimed to include all known healthcare professionals who from some adult and all children's services who looked for children before transition. As there was no centralized information on services, there were identified using the internet and personal information, and were confirmed by telephone calls. An anonymous questionnaire was sent to all HCPs with a comprehensive information sheet. Data collection 4 weeks were allowed for questionnaires to be returned, after a reminder was sent. All data was	Themes/categories Criteria and age for transition Young people with CF and parents were also concerned about the lack of single rooms for people with CF, which lead to a fear of cross-infection: "Young people and their parents have real concern re cross-infection in mixed wards. They do not want to share wards with elderly patients" (healthcare professional) Age of transition Healthcare professionals found problematic for young people to be transferred at an "early age". "Historically the age at which children attend adult services in this hospital is 14, which I consider too young and my training as an adult physician leaves me less able to deal with the 14-16 age group. I have difficulty in managing patients who in my mind are "children" and I find teenage/ adolescent emotional aspects of	Limitations The methodological limitations of the study were assessed using an adapted Critical Appraisal Skills Programme (CASP 2006) Aim(s): Aim of the study clearly reported, research method was adequate for answering the research question, but a using interviews or focus groups would have been more useful to retrieve richer data. Sample selection: The sample selection process was not clearly reported, although the authors tried to involve all participants caring after young people before the transition process. The relationship between the researcher and the respondents clearly reported. The participants were appropriate to address the topic. Age of young people was not reported. Only 56% response rate

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		anonymized. The response rate was 54%. Data analysis The open-ended questions were analysed using content analysis and constant comparison process (Glaser and Strauss 2008). This way each portion of data was compared to all other data to allow comparisons across respondents and information was merged to generate themes.	illness to be an unwelcome challenge" (healthcare professional)	Data collection: Data collection relied on postal survey, with closed and open questions. Description of data collection method was vaguely described. Data analysis: The analytical process was reported vaguely. Content analysis reported, but description of how emerging and overarching themes was constructed. The authors do not explain whether data saturation was reached, but given the limited number of quotes presented in the study it is unlikely. Findings/results: Results were well presented and were applicable to the aim. Overall quality: Low Other information Conflict of interest: none This study includes healthcare professionals looking after young people with CF and diabetes. Only quotes relevant to CF have been extracted.
Full citation Brumfield, K., Lansbury, G., Experiences of adolescents with cystic fibrosis during their transition from paediatric to adult health care: a qualitative study of	Sample size N = 4 people with CF Characteristics Age 19 to 22 years	Setting Participants' own home. Sample selection Opportunistic sampling. Advertisement and word of mouth for recruitment of participants.	Themes/categories Pediatric health care: Good paediatric care not only optimize the health of patients, but also to prepare them for a change to adulthood.	Limitations The methodological limitations of the study were assessed using an adapted Critical Appraisal Skills Programme (CASP 2006) Aim(s): Aim of the study clearly reported, research method was

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young Australian adults, Disability & Rehabilitation, 26, 223-34, 2004 Ref Id 329552 Study type Qualitative study Aim of the study To explore the experiences of Australian adolescents with Cystic Fibrosis (CF) as they made the transition from paediatric to adult care. Country/ies where the study was carried out Australia Study dates Not reported Source of funding Not reported	No other characteristics reported Inclusion criteria No inclusion criteria. All CF patient who expressed interest were included in the research. Exclusion Criteria Not reported	Data collection The focused in-depth interview which allowed the interviewer to follow up and continue along a line of questioning raised by the informant to identify new themes and issues and to use probing questions and follow up ambiguous ideas. The topic guide was used which was adapted after the first interview as new issues were identified after analysis of previous information. Data analysis Data analysis was completed using a system after the completion of each interview, a dictating and transcribing system was used to create a written transcript of the entire interview. Thematic analysis, was applied to the transcripts of the interviews. Each interview was initially coded by the first named author according to issues which were raised as being significant by the informants and themes identified in the literature cited. The interviews were also read by the second named author who independently coded each one. The two authors then discussed the suggested coding	"Sometimes it was like he (pediatric doctor) could read your mind . . . he always eased you, whatever your problem was, if you had a problem, you always went out feeling better." (22 year old with CF) Positive and supportive attitude helped in transition from children to adult health services. "He (pediatric doctor) really highly recommended Dr B. (adult doctor), which was good . . . the fact that he recommended him strongly would have helped." (21 year old with CF) Age appropriate treatment was considered and issue by CF patients "As I grew up, he (pediatric doctors) sort of treated me . . . as if I was older . . . he didn't start treating me like a little kid and stuff, so that was good." (19 year old with CF) However, another individual said that they were treated as children even when they were young adults ready for transition. "I thought . . . if only the (pediatric) doctors knew that we were becoming adults, you know, we were in our mid-teens thinking, they still treat us as if we were ten years old." (20 year old with CF) Elements of the transition programme: Common element of transition was the inclusion of orientation tour of adult health centre. This helps them	appropriate for answering the research question Sample selection: Sample size was low (N=4). Opportunistic sampling and no inclusion and exclusion criteria reported. The relationship between the researchers and the respondents clearly reported. Data collection: Data collection relied on the in depth interviews for CF. Information on type of interview and topic guide was reported. Description of how "themes" were arrived at was discussed but information was not sufficient to conclude if data collection process was robust. No information on data saturation and full exploration of theme. Data analysis: The analytical process was described with description of themes and categories. No critical review of the researchers' role in the process. Findings/results: Results were presented clearly with themes supported by quotes. Researchers' role and potential influences in the analytical process not critically reviewed. Overall quality: Moderate Other information Ethical approval process reported.

