G.2 Information and support

Review question: What information and support should be given to children, young people and adults with cystic fibrosis?

Study details	Participants	Methods	Findings	Comments
Full citation Angst, D. B., Deatrick, J. A., Involvement in health care decisions: parents and children with chronic illness, Journal of Family Nursing, 2, 174-194, 1996 Ref Id 473335 Study type Qualitative study with interviews. Aim of the study To describe how children with chronic illness and their parents are involved in health care decisions through a	Sample size N=20 children with CF and both parents of each child (20 families). Characteristics Age of children: range 7 to 11 years (median 9 years). Severity of illness: mild to severe, with majority in the mild and moderate categories. All families were intact, two-parent families. Inclusion criteria Children with CF and their parents. Exclusion criteria Not reported.	Setting Not reported. Sample selection Not reported. Data collection Data was collected through interviews regarding family demographics, and health/illness status of the child. All interviews were transcribed verbatim and processed. Data analysis Data was coded into categories, and analysed by each investigator. Themes derived were further explored and used for secondary analysis.	Themes/categories CF data set Decision making: Information from the health care provider Parents did not see themselves as having much room to make decisions. Decisions were based on recommendations made by health care professionals. None of the families recalled talking to the health care professional regarding decision making, or how or when to include their children in health care decisions (author's comment). "We pretty much get the plan from [the doctor] and then we just implement it...I just do what he tells me, basically. I think if I had something that was a nagging concern, I certainly know he would listen and respond to those concerns, but to date I've just not had any...I figure when he wants to change the programme, he'll tell me and we'll just do it" (mother of child with CF). Parents viewed the outcome of decisions about their child's health as potentially very serious. They identified the outcome of making the wrong decision as illness progression and even death, which is why they considered the health care professional's recommendations seriously. (author's comment) Most families were not given information about alternative care (for example, home vs hospital antibiotic therapy, and different means to enhance their child's nutritional status). (author's comment)	Limitations Aim(s): Clearly reported Aim of the study clearly reported, research method was appropriate for answering the research question Sample selection: Sample selection was not 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 vaguely described. 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) Overall quality: Low Other information Population included two data sets, one set with children who had CF, and the second set included children with scoliosis

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secondary analysis of two data sets. Country/ies where the study was carried out USA Study dates Not reported Source of funding Not reported			Parents as decision makers: Most parents viewed themselves as involved in the decision making process (discussion with the health care provider, decisions at home regarding enzymes and respiratory therapies). (author's comment) Fathers acknowledged that they were less involved in looking after their children due to unavailability to attend clinics. Most parents did not view their children to be involved in decisions or planning related to ongoing care, and considered themselves to make ultimate decisions about whether and what their children received: "I don't think he really should have much choice. I think we should just tell him. He certainly has as much right to ask questions and get answers as I do, but I want him to know that it's very important to do what we're told in this case. Not to be a creative thinker." (mother's comment) Parents decisions not to involve children regarding gastronomy tor central lines for supplemental nutritional therapies: Children considered for gastronomy tubes or central lines for supplemental nutritional therapies were not involved in the decisions. Children were not consulted on their feelings or opinions related to these interventions: "It was presented as a need for him to get back to approximately where he was on the growth curve. And if he does, then he avoids the tube. If he doesn't, then he gets the tube...We don't have that much that's negotiable...I don't see that there's two equivalent paths of therapy that are offered. Generally there's only	secondary to another chronic illness, Duchenne's muscular dystrophy, cerebral palsy, systemic juvenile rheumatoid arthritis, and Werdnig-Hoffman's disease.

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			one. Therefore, there's no need for discussion." (father's comments) Health care professional not acknowledging children in planning or decision making: Children did not see themselves as involved in planning or decision making: "When I go to clinic, he doesn't usually talk to me...when I loose weight, he yells at my mom for it". (Girl's comment) When children should be involved in decision making: Parents did not previously think about involving their children in decision making as they waited for a cue from the health care providers as to when it was appropriate to involve their children: "I guess I never thought to ask [child]...I guess as he's gotten older, there's no reason not to ask his opinion". (mother's comments) "As a parent, I guess I need to push or just be told it's OK to do this now. You know that this is the stage that the child can handle it. You know, because when [the health care professional] tells you it's OK, it's a lot easier than you making that decision". (father's comments) Children's satisfaction of involvement: Most children liked being uninvolved; however, many children wanted greater involvement: "Sometimes they want me to take more medicine, and I don't even know what the medicine is, and if I stop taking other medicines. And so I have to ask my parents and they have to ask. If they at least told me, I think I would feel a little better about why I'm taking this medicine..I think I'd feel more comfortable if I got to talk to them". (girl's comment)	