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		and reconciled any differences.	to make a more informed choice of the provider. "Oh, when I went to . . . (the first adult hospital) the Doctors were, sort of, a bit stand-offish . . . said something when they were asked, not . . . they didn't come out and . . . then we went over to . . . (the second adult hospital), they were giving us information about the clinic and how it was run and stuff like that which I thought was pretty good . . . I suppose if I went to . . . (the first hospital) they were a bit stand-offish then I'd feel uncomfortable even more than what I was at . . . (the second hospital)." (19 year old with CF) Having a familiar face around after transition to adult services was reassuring for the CF patients. "I knew her from before . . . even though it might not be a lot of contact with her, um, it was still a familiar face, and that was enough to give me reassurance in that regard." (20 year old with CF) Psycho-social factors that may affect transition: Support network for the CF patient was considered important for transition. CF patient are anxious and the lack of support network does not help if fully utilising the services	Data collected by lone researcher and may lack some of the formal research vigour. Analysis was supported by one additional researcher.

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			"I go to clinic, and I go in and I come out as quickly as I can." (22 year old with CF) Impact of transition experience: The bad transition experience created a negative impact and discouraged people in seeking care. "I always say to Mum that it's a waste of time going . . . I don't . . . I don't really trust them, because of the way they treat you, because you are a number . . . if it was up to me I probably wouldn't go back to clinic, but Mum has always told me that you've got to keep your foot in the door in case we need them (the clinic) . . . So I sort of go back on the off chance that I may need them." (22 year old with CF)	
Full citation Dupuis, F., Duhamel, F., Gendron, S., Transitioning care of an adolescent with cystic fibrosis: development of systemic hypothesis between parents, adolescents, and health care professionals, Journal of Family Nursing, 17, 291-311, 2011 Ref Id 367032 Study type	Sample size N=26 participants 7 young people with CF; 7 mothers; 4 fathers; 8 members of the health care team Characteristics Age of young people with CF: 15 to 18 years No other characteristics reported.	Setting Participant's home and principal investigator's office. Sample selection Recruitment took place over a 16-month period. Families were informed about the study by the nurse coordinator during a routine visit to the CF clinic. Those who agreed to receive more information were introduced to the first author (principal investigator) who remained on site. The first author contacted the family 5 days	Themes/categories Suffering unrevealed to health care professionals: Health care professionals in adult services appeared to concern themselves mainly with giving information around clinical parameters rather than dealing with emotional factors in young adults associated with transition. As stated by one health care professional: "We talk to them about their medications, about physiotherapy, the respiratory therapist sees them at every visit to go over the techniques. But other	Limitations The methodological limitations of the study were assessed using an adapted Critical Appraisal Skills Programme (CASP 2006) Aim(s): Aim of the study clearly reported, research method was appropriate for answering the research question Sample selection: Sample selection process was clearly dscribed. The relationship between the researcher and the participants was not reported Data collection: Data collection relied on the semi structured

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Qualitative study Aim of the study To explore the experience of parents and adolescents living with cystic fibrosis prior to the transfer of the adolescent's care from a pediatric to an adult health care facility. Country/ies where the study was carried out Canada Study dates Not reported Source of funding The Faculty of Nursing, University of Montreal, the Quebec Inter university Nursing Intervention Research Group, the Canadian Nurses Foundation (CNF), the Quebec Ministry of Education, Leisure and Sports (MELS).	Inclusion criteria Not reported Exclusion Criteria Not reported	later to confirm whether they wished to participate. Data collection On providing signed informed consent, each family completed a brief self administered questionnaire to describe family living arrangements, socioeconomic status and composition, including the number of children with CF in the family. Semi structured interviews were conducted separately with the young adults and their parents. The interview guides contained both linear and systemic questions to explore the relationships between individuals and events. Data analysis All data from interviews and the group discussion were recorded and transcribed verbatim. A content analysis based on five interrelated steps was conducted: (a) immersion in the data, (b) reconstitution of families' stories, (c) coding, (d) categorizing, and (e) modeling.	times, we show them that their X-ray has deteriorated. We show them the film, we explain that it's important for them to take control. We shake them up a bit."	interviews for CF. No information on structure of interview or whether topic guide reported. Description of how "themes" were arrived at was discussed but information was not sufficient to conclude if data collection process was robust. No information on data saturation and full exploration of theme. Data analysis: The analytical process was described with description of themes and categories. Use of qualitative software not reported. No critical review of the researchers' role in the process Findings/results: Results were presented clearly (e.g., citation/data and the researchers' own input distinguished) Overall quality: Low Other information Most of the information was not relevant to process of transitions to adult health services. Ethical approval process reported and necessary consent obtained. Multiple researchers involved but the level of consistency between them not reported.
Full citation Iles,N., Lowton,K., What is the perceived nature	Sample size	Setting Participant's home, CF clinic or over the telephone.	Themes/categories Parent-as-partner:	Limitations The methodological limitations of the study were assessed using an

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of parental care and support for young people with cystic fibrosis as they enter adult health services?, Health and Social Care in the Community, 18, 21-29, 2010 Ref Id 168982 Study type Qualitative study Aim of the study This study examines how young people and staff perceive the nature of parental care and support for those with CF who have left paediatric services. Country/ies where the study was carried out UK Study dates Not reported Source of funding Burdett Trust for Nursing, Uk	N=50 young people and young adults with CF N=23 healthcare professionals Characteristics Age of young people and young adults: 13 to 24 years 32 out of 50 adults had already experienced transition Inclusion criteria Age 13 to 24 years Fuency in English Exclusion Criteria Near to death, or having experienced a recent bereavement, were excluded.	Sample selection Letters requesting participation were sent to 125 young people who were registered at either of two CF clinics in South-East London. Interested young people were asked to return a reply slip in a prepaid envelope to the researchers, who then contacted them to arrange an interview. Informed consent was obtained from all young people, with consent additionally obtained from the parents of those under 18 years. 23 health professionals were also interviewed. Staff were purposively sampled to include a range of team members from adult and paediatric services. Data collection Semi-structured interviews were conducted using a topic guide. To enable respondents to speak freely about their experiences and expectations, the interviewer had no clinical contact with any of the respondents and introduced herself as a researcher employed by the local University. All participants were assured of confidentiality and that their	Young people preferred active involvement in their clinic appointments; and their desire for a confidential consultation. Many young people reported embracing opportunities to take the lead in adult clinic consultations, negotiating with their parents to facilitate this: "Since I went over to the adults' [clinic] it's been me more involved and she's just sat back and she'll take me if I want her to and she'll sit there and she won't say anything unless I ask her." (17 year old with CF) But some young adults did not want their parents to be involved during hospital consultations "My mum used to come with me to the clinic when I first transferred. I mean she'd come with me now if she could get time off work, if I'd let her, but sometimes I'd rather she wasn't there because there are obviously personal things you want to talk to the doctor about, like when I got my first boyfriend and stuff, I didn't want her to be there." (23 year old with CF) "I didn't tell my mum I was transferring. I didn't tell her, because my mum's a bit obsessive about the clinic and she feels she has to know everything, you know, even though I'm 17... I mean I know it's the duty of the parent, I know that's their job…But that's the good thing about the adult clinic, is the parents don't	adapted Critical Appraisal Skills Programme (CASP 2006). Aim(s): Aim of the study clearly reported, research method was appropriate for answering the research question. Sample selection: Sample selection was clearly reported. The relationship between the researcher and the respondents was reported. Data collection: Data collection relied on the semi structured interviews for CF. Information on structure of interview or topic guide reported. Description of how "themes" were arrived at was discussed but information was not sufficient to conclude if data collection process was robust. No information on data saturation and full exploration of theme. Data analysis: The analytical process was described with description of themes, categories and use of qualitative software. No critical review of the researchers' role in the process. Findings/results: Results were presented clearly with themes supported by quotes. Researchers' role and potential influences in the analytical process not critically reviewed. Overall quality: Moderate

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		data would remain anonymous. Issues covered with young people included their focusing on expectations and⁄or experience of transition to adult services. Interviews with staff focused on professional expectations and experiences of providing transition services. Interviews lasted between 15 to 60 minutes. Data analysis All interviews were audiotape recorded and transcribed verbatim. A thematic approach to analysis was taken. Transcripts were anonymised, checked against the original tapes and coded using the ATLAS-ti programme for qualitative data. Categories were generated inductively through identifying patterns of experiences recounted by respondents, which were grouped through codes into themes.	have to be there, just the child or the patient's wishes. That's the good thing about being in the adult [service]." (17 year old with CF) Health professionals stressed the need for understanding the family dynamics but also recognised that young adults is a decision maker. "I think that when they move to the adult side we very much leave it up to the young person. Some of them leave their parents in the waiting room, others very firmly bring them in." (Specialist physician) "I make it very clear to the parents, when they come up, that I am quite happy to discuss anything with them that the patients want me to discuss with them, but that they are now adults and it's up to them if I speak to them. I mean I will ask my patients, 'Do you mind if I discuss your treatment options with your parents?' And nine times out of ten, they have no problem with it. But I make it very, very clear to the parents that I can't talk to them the way that I could do or [others] used to when they were children and it's really part of learning to let go for them." (CF Nurse Specialist) Parent as a protector: The main way in which young people perceived their parents to protect them was in withholding information during childhood about the terminal nature of CF.	Other information Ethical approval process described. Participants assured of confidentiality and consent were obtained from the participants. Consistency between the researchers not reported.