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Full citation Bagnasco, A., Petralia, P., Furnari, S., Ghio, S., Calza, S., Sasso, L., Paediatric nurses' perception of the child-family dyad's autonomy in managing a chronic disease situation: the experience of an Italian paediatric department, Journal of Preventive Medicine & Hygiene, 54, 124-9, 2013 Ref Id 363810 Study type Qualitative study Aim of the study	Sample size Number of pediatric nurses for CF=7. Characteristics Nurses working in the CF unit Inclusion criteria Not reported Exclusion criteria Not reported	Setting Children's hospital Sample selection Nurses working in the CF Unit. Participants were personally contacted to participate. A priori written consent was obtained from the participants. Data collection Data collected through individual semi structured interviews inside the hospital unit. Question was both general as well as technical aimed at identifying the major factors influencing the field. Data analysis All the interviews were transcribed, analysed and coded according to the 'thematic analysis'. The three researchers analysed them independently, and then compared the codes they had identified to reach an	Themes/categories Attitude of nurses towards education: All nurses stated that they play a crucial role in helping parents and their children to increase the level autonomy and safety. "Our job is to educate parents to help them increase both their self-esteem and their confidence in our competences and in nursing techniques". Adolesence and transition All nurses reported that, at least in the hospital, they tend to give greater independence and priority to young adults, and reduce the role of the parents. "You have to communicate with him/her as if he/she wasn't ill, for example, you have to ask simple questions related to his/her hobbies, favourite movies / books. This relationship based on mutual trust helps us to make fun of the disease" Parents' attitude in facing the chronic disease All nurses reported that children are less rebellious than young adults and influenced by their parent's perspective and knowledge. "The acceptance or denial of the disease of the child are related to the parents' perspective and ideas" Availability of information Nurses reported that the information were easily available in the internet which is helpful but may also create confusion and mistrust.	Limitations Aim(s): Clearly reported Aim of the study clearly reported, research method was appropriate for answering the research question Sample selection: Mixed sample with Neuro muscular and CF unit. No clear differentiation with overlap between samples. The relationship between the researchers and the respondents not clearly reported. Data collection: Data collection relied on the semi structured 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. No critical review of the researchers' role in the process. Findings/results: Results were presented clearly with themes supported by quotes. Researchers' role and

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To explore how nurses perceived autonomy in parents, adolescents, and children related to the management of chronic disease. Country/ies where the study was carried out Italy Study dates 2011-2011 Source of funding Not reported		agreement on the emerging categories.	"The Internet is the most consulted tool for the resolution of their cares, although in some cases, it is a source of misunderstanding"	potential influences in the analytical process not critically reviewed. Overall quality: Poor Other information Ethical approval process not described. Consistency between the researchers not reported.
Full citation Barker, D., Driscoll, K., Modi, A., Light, M., Quittner, A., Supporting cystic fibrosis disease management during adolescence:	Sample size 24 Young adults Characteristics Young adults with cystic fibrosis Inclusion criteria Not reported Exclusion criteria Not reported	Setting Not reported Sample selection Recruited from two specialty care clinics in South Florida and Cincinnati. Participants were identified by the medical teams, sent a letter informing them about the study and	Themes/categories Adolescents' perceptions of non-supportive treatment-related behaviours: Young adults clearly identified some treatment-related behaviours, such as nagging, annoying or feeling unwanted from families. They were reluctant to rate family members or friends as being 'unsupportive' even when annoyed by them. They recognized the need for persistent reminders and their benefits even when they are annoyed by them.	Limitations Aim(s): Clearly reported Aim of the study clearly reported, research method was appropriate for answering the research question Sample selection: Sample selection was clearly reported. The relationship

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The role of family and friends, Child: care, health and development, 38, 497-504, 2012 Ref Id 473360 Study type Qualitative semi structured interview study Aim of the study To explore the role of family and friends in supporting		approached following a regularly scheduled clinic visit. Parent consent were obtained prior to participation. Data collection The semi-structured interviews address both supportive and non-supportive behaviours from family and friends. Interviews were audiotaped and then transcribed for coding Data analysis The transcripts were coded using template analysis in which specific supportive and non-supportive behaviours were first identified and then assigned to hierarchical categories based on a template developed from prior literature. This template was then modified through an iterative process to better represent the data from the transcripts.	One participant reported, "[Mom] keeps telling me to do it whether I want to or not, she knows that it's going to help me so it's pretty supportive." While another stated, "[Mom] usually tells me to do [airway clearance] daily 'cause sometimes I don't like doing it so she usually has to tell me or else I won't do it." One adolescent stated, "Their intentions are good but the way they pursue it isn't that wonderful. I'd rather them tell me to do it instead of them yelling at me to do it. I mean I'm a person, too, I forget things." Similarly, one adolescent talked about reminders from her friend, She pretty much says, "Hey ok, if we're going to go out, you know, just like, let's get your meds done.' She wouldn't say, 'Ok you have to do your meds now' she'd say, 'So let's get your meds done just before we go or whatever so we don't have to do it later.' She'll present it in the way that it's not like something I have to do." She rated her friends' reminders as very supportive because they were as encouraging and not as demanding the treatment be completed. Young adults reported becoming annoyed when reminders were given after the treatment was completed or when the adolescent has a plan to complete the treatment. For example, one youth stated, "I get annoyed 'cause sometimes [mom] reminds me and I already did them. When talking about support from a close friend,"	between the researcher and the respondents not clearly reported. Data collection: Data collection relied on the semi-structured interviews. Process for semi structured interview was clearly reported but topic guide was not reported. Data analysis: The analytical process was described, with the use of predefined template analysis from the literature. No description of how "themes" were arrived at; researchers did not critically review their own roles in the process. Findings/results: Results were presented clearly with the generous use of quotes where appropriate (e.g., citation/data and the researchers' own input distinguished; the researchers' roles and potential influences in the analytical process not critically reviewed Overall quality: Moderate Other information Study approved by review boards. Multiple researchers but