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			"You know, I know a person [with CF], my mum knew him. And my mum never wanted to tell me [he had died] until I had turned 15." (16 year old with CF) Staff also acknowledged the difficulties communicating limited life expectancy with parents because of their protective nature, where it seemed that young people were perhaps more able than their parents to have these discussions with staff "We had to have a discussion whether to go on to mechanical ventilation would be the right thing ...... And she was able to have that discussion. And I asked her did she want me to let her mother know, if she wasn't going to tell her, that we had had that discussion? She asked me to tell her [mother]. And her mother was initially comfortable that we had had that discussion. Then over the space of about two or three hours, became very agitated and very upset that we'd had it… it was a huge stress for the mother, whereas her daughter, although finding it very difficult, was actually able to have [the conversation] and was – in the end, I think, glad she had had it." (Chest Physician) Some young adults had also started to protect their parents from knowing the extent of their deteriorating health "Mum always used to sit in on consultations until, until I could get rid	

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			of her about three years ago. That made it really hard to talk about anything, because Mum obviously gets upset if you mention stuff like dying. So you have to be really careful. (23 year old with CF)	
Full citation Moola, F. J., Norman, M. E., 'Down the rabbit hole': enhancing the transition process for youth with cystic fibrosis and congenital heart disease by re-imagining the future and time, Child: Care, Health & Development, 37, 841-51, 2011 Ref Id 329912 Study type Qualitative study Aim of the study To explore how young people with CF and CHD and their parents understand their health in the future and the perspectives they bring towards the concept of time. Country/ies where the study was carried out Canada Study dates	Sample size N=78 50 young people; 28 parents affected by CF and coronary heart disease Characteristics Age of young people: 11 to 17 years Age of parents: 35 to 55 years The severity of the condition ranged from mild to severe No other relevant characteristics reported Inclusion criteria Not reported Exclusion Criteria Not reported	Setting Clinic rooms Sample selection The study took place at the Hospital for Sick Children, a research/ teaching clinical care facility for children with acute and chronic conditions. No further details reported. Data collection 1 author conducted semi-structured interviews. A general interview guide was developed based on a review of the literature. Although interviews were semi-structured, participants' responses lead further lines of enquiry. Interviews lasted between 45 to 90 minutes. Data analysis All interviews were audio taped and transcribed verbatim. Field notes during data collection were also analysed. The authors first engaged in multiple in-depth readings to	Themes/categories The future as an uncertain terrain Young people in the study expressed they would want to get more actively involved in the future: My mum usually takes care of all the appointments and everything… it will probably change when I get older. When I'm an adult, I'll probably have to make all the appointments and everything" (young girl with CF, age 13) Time losses/ occupational restrictions Although they showed future aspirations, they contemplated if their health would deteriorate in the future, and the impact this would have on their lives. For example, they suggested it might be important to choose a school or work environment that is in close proximity to a hospital: "I will probably not live in the residence in the future and I will probably live at home with all the medicine near and staff right near me… It is easier to get all of the medicine and stuff; my mum is always driving down to get the	Limitations The methodological limitations of the study were assessed using an adapted Critical Appraisal Skills Programme (CASP 2006) Aim(s): Aim of the study clearly reported, research method was appropriate for answering the research question. Sample selection: The sample selection process was vaguely reported. The relationship between the researcher and the respondents was not reported. The participants were appropriate to address the topic. Data collection: Data collection was done using semi-structured interviews, but allowing new questions depending on the responses of participants. The interview questions are not reported in the paper, and it is uncertain if they are relevant to the aim of the study. Interviews were recorded for analysis. Data analysis: The analytical process was well reported. All the steps of the thematic analysis were reported, but it was unclear

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Not reported Source of funding Not reported		familiarise themselves with the data (following Braun & Clarke 2006, and Byatziz 1998). Second, for the purpose of coding the raw data, the data were read again and coded. Commonly occurring words were coded. Third, the coded data were collated and organised into higher order themes. This process involves judgement about which themes are similar, and can be grouped together. Fourth, through a process of revision, the themes were collapsed and refined. Fifth, the themes were defined and named.	medicine. And then I can just bring it home and get it right away. Instead of me living somewhere else and then having to get it. It would be so much more complicated" (young female with CF, age 15) Young women expressed sadness and resignation regarding the potential impact that illness could have on fertility. They were worried that illness would preclude them from being able to have a normal pregnancy: "I want to have a family, but I cannot have children because of CF" (young female with CF, age 16) Young people with CF and their parents described they feel threatened by CF, and expressed sadness for the lost time that would result in an early death: "I also know that I am not going to live as long as everybody else, so that is hard. I feel like it is out of my control, I feel helpless, how I used to be able to do it (physical activity), and now, I can't. It is kind of depressing. It makes me think that it is a progressive disease, and it makes me think that it is getting worse… it makes me worried" (young female with CF, age 15) "A parent never wants to have a kid die before her and what is what she (wife) was upset about. That is why I was trying to tell her to spend as much time as you can, with her (CF child). And just think; every waking	whether data saturation was reached. Findings/results: Results were presented clearly, but they were only partially applicable to the aim of the study, as very few themes referred to the transition from child to adult services. The citation/data and the researchers' own input distinguished. Overall quality: moderate Other information: Conflict of interest not reported This study includes a mixed population. Only quotes relevant to CF have been extracted.

Study details	Participants	Methods	Findings	Comments
			moment that you have, spend it with her. Even if you have both of them, of one by themselves, spend that time with her. I had her quit her job and that is why I work 16 hours a day. So that she can spend more time with them) (parent of a young person with CF). “It (CF) is part of who I am… I was thinking about life in general and how I knew that my disease was going to kill me off younger – I will probably not be able to see my grandchildren grow up, kind of thing… It really got to me that whole year and eventually, I just accepted the fact that everybody dies. It does not matter when you go, but you go. I just kind of got a positive attitude, that I might as well be happy and make the most of it” (young male with CF, age 17)	
Full citation Russell, M. T., Reinbold, J., Maltby, H. J., Transferring to adult health care: experiences of adolescents with cystic fibrosis, Journal of Pediatric Nursing, 11, 262-268, 1996 Ref Id 406459 Study type Qualitative study Aim of the study	Sample size N=17 participants N=7 young people and young adults with CF N=8 parents of young people and young adults with CF Characteristics Age of people with CF: 11 to 20 years Gender: 5 females and 2 males with CF	Setting At participant's home. Sample selection A convenience sample was selected. A letter was sent to the potential participants. As these subjects were all older than 18 years of age, direct telephone contact was made explaining the study and estimated length of time for involvement. Data collection At the first interview, any questions the adolescents	Themes/categories Adolescent Developmental Tasks: Adolescent wants to create their own identity and perform task to gain independence. To gain independence, the adolescents were in the process of developing autonomous and self-determined lives and separating from their parents. Many of the adolescents had begun attending clinic appointments on their own when they had acquired a driver's licence. Parental Adaptive task:	Limitations The methodological limitations of the study were assessed using an adapted Critical Appraisal Skills Programme (CASP 2006) Aim(s): Aim of the study clearly reported, research method was appropriate for answering the research question. Sample selection: Sample selection was clearly reported. Inclusion criteria process described in detail. The relationship between the

Study details	Participants	Methods	Findings	Comments
To investigate the experience of transferring to adult health care from the perspective of adolescents with CF and their parents. Country/ies where the study was carried out Australia Study dates Not reported Source of funding Not reported	7 mothers and 1 father Inclusion criteria 11 to 20 years of age; with a diagnosis of CF of at least 6 months duration; to have transferred health care management from the pediatric to adult hospital, and had either attended the respiratory medicine outpatient clinic of the adult hospital or had at least one admission to the adult hospital of 7 days or more, for treatment of CF. Exclusion Criteria Not reported	had pertaining to the study were answered, written consent obtained, and the demographic data collected. A second interview was then arranged to collect data using the Interview Guide. After completing the first interview with the adolescent, a parent of the adolescent was contacted for inclusion in the study. Parents were interviewed once using the same questions as the adolescents. All the interviews were tape-recorded with interview length ranging from 30 and 60 minutes. Data analysis All interviews were transcribed verbatim. Interview Guide data was categorised using the adaptive modes of Roy's Model. The data categorization was further refined using the subsections of each adaptive mode. Data was transcribed and coded and the data were clustered around emerging themes.	Even after the transfer of young adults to adult health services, the parents persisted in their attempts to be included until they were recognized as an integral part of the adolescent's care. One mother described this as, "I don't know whether they realized that we just weren't going to go away, that they would then have to get on with us and we were going to have to get on with them." Transition: Both the young adults and their parents are undergoing transition. During the transition phase, young adults start to feel more independence whereas parents start to relinquish responsibility. "I felt like an adult, I'd never felt like an adult before." (young adult) Preparation for the transfer was unplanned and in an ad hoc and for some young adults. Few parents were given the option of joining this visit, although they also would have liked to become acquainted with the adult hospital environment before the transfer.	researcher and the participants was not reported. Data collection: Data collection relied on the semi-structured interviews. Description of data collection method was well described with the use of topic guides and consistency in the interview process reported. Data analysis: The analytical process was reported vaguely. Description of emerging and overarching themes was reported, but saturation of data was not reported. Findings/results: Results were presented clearly (e.g., citation/data and the researchers' own input distinguished). Some of the themes were not supported by quotes from the participants. Overall quality: moderate Other information Ethical permission was obtained. Consistency between the researchers not reported.
Full citation	Sample size	Setting	Themes/categories Fracturing:	Limitations