Study details	Participants	Methods	Findings	Comments
cystic fibrosis disease management during adolescence Country/ies where the study was carried out USA Study dates Not reported Source of funding National Institutes of Health Postdoctoral Training Grant (T32 DK063929). Cystic Fibrosis Foundation Therapeutics, Inc. Student Traineeship (BARKER09A O);			another participant said, "It starts to get a little nagging at times, he's like 'You gotta do it, you gotta do it.' And I'm like, 'I know, I have a set time for this. I'll do 'em, don't worry!" They also found reminders annoying when the reminder interrupted other activities. For example, one participant stated, "Well, like they'll tell me to do stuff. And if I'm talking on the phone or hanging out with my friends, then I don't want to do it and it gets on my nerves." Another participant said, "Well sometimes like when I want to watch a show or something, she tells me to do my treatment, so I have to stop the activity and I go do it – that gets annoying." One adolescent said, "cause sometimes she'll say it and it'll really get to me and I'll be like, 'Don't tell me what to do' or 'I'll do whatever I want', you know, 'I can take care of myself '. So it's not that she's saying anything differently, it's just the way I'm perceiving it that day." Another adolescent stated, "If I'm in one of those aggressive type of 'Don't tell me what to do' kind of moods, if somebody reminds me to do something, it makes me very angry, and I'll not do it just to spite them."	consistency between them not reported
Full citation Beresford, B. A., Sloper, P., Chronically ill adolescents' experiences of communicating with doctors: a	Sample size N= 63 children and young people Characteristics Respondents had chronic conditions which were CF, juvenile chronic arthritis,	Setting Individual interviews took place in respondents' homes. The group meetings were held in venues that were geographically close to	Themes/categories Features of the encounter: "It would be better just to have one doctor so we could move on to different parts of epilepsy instead of getting the same questions again and again." "You don't tell the doctor anything because you don't want them [student doctors] to hear."	Limitations Aim(s): Clearly reported Aim of the study clearly reported, research method was appropriate for answering the research question

Study details	Participants	Methods	Findings	Comments
qualitative study, Journal of Adolescent Health, 33, 172-9, 2003 Ref Id 366784 Study type Qualitative study with semi structured interviews Aim of the study To explore the experiences of chronically ill adolescents in communicating with health professionals, including the identification of factors which hinder or facilitate their use of health professionals as an information source. Country/ies where the study was carried out United Kingdom	diabetes, epilepsy, Duchenne muscular dystrophy (N=11 with CF). There were 27 boys and 36 girls. They fell into one of two age bands: 10–12 years (n=29) and 14–16 years (n=34) Inclusion criteria A diagnosis of chronic condition had been made at least 12 months prior to participation Exclusion criteria Not reported	participants and, where appropriate, were accessible to people with physical impairments. Sample selection Recruitment letters and project information leaflets (different versions for parents, younger and older adolescents) were sent out by the hospital consultants. Families interested in taking part contacted the research team. The average response rate was 46%. Written informed consent was obtained from the adolescent and a parent during a home visit. Data collection Individual interviews (n=63) and group discussion meetings (total number of meetings=20) Data analysis Data were analyzed by a process of data reduction, data display and drawing/verifying conclusions	Parental presence: “I go to see him, but not sure why ‘cos mum talks about things.” Issue of status: “He doesn’t talk at my level. He ignores me and talks to my mum.” Doctor-centred factors: The communication skills of the doctor affected information exchange. “‘How are you?’ is not a good question!” Adolescent-centred factors: Lacking communication skills. “I’m normally quiet. I never know what to say.” The type of information needed: Specific nature of an information need could act as a barrier to communication. “Sometimes I think the question would be hard for the doctors, and the answer might not be a nice answer. I might not want to know it... One day I might get so weak I can’t move. I might like to know but it might make me sad, so I don’t want to know. I’ll just wait until it happens and I’ll manage it.”	Sample selection: Sample selection was clearly reported. The relationship between the researcher and the respondents not clearly reported. Data collection: Data collection relied on the semi-structured interviews and group meetings. Unclear about topic guides and limited information about group meetings. Data analysis: The analytical process was not described in detail, no description of how "themes" were arrived at; researchers did not critically review their own roles in the process. Findings/results: Results were presented clearly (e.g., citation/data and the researchers' own input distinguished; the researchers' roles and potential influences in the analytical process not critically reviewed Overall quality: Low Other information The study was not clear about ethical issues or the number of