Study details	Participants	Methods	Findings	Comments
Tierney, S., Deaton, C., Jones, A., Oxley, H., Biesty, J., Kirk, S., Liminality and transfer to adult services: a qualitative investigation involving young people with cystic fibrosis, International Journal of Nursing Studies, 50, 738-46, 2013 Ref Id 367061 Study type Qualitative study Aim of the study To explore young people's with cystic fibrosis experience of transferring to adult services. Country/ies where the study was carried out UK Study dates 2010 to 2011 Source of funding Manchester Academic Health Science Centre, UK	N=19 young people and young adults with CF Characteristics Age: 17 to 19 years Gender: 12 male participants Inclusion criteria Participants were eligible to take part if they had transferred to adult services no more than 12 months prior to interview and were not in the end stages of the disease. Exclusion Criteria Excluded for current acute psycho-social difficulties.	One adult cystic fibrosis unit in the UK. Sample selection Young adults with CF were recruited through one adult CF unit in the north west of England that does not have an adolescent centre and is not based in the same hospital as paediatric clinics. All eligible pariticpants were requested to take part in this study. Young adults were purposefully sampled to ensure variation in terms of gender, children's hospital attended and severity of illness. Recruitment continued until data saturation occurred. Data collection Data collection from semi-structured interviews carried out face-to-face or by telephone, which were digitally recorded and transcribed verbatim. The option to respond via email was available. Responses provided through email were saved as a Word document. A topic guide was developed by the team prior to data collection, based on reading of relevant literature. Data analysis Preliminary interpretation of data was conducted	Transfer involved the severing of bonds developed over several years with a trusted paediatric team. Some participants described their feelings about moving to adult services were superseded by procedural tasks, such as gathering relevant documents to forward to the adult team As one young adult with CF stated ''.. didn't seem to show interest in how you felt about moving over. It was more like we've sent your notes over to that side so we're just waiting for them to reply.'' Some interviewees believed their needs were neglected while they waited to move and described being uncertain about who was responsible for their care because they were straddled between two services: ".. they [paediatric staff] knew I was moving up so they'd gone a bit, put me last kind of thing, so I wasn't a priority because they knew I was going to be moving up soon that they'd lost interest but they were making sure that the younger ones were alright because they knew I was going soon" (young adult with CF). For young people , transition also meant that they had to take more responsibility .. I've never took it [CF] so serious. I've just always pushed it to one side and just tried to live a normal life but	The methodological limitations of the study were assessed using an adapted Critical Appraisal Skills Programme (CASP 2006) Aim(s): Aim of the study clearly reported, research method was appropriate for answering the research question. Sample selection: Sample selection was clearly reported. Inclusion and exclusion of participants were clearly reported. The relationship between the researcher and the participants was not reported. Data collection: Data collection relied on the semi-structured interviews. Description of data collection method was well described. Option of email targeting young adults as data collection method was justified. Data analysis: The analytical process was reported in detail. Description of emerging and overarching themes was reported along with the use of specific software. Saturation of the data reached according to this study. Findings/results: Results were presented clearly (e.g., citation/data and the researchers' own input distinguished. More than one analyst checked the robustness of the findings.

Study details	Participants	Methods	Findings	Comments
		in tandem with interviewing. Once all interviews had been completed, a systematic thematic analysis was carried out, using a recognised approach known as ‘Framework’. First author coded data using the computer package NVIVO-9 and developed an indexing scheme. A summary of the analysis was passed to the remaining authors, who contributed to the refinement of themes.	then you’ve got to, you can’t always just put it to one side because at the end of the day it’s a big part of your life... (Young CF patient). Acclimatising: Some interviewees welcomed a more direct approach and associated adult care with being listened to, making choices and playing a greater role in decision-making. “. . .as soon as the doctor started talking to me I was like, oh you’re talking to me rather than me mum, which was good. . .’’(CF patient) However, a few who had transferred very recently felt ill-equipped emotionally to cope with this change. ".. the doctor did ask me “what do you want to do?’’.. in childrens they wouldn’t do that, they’d just say ‘you need IVs, you should come in.’ So it was quite a bit, it was a bit confusing because I didn’t really know what to do myself. I was like, I don’t know, you tell me what should I do’’ (CF patient). Presence of parents were reassuring especially during the early transition phase. ".. if my mum hadn’t come, I wouldn’t have asked half as many questions. I don’t think I’d have been as open with the doctors talking to me.. I think I’d have been a little bit more introvert and worried.. I know it sounds dead daft, me mum was	Overall quality: Moderate Other information Ethical approval granted and necessary consent obtained. Confidentiality and anonymity maintained.