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Study dates 1997-1999 Source of funding NHS (Executive), UK; Research & Development Programme (Mother and Child Health): Project Number MCH: 16-12.				researchers involved in data collection/interviews.
Full citation Braithwaite, M., Philip, J., Tranberg, H., Finlayson, F., Gold, M., Kotsimbos, T., Wilson, J., End of life care in CF: patients, families and staff experiences and unmet needs, Journal of Cystic Fibrosis, 10, 253-7, 2011 Ref Id 406070 Study type	Sample size N= 42 (12 patients, 10 family members of people with CF who had died and 20 staff) Characteristics All participants were over 18 years and were able to speak and understand English, without obvious cognitive impairment as judged by the CF coordinator. Inclusion criteria Not reported Exclusion criteria Not reported	Setting All interviews and focus groups were conducted at the Alfred Hospital. Sample selection A randomised block design was employed. Using a measure of lung function, Forced Expiratory Volume in the first second (FEV1), as a measure of illness severity, patients were allocated to one of three groups (FEV1 severe >40%, moderate 41–70% and mild >70%) until 4 participants were recruited into each	Themes/categories Knowledge of Palliative care: Patient: “Oh, there really is no hope for me.” Family: “I had only seen my mother die and she had cancer so I guessed it may be similar but it wasn't and it would have been helpful to have known more.” Psychological frame: Patient: “I would need some psychological support … I worry about my family and how they will cope… knowing there is counselling is a comfort to me.” Family: “we had spoken about death and his wishes ....I could just focus on (patient), say the things I needed to say… have no regrets… prepare myself for the worst…which I think helped me to accept” Treating team: Patient: “The team has rescued me a number of times now and I hope they can just keep doing that until transplant” Family: “Even though there is no new information we still want to hear from	Limitations Aim(s): Clearly reported 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 clearly reported Data collection: Data collection relied on the semi-structured interviews and group meetings. Structure of interview and topic guide decided by the experts within the hospital Data analysis: The analytical process was described in detail. Description of

Study details	Participants	Methods	Findings	Comments
Qualitative study Aim of the study To explore the unmet needs and key issues for people with CF, their families and the staff providing their care while awaiting organ transplantation Country/ies where the study was carried out Australia Study dates Not rerported Source of funding Research grant from the Australian Cystic Fibrosis Research Trust.		group. The next of kin (determined from the medical record) of the CF patients who had died in the past 4 years were recruited. Alfred Cystic Fibrosis staff, currently providing clinical care to CF patients (excluding those involved in the projects research group) Data collection Semi-structured interview format (developed by the research team consisting of medical consultants, palliative care consultants, psychologist, nurse, and medical social worker) conducted by the same investigator who had both psychology and research experience (neither known to the patients, families or staff). Data analysis Interviews and focus groups were audio-taped, transcribed and analysed using thematic analysis. All investigators read and	the team …otherwise you know you're not being abandoned but you feel abandoned". Communication: Patient: "Probably the CF team [should initiate end of life discussions] because I'll be forever in hope that I won't need it. Patient: Sometimes you want to know; sometimes you don't. When you're feeling good you want to know and when you're not feeling good you don't want to know." Family: "You get a bit overwhelmed by the information … when you think about it later you think, Oh, what did they say?" Engagement with palliative care service Patient: "I would not want my care managed by another team but happy for others input" Family: "I would have accepted the advice of palliative care expertise" Unmet needs: Patient: "I need to ask more questions but sometimes I don't even know what to ask" Family: "I would have liked more information when (patient)'s health was better so I wasn't in shock."	how "themes" were arrived at; saturation of data and exploring all the themes in detail was reported Findings/results: Results were presented clearly (e.g., citation/data and the researchers' own input distinguished Overall quality: High Other information The study unclear about ethical process but ethical approval obtained. Study conducted by lone researcher and may lack some of the formal research vigour

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		independently coded the transcripts. The research team generated coding categories from the data until no further new categories were forthcoming (saturation) and then applied the entire set of coding categories to all transcripts to identify emergent themes.		
Full citation Coates, Nicola, Gregory, Maggie, Skirton, Heather, Gaff, Clara, Patch, Christine, Clarke, Angus, Parsons, Evelyn, Family communication about cystic fibrosis from the mother's perspective: An exploratory study, Journal of Research in Nursing, 12, 619-634, 2007 Ref Id 473478	Sample size Mother of CF children (N=8) Characteristics Mother of living CF children Inclusion criteria Mothers of living children who were born between 1996 and 2000 and who had been diagnosed with CF shortly after birth Exclusion criteria Not reported	Setting Participants' homes. Sample selection All participants were recruited through a specialist paediatric respiratory unit. Specialist nurses working within the unit identified mothers who were eligible for study. Mothers were invited to be involved in the study via a study information pack sent to them by post. Response rate was 62% out of 13 mothers contacted. Data collection Participants were	Themes/categories Reason for disclosure to family members Two primary reason for disclosure elicited. Firstly disclosure for support from close relatives. "I think it was just that we were saying because it was all too much for us … so … it was really nice because they were there just … to support us at the time …" "I think I'd rather just get on with it myself, I think … moan to my mother." And secondly, to make them aware of the risk of CF. "When Thomas was born and I found out he had cystic fibrosis, it was the fact … that I had 3 younger sisters to me … and I knew one day they were going to have children … like every time they phone up pregnant I'm like,"go and get tested". Barriers to disclosure	Limitations Aim(s): Clearly reported Aim of the study clearly reported, research method was appropriate for answering the research question Sample selection: Sample selection was clearly reported although the number of sample was lower (n=8). The relationship between the researchers and the respondents not clearly reported. Data collection: Data collection relied on the semi structured interviews. Structure of interview and topic guide reported. Description of how "themes" were arrived at was discussed. Data saturation and

Study details	Participants	Methods	Findings	Comments
Study type Qualitative study Aim of the study The aim of this study was to supplement existing research to gain insight into mothers' experiences of informing relatives about CF and to look at patterns of communication within these families. Country/ies where the study was carried out UK Study dates Not reported Source of funding Not reported		interviewed in their homes after obtaining consent. Semi-structured interview based on previous literature was conducted. As this was an exploratory study, new emerging themes were taken into account and the schedule was modified accordingly. All interviews were audio-recorded and later transcribed. Data analysis The anonymised transcripts were analysed using existing method described. No computer-based analysis done because of small sample. Coding took place both within and across transcripts (axial coding).The themes discussed in the results were organised according to the topic areas.	The main barrier was the lack of closeness or contact with other family members. "… He's never been tested anyway 'cause they [referring to her father and his brother] are not in close contact." Information and support from health professionals Mothers reported that they were not given specific advice/ support about whom they should disclose information in the family. "I think … when it … comes to actually going down that road of like we were talking about earlier,with kids and things like that,then obviously … I think I'd rather have someone come in … and see him, you know tell him myself but also have that person … as back up … to answer questions." However in other instances, doctors had been very helpful. "He [the doctor] did say … whatever relatives you want to be told … like immediate ones and that, you know, they can all come and he sat down and he explained … cystic fibrosis to them.…" Leaflets were particularly useful in informing relatives as suggested by most of the mothers. "....There was one leaflet, I remember, with a diagram of … the like 1 in, say 25, and then the 4 and one red for the CF and one blue for the, and the two green for the in-betweens … that was good. Like once you told people and they'd have a look at that.…"	full exploration of theme not clear. Data analysis: The analytical process was described with description of themes and categories. No user of any specific software for analysis as the data generated was too low. Whether sufficient data were gathered to fully explore the themes is not clear. No critical review of the researchers' role in the process. Findings/results: Results were presented clearly with themes and quotes and with citation/data. Researchers' role and potential influences in the analytical process not critically reviewed. Overall quality: Moderate Other information Ethical approval process described. Discrepancies between the researchers were addressed by the senior researcher with oversight.
Full citation	Sample size	Setting Not reported	Themes/categories Losing Ground:	Limitations Aim(s):

Study details	Participants	Methods	Findings	Comments
D'Auria, J. P., Christian, B. J., Henderson, Z. G., Haynes, B., The company they keep: the influence of peer relationships on adjustment to cystic fibrosis during adolescence, Journal of Pediatric Nursing, 15, 175-182, 2000 Ref Id 473508 Study type Qualitative study Aim of the study To explore the influence of peer relationships on adjustment to CF Country/ies where the study was carried out USA Study dates Not reported	N=15 young people and adults. Characteristics Repondents' with CF age between 17 -22 years with mean age of 19 years. Inclusion criteria Not reported Exclusion criteria Not reported	Sample selection Recruited from a regional CF center in the Southeast. Other information not available. Data collection A retrospective interview approach was used to explore the meaning and nature of chronic illness for these youths with CF. All interviews were collected by experienced advanced practice pediatric nurses who were not members of the CF team. Open-ended questions were used to explore past and present details of their chronic-illness experiences. Data analysis Transcribed interview data were analysed systematically by using the constant comparative method. The investigators checked each transcription against the original audiotape to ensure accuracy of data. Each interview was read several	"I think it's hard for people that have CF because they're different because a lot of them look perfectly normal . . . like there's nothing wrong with them. But, it's inside and sometimes when you can't see what's wrong with you, you don't think there's something wrong with you." Being out of a loop: "CF makes it harder in terms of I'm not at school as much as some of the others, so you're kind of out of the loop when you come back after 3 weeks. Who's seeing who, you know. That can change radically in 3 weeks." Finding a new company of friends: "There were 16 cystic fibrosis patients on the floor that holds maybe 30. We all went out to dinner. That's the kind of thing that balances out even though you miss school and the occasional homecoming dance. You have at least something to balance out and just say, Yeah, I missed that, but I've made a lot of good friends here, too.'' Fighting a never ending battle: "It [CF] just keeps coming back. I'll get better, and then I'll get sick again. . . . I just don't understand why I can't take something like people with cancer. They take their chemotherapy, and they'll get rid of it. . . . I'm just fighting to get rid of something for a certain amount of time. . . . It's a never-ending battle."	Clearly reported Aim of the study clearly reported, research method was appropriate for answering the research question Sample selection: Sample selection was not clearly reported. The relationship between the researcher and the respondents not clearly reported Data collection: Data collection relied on the open ended interviews. Structure of interview and topic guide not reported. Description of how "themes" were arrived at was discussed. No any discussion on whether saturation has been reached for any of the themes reported. 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 (e.g., citation/data and the researchers' own input distinguished. Researchers' role and potential influence s in the analytical process not critically reviewed Overall quality: low Other information