Study details	Participants	Methods	Findings	Comments
			there and I'm 19 but because me mum was there I was more confident in asking questions because I knew if I'd said something that had come out a funny way or the wrong way, mum would go well what she actually means is this" (CF patient) Online forums were a good source of information for young adults about to transfer to adult services as one CF patient stated. ".. since it was mentioned in the [adult] clinic about the forums.. I went on there and it's a big eye opener that there's loads of people going through it, been through it, and they can just offer you a lot more advice from a patient side of it.." Integrating: Integrating with the adult services was one of the challenges for young adults and was difficult to begin with. They believed that their issues would not be easily understood in adult health services. ".. I was with them for so long I got to know them really well and they knew I was a fussy person. But I'm sure it will all be the same with the adults." (CF patient) " .. he [paediatric consultant] could tell if I was ill. I've got like a problem with my stomach and he could feel straight away if I was having, if it was worse or if it was manageable..	

Study details	Participants	Methods	Findings	Comments
			So he's known me for a long time. That's why I was worried about moving here.. he knew a lot of the problems that I've had..." Relocating to a new healthcare system is one of several transitions young people with a long-term condition. Hence, transfer takes place against a backdrop of additional pressures and might not be a top priority. "It was very busy actually because you know you've got to come in here at some point but then you've also just started at college, a new course, you don't want to miss all the beginning of your course. It's a new start both sides so you don't want to miss either one." (CF patient)	
Full citation Tuchman, L. K., Slap, G. B., Britto, M. T., Transition to adult care: experiences and expectations of adolescents with a chronic illness, Child: Care, Health & Development, 34, 557-63, 2008 Ref Id 367066 Study type Qualitative study Aim of the study	Sample size N=5 young people and young adults with CF Characteristics Age: 15 to 21 years Inclusion criteria Not reported Exclusion Criteria Not reported	Setting Tertiary care hospital. Sample selection Subset of the sample recruited for larger study voluntarily participated when requested in a hospital over an 18 month period. Data collection Data collected through individual semi structured interview Following each interview, interviewers completed a brief report including a short free text summary of the interview, and indicated themes	Themes/categories Feelings about timing of transfer: Participants with CF noted that the timing of transition seemed arbitrary and unfair. One young adult said: "And right now it's like, maybe in a year, but right now I'm, I've just gone off to college. It's like, I don't want to make that transition now. And they're like, well you need to. It's like, and you have patients here that are 30 years old and you're telling me I have to go?" Another one said: "I think maybe if it wasn't just an all of a sudden strange situation. Slam the door	Limitations The methodological limitations of the study were assessed using an adapted Critical Appraisal Skills Programme (CASP 2006) Aim(s): Aim of the study clearly reported, research method was appropriate for answering the research question Sample selection: Mixed sample with other chronic diseases. Part of a much larger study. The relationship between the researchers and the respondents

Study details	Participants	Methods	Findings	Comments
To describe expectations and concerns of adolescents with chronic illness regarding transition from subspecialty paediatric to adult-centred care during the transition process in order to guide effective programme design and implementation. Country/ies where the study was carried out USA Study dates Not reported Source of funding Robert Wood Johnson Foundation Generalist Physician Faculty Scholars Program, USA.		and topics discussed with the subject in a set of pre-coded boxes. Data analysis Two investigators independently reviewed each transcript, extracted portions related to transition, and independently identified all unique themes using an editing organizing style. An overall emergent coding scheme was developed based on these themes and data were coded using QSR N6, a qualitative data analysis software programme. Theoretical constructs were developed for content related to concerns of subjects before and after transition to adult care.	behind you, you know. You're at university, you can't come back." Parent's changing role: Young adults appreciated the support of parents but also wanted independence in decision making. One young adult said: "My mom doesn't want to let go. She has flat out told me. You put 18 years into your child's health and it becomes your health as well" Another young with the similar view: "My mom has mixed emotions about it because she's not sitting back in the room with me anymore. She likes being able to put her two cents in. And I like being able to do it myself." Adolescents attitudes and concerns following transfer : Young adults appreciated the efficiency of adult services whereas others were concerned about the shorter appointment with less information which implied to them that people were less qualified than pediatric services. "It's just different. I mean I like how you kind of rush through it. It's not like where you have to talk to a million people. They don't seem as qualified there, it seems like the people that I talk to at Children's really knew what they were doing.Maybe it's because they don't talk to me as much."	not clearly reported. Inclusion and exclusion criteria not reported Data collection: Data collection relied on the semi structured interviews for CF. Information on structure of interview or whether topic guide were vague. Description of how "themes" were arrived at was discussed but information was not sufficient to conclude if data collection process was robust. No information on data saturation and full exploration of theme Data analysis: The analytical process was described with description of themes and categories. No critical review of the researchers' role in the process Findings/results: Results were presented clearly with themes supported by quotes. Researchers' role and potential influences in the analytical process not critically reviewed. Credibility and robustness of findings not reported Overall quality: Low Other information:

Study details	Participants	Methods	Findings	Comments
			The main positive differences that subjects noted between paediatric and adult care were feeling greater control over and more involvement in decision making. One subject who was very resistant to transition was impressed with pulmonolgist: "She gave me this big talk about some of the new things [I'm] going to encounter as an adult with CF. And she just opened my eyes to a lot of things." Participant suggestions: Few young adults expressed ideas about how to smooth the transition process. One 18-year-old young adult with CF anticipating transition explained "I think it would have been easier if they would have really started pushing when I was younger. Like, even at 15 or 16, start really suggesting it. Really being like, you know you might want to look into this. You might want to start meeting some of the doctors over there."	Mixed population study with other chronic diseases. Appropriate approval for this study was obtained. Multiple researchers but consistency between them not reported.
Full citation van Staa, A. L., Jedeloo, S., van Meeteren, J., Latour, J. M., Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults,	Sample size N=8 participants 3 young adults 3 parents 2 healthcare providers Characteristics	Setting At participant's home. Sample selection In each diagnostic group, three young adults were randomly selected from a list of patients officially in adult care for 2 years. Parents were approached after the	Themes/categories Moving on to adult services Sub-themes Leaving paediatric care is a logical step: Young adults and their parents recognised the inevitability that they	Limitations The methodological limitations of the study were assessed using an adapted Critical Appraisal Skills Programme (CASP 2006) Aim(s): Aim of the study clearly reported, research method was appropriate for answering the research question.

Study details	Participants	Methods	Findings	Comments
parents and providers, Child: Care, Health & Development, 37, 821-32, 2011 Ref Id 330156 Study type Qualitative study Aim of the study This study has 2 objectives: to map experiences with the transfer to adult care of young adults with chronic conditions; to identify recommendations for transitional care of young adults, their parents and healthcare providers Country/ies where the study was carried out The Netherlands Study dates 2004 to 2007 Source of funding No external funding. Funded internally by Rotterdam University & Erasmus University Medical Center.	Young adults with cystic fibrosis their parents and health care providers from tertiary care centre Inclusion criteria They were eligible for participation if they had no record of intellectual disabilities and had been transferred to adult care in the past 2 years. Exclusion Criteria Not reported	young adults had given consent. When no consent was given or the young adults could not be reached, new patients were approached – until 3 in each group had consented in an interview. Data collection All interviews were carried out by a trained nursing or physiotherapy student after extensive training. The patient and parent interviews were conducted at home and lasted 45 to 120 min. Parents and young adults were interviewed separately with an interview guide developed by the researchers. Health care providers were interviewed at their workplaces and interviews lasted from 25 to 60 min. Data analysis Interviews were digitally recorded, transcribed verbatim and then imported into the qualitative software package ATLAS.ti 5.0. Thematic analysis was done. Initial codes (sub-themes) were formulated on the basis of the interview guide. Subsequently, these were modified, expanded or merged as new issues	will be transferred to adult health care. "I'll need to get used to it. I've known my doctor awfully long,for 18 years.But I'll just see what's going to happen. [. . .] Actually, I'm getting too old now for a children's hospital. Seems to be the right age [for transfer] because I'm an adult now, aren't I?" (19-year-old male, CF) Health care providers recognised transfer as 'a natural process 'that is' age-appropriate. Transition is complicated by cultural gaps between paediatric and adult services: Some parents and young adults looked back at transfer as 'no big deal' and even as 'peanuts', when the process had been smooth or 'seamless'. But most young adults and especially parents said it had been more stressful and difficult than anticipated. Parents and young adults said that pediatric was more warm and friendly. On the other hand, they used metaphors like 'being lost', 'falling into a deep hole', 'feeling abandoned' and even 'waking up in a horror movie' for adult care. However, this was seen as temporary; transition was perceived as a rite of passage:"you have to get used to it, that's all."	Sample selection: Sample selection was vaguely reported. The relationship between the researcher and the participants was not reported. Data collection: Data collection relied on the semi-structured interviews. Description of data collection method was described in detail. Data analysis: The analytical process was reported with the use of thematic analysis and qualitative software package. Description of emerging and overarching themes was reported, but saturation of data was not reported. Findings/results: Results were presented clearly but use of quotes to support the findings was inadequate. Use of citation/data and the researchers' own input distinguished in this study. Overall quality: moderate Other information Mixed population study with multiple chronic condition reported out of which CF sample and findings were extracted. Ethical process was adequate and confidentiality and anonymity of the data reported.

Study details	Participants	Methods	Findings	Comments
		emerged during the analysis. The third step was collating subthemes to identify potential themes; emerging themes were checked iteratively in other interviews.	Young adults noted that more independence and self-reliance was expected of them. Parents wondered whether their children could take up the full responsibility for their treatment. Health care providers recognized cultural differences between the paediatric and adult specialities that complicated transfer. The adult care had more 'business-like approach' which often contrasted with the paediatric 'holistic, system-oriented approach'.	