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Source of funding University Research Council Grant from the University of North Carolina at Chapel Hill		times, and a summary of themes for each participant was prepared. Text base Alpha was used for data management and comparative analysis of qualitative data.		The study did not report ethical approval or described the ethical process such as confidentiality of research. Study conducted by multiple researchers but the level of consistency between them not reported
Full citation Dellon, E. P., Sawicki, G. S., Shores, M. D., Wolfe, J., Hanson, L. C., Physician practices for communicating with patients with cystic fibrosis about the use of noninvasive and invasive mechanical ventilation, Chest, 141, 1010-7, 2012 Ref Id 366826 Study type Web based survey followed by qualitative study using	Sample size Cystic fibrosis physicians completing the survey=34 Cystic fibrosis physicians interviewed=26 Characteristics Cystic fibrosis physicians at the University of North Carolina and Children's Hospital Boston CF care centers Inclusion criteria Pulmonologists (physicians) currently providing care to patients with cystic fibrosis Exclusion criteria Not reported.	Setting Survey was web based. Setting for interview not reported. Sample selection No reported. Data collection Survey questions were based on existing surveys. In the follow up interview, seven semi structured interview questions with scripted probes was developed based on survey responses. Interviews were conducted in person or by telephone and were recorded and transcribed verbatim. Data analysis Summary statistics used for survey questionnaire. For interview, two independent coders	Themes/categories Timing and content of communication Incorporating into routine CF care “normalizes” a difficult topic “We have standards for everything else about the care of these patients. This seems like in many ways the most important thing you could possibly discuss and yet we have no standards.” Proactive rather than a reactive approach “Maybe if we can find a way of bringing this up at earlier points in the disease it wouldn’t become such a heavy weight on the patient. It would be helpful to be able to say, ‘This is not something we are doing uniquely for you, this is just part of what we do.’” Ensures access to same information for all patients and families “It would be helpful to formalize the structure. We do a lot of this stuff in a pretty informal ad-hoc fashion.” Educational and decision support tools for patients and families Balanced, unbiased information is essential to the process of informed decision making	Limitations Aim(s): Clearly reported Aim of the study clearly reported, research method (semi structured interview) was appropriate for answering the research question Sample selection: Sample selection was process was not clearly reported. The relationship between the researcher and the participants was not reported. Data collection: Data collection relied on the survey followed by semi-structured interviews. Development of interview questionnaire which was based on responses to web based survey was not clearly described. Description of data collection method was vaguely described and the setting of the interview was unclear. Data analysis:

Study details	Participants	Methods	Findings	Comments
semistructured interview Aim of the study To give an account of physician perspective on communication with patients about the use of non invasive and invasive mechanical ventilation for respiratory failure Country/ies where the study was carried out USA Study dates Not reported Source of funding Supported by a Junior Faculty career Development Award from the National Palliative Care research Center		reviewed interview transcripts. Deductive coding was used to categorise the findings and qualitative content analysis was used to delineate themes.	"Some sort of handbook would be helpful because a lot of times when you talk about things like this, they remember very little of it or they kind of get things kind of messed up. So if they had something they could refer to later, this would reinforce some of the discussions." Educational and decision support tools may prompt in-depth discussions about treatment options and preferences "Having tools to facilitate the discussion would help. We may misread the kind of information people want. And if you are trying to explain treatments, I have no materials to give people about things like bilevel pressure ventilation." Multidisciplinary care Use the multidisciplinary CF care team to facilitate communication The multidisciplinary care team is the current standard for CF care in the United States "The best person to start these discussions is the person who knows the patient well. It may be the physician, a social worker, a nurse coordinator. It has to be someone who has a good feel for the patient and is in a position of trust" Providers from different disciplines may help to keep each other on task Support from the team makes discussing diffi cult issues easier for everyone involved "It is all about communication. It is a question of including everybody as much as possible."	The analytical process was reported vaguely. No information on validity and reliability of interview questionnaire which was developed in response to web based survey. Description of emerging themes and data saturation was not reported. Findings/results: Results were presented clearly (e.g., citation/data and the researchers' own input distinguished) Overall quality: Low Other information

Study details	Participants	Methods	Findings	Comments
Full citation Fair, A., Griffiths, K., Osman, L. M., Attitudes to fertility issues among adults with cystic fibrosis in Scotland. The Collaborative Group of Scottish Adult CF Centres, Thorax, 55, 672-7, 2000 Ref Id 366844 Study type Postal open ended questionnaire survey Aim of the study The aim of the study was 1) to determine attitudes about fertility and pregnancy among subjects with cystic fibrosis aged 16 years and over	Sample size N= 195 N (responded)= 136. Male =82, female=54 Characteristics Participants were aged 16 years and over and recruited from Scottish Cystic Fibrosis clinics Age: Male 24.5 (20-31), Female 24.0 (19-31) Age at diagnosis: Male 1.3(<1-2.3), Female 2 (<1-10) FEV1 (%predicted): Male 52.6 (32.3-72.6), Female 59.9 (44.5-75.5) BMI(KG/m2): Male 20.1 (18.5-22.6), Female 21.0 (19.1-23.1) Inclusion criteria Not reported Exclusion criteria Not reported	Setting Postal questionnaire at participant's home Sample selection All the population were from four Scottish Cystic Fibrosis clinics Data collection Collected through open ended postal questionnaire. A questionnaire was developed by nurses from the cystic fibrosis clinics, consultants, and representatives of National services division, NHS. This was pilot tested and amended before finalising the questionnaire. Data analysis Statistical software used for summarising quantitative data. The NUD*ist package used to classify open ended qualitative responses.	Themes/categories General questions about fertility Participants commented on how they would feel talking to a HCP about having a child. Talking to health professionals “I have never had the courage to bring up the subject” (M, 26 years, FEV1 65% predicted). “I would welcome an honest opinion because I wouldn’t want to make the wrong decision” (F, 19 years, FEV1 53% predicted). “When I was pregnant with my second the doctor at the maternity said to me ‘Who gave you permission to have another child?’” (F, 41 years, FEV1 47% predicted). (The doctor said to me) “I hope you’re not going to get pregnant because if you do it will kill you” (F, 20 years, FEV1 20% predicted). How would you feel if a health professional questions if you should have a child? “I would be very angry because you are a normal woman and if in a relationship both you and your partner feel the same as any young couple and having a family may feel like the next step” (F, 32 years FEV1 58% predicted). “I think this would be beneficial, but sad if he/she tells you it’s best not to have a child. It is best if they tell you the exact truth” (F, 17 years, FEV1 66% predicted). “It’s up to the individual, nothing to do with anyone else” (25 years, FEV1 43% predicted). Women	Limitations Aim(s): Clearly reported Aim of the study clearly reported. Research method was adequate for answering the research question. However, qualitative study design would have been better for answering the research question. Sample selection: Sample selection was not clearly reported with no information on inclusion or exclusion criteria. The relationship between the researcher and the participants was not reported. Data collection: Data collection relied on the open ended postal questionnaire. Limited information on the development of questionnaire. The response rate of 70% was adequate. Study design limits the exploration of themes or development and eliciting further information. Data analysis: The analytical process of interpreting open ended question was not reported although use of specific qualitative software (NUD*ist) reported. No information on data saturation or identification of specific themes Findings/results:

Study details	Participants	Methods	Findings	Comments
attending the clinics and 2) to determine satisfaction with communication on this issue from health professionals. Country/ies where the study was carried out UK Study dates Not reported Source of funding National Services Division, NHS, Scotland			Women commented on the information they thought should be given. Three themes emerged from female responses: (1) wanting more information about health consequences of pregnancy "(explain that) you will feel ill during and maybe for years after giving birth and when you have your baby, there's almost no time to be unwell yourself which can cause problems" (F, 23 years, FEV1 44% predicted). "Information about general health during pregnancy and risks about the actual birth" (F, 16 years, FEV1 50% predicted). (2) suggesting information to give to other women, particularly about the long term health effects from pregnancy "To let them know that 14 days of IVS will be administered at home after the birth of the baby" (F, 29 years, FEV1 60% predicted). (3) describing satisfactory and unsatisfactory discussion with cystic fibrosis doctors and nurses. "I felt no one would help me at least try and come to a decision. I had so little information. I was constantly told the risks were too high and now it's too late and I feel there's a huge gap in my life" (F, 33 years, FEV1 62% predicted). Men Men suggested what information they wanted and seemed to divide into those who wanted "the facts:	Results were presented clearly (e.g., citation/data and the researchers' own input distinguished). Overall quality: Low Other information Ethical approval process not described. Consistency between the researchers either in developing the questionnaire or in analysis not reported.

Study details	Participants	Methods	Findings	Comments
			"Simple cans and can'ts, facts ... to the point, no 'maybe you can but ... etc'." (M, 20 years) "I feel that there should be discussions and literature handed out in CF Clinic at an earlier stage e.g. not later than 16" (M, 20 years, FEV1 65% predicted). "Facts as they stand with hope via assisted fertility information" (M, 28 years, FEV1 22% predicted). and those who wanted the emotional impact of infertility to be recognised by their health professionals: "I do feel this can be a very emotional issue" (M, 23 years, FEV1 45% predicted). "Make sure he knows about it early so he can learn to accept it easier" (M, 27 years, FEV1 40% predicted). Lack of knowledge about assited fertility Most men did not seem to be aware of the relatively low success rate of assisted fertility treatment. Of 30 comments from men, nine were on the positive chance that they would be able to have children through assisted fertility and no man commented on the low success rate of fertility programmes (authors comment). The authors noted that younger men aged < 20 years were much less likely than women or older men to make any comment on what information they wanted. Older men with good lung function seemed most likely to be distressed by their infertility: "I would like more information on how other people are handling the fact that they cannot have children" (M, 35 years, FEV1 84% predicted).	

Study details	Participants	Methods	Findings	Comments
			"Give some hope of being able to father and try and make them not feel a failure if they can't father children" (M, 31 years, FEV1 96% predicted). "It is terrifying for men not to be able to father a child" (M, 34 years, FEV1 84% predicted).	
Full citation Filigno, S. S., Brannon, E. E., Chamberlin, L. A., Sullivan, S. M., Barnett, K. A., Powers, S. W., Qualitative analysis of parent experiences with achieving cystic fibrosis nutrition recommendations, Journal of Cystic Fibrosis, 11, 125-30, 2012 Ref Id 367036 Study type Qualitative study with semi-structured interview. Aim of the study To better understand	Sample size N=8 parents of children with cystic fibrosis Characteristics Mean age of children at the time of interview=8.2 years (SD 0.8). 5/8 children were male. BMI of children ranged from 30.7% to 97.5%. Forced expiratory volume in 1 second ranged from 71% to 120%. Inclusion criteria Parents of children with CF. Exclusion criteria Not reported	Setting Interviews were conducted via telephone or while the child was admitted to the CF inpatient unit. Sample selection Parents were recruited from a clinical trial that had been completed 5 years previous to this study. Data collection The interviews were conduced over the telephone or face to face while the child was admitted to the CF inpatient unit. The average length of the interviews was 24 minutes (SD=8.8). Interviews were audio-taped. Information was systematically collected from parents by asking uniform stem questions while offering parents flexibility to provide	Themes/categories Behaviour and nutrition: Parents recalled that learning how to deliver both positive consequences (praises and rewards) and negative consequences (removal of privileges) to manage mealtime behaviour was helpful. Parents also reported intense desperation to get their child to eat, inkling preparing meals for the child so that the child would eat. Parents found that an ongoing challenge was general behavioural non-compliance including refusal to eat, take enzymes, and complete a fecal fat test. Parents found challenges with transfer of treatment responsibility from them to their child for certain aspects of CF management. Transition to school: Parents/families reported that managing transition to school was difficult as parents were not able to monitor their child's nutrition during the school day, and found that they were compensating their child's food intake at home (dinner). Parents also reported that there was a negative impact of missing school due to hospitalisation and illness. Parents struggled with partnering with schools to ensure that their children received appropriate accommodations.	Limitations Aim(s): Clearly reported 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 clearly reported Data collection: Data collection relied on the semi-structured interviews. Description of data collection method was described Data analysis: The analytical process was reported. Description of emerging and overarching themes, and saturation was reported. Use of specific software for data collection and analysis reported. Coding done based on the approach widely recommended in the literature. Findings/results: Results were presented, however, quotations/citations

Study details	Participants	Methods	Findings	Comments
how families used the strategies taught in a behaviour-nutrition intervention and to identify the challenges with CF management families experienced during this developmental transition, particularly nutrition. Country/ies where the study was carried out USA Study dates Not reported. Source of funding National Institutes of Health.		additional relevant information Data analysis Interviews were audio-taped using USBBLASTTM recordi ng device and were anonymise with unique identification number. Thematic analysis was informed by grounded theory. Interview content/transcripts were coded using the recommended approach described in previous literature. Themes were identified, reviewed, defined, and refined. Each transcript was reviewed independently, and themes were excluded when saturation was achieved.		from respondents/author were not reported clearly Overall quality: Moderate Other information
Full citation Grob, R., Is my sick child healthy? Is my healthy child sick?: changing	Sample size N=35 parents of children diagnosed with CF (33 mothers and 2 fathers) Characteristics	Setting Not reported. Sample selection Not reported. Data collection	Themes/categories Diagnosis of CF Delayed diagnosis: Parents were concerned about their observations and suggestions being	Limitations Aim(s): Clearly reported Aim of the study clearly reported, research method was appropriate for answering the research question

Study details	Participants	Methods	Findings	Comments
parental experiences of cystic fibrosis in the age of expanded newborn screening, Social Science & Medicine, 67, 1056-64, 2008 Ref Id 332737 Study type Qualitative study with semi-structured interviews Aim of the study To explore how rapid growth in the USA of mandatory new born screening leading to a diagnosis of CF is changing, for affected families, their experience of illness versus disease Country/ies where the study was carried out	Parents: 34/35 were Caucasian, 1/35 was Hispanic. Parents ages ranged from 23 to 53 years (mean 34 years). Approximately 2/3 of parents interviewed were of middle class, 1/3 of parents was of working class. Inclusion criteria Children were diagnosed with CF via new-born screen, prenatally or after development of symptoms. Exclusion criteria Not reported.	Semi-structured interview format. No other information about data collection was reported. Data analysis Interviews were recorded and fully transcribed, and analysed using a grounded theory methodology. Overarching themes and specific categories were derived from the data, which were reviewed twice to verify congruence of the data.	dismissed by the health care professional regarding their child's health: "At the doctor's office, I would cry every time because he wasn't gaining [weight]. I think they kind of looked at me like this hysterical first-time mother, and the doctor whom I kept going to see kept saying 'Oh he'll kick in, some babies take a while to kick in.' That was really hard, being so powerless..." (mother of child who had delayed diagnosis) However, parents were relieved when they received a diagnosis of CF: "..when we got it I was totally relieved. Even though he cystic fibrosis and I knew what it was and I knew the outcome of it, it was a relief, because I knew I was gonna be treated correctly. I knew..that I wasn't crazy, that I wasn't looking for something to be wrong with him, you know?" (mother of a child aged 7 years with delayed diagnosis of CF) Information about new born screening: One mother reported that she received little information from the paediatrician about new born screening, and none about CF when discussing screening results of her child: "I didn't know anything about it and I got sent home with a little bit of information but it was like a week later before I had my first clinic. I was there all by myself and calling like half of [city name] it felt like trying to find somebody that...was home and that could talk...They told me it was genetics but I didn't understand what genetics truly meant either so I was like well what did I do and you know what I can have done different.." (Mother of a one month old infant diagnosed with CF).	Sample selection: Sample selection was not reported. The relationship between the researcher and the respondents not reported. Data collection: Data collection relied on the semi-structured interviews. Description of data collection method was not described clearly. Data analysis: The analytical process was reported, but vague in description. Description of emerging and overarching themes was reported, but saturation of data was not reported. Findings/results: Results were presented clearly with adequate discussion of findings (e.g., citation/data and the researchers' own input distinguished). Overall quality: Low Other information New born screening for diagnosis of CF

Study details	Participants	Methods	Findings	Comments
USA Study dates Not reported Source of funding The Investigator Awards in Health Policy Research from Robert Wood Johnson Foundation Programme			Another mother reported that she did not know of CF until she received a positive new-born screen result for CF: "[Margo was] chunky,'' she recalls. ''She was over nine pounds at birth, so I mean there was no indicators, you know, I mean visually, you knowlooking at her there wasn't anything to think therewas anything wrong with her..'' (Mother of child of 2.5 years diagnosed at birth). Support at diagnosis (at birth): Mothers reported that they seek support from professionals upon receiving a positive screening test for CF: "Well, I would say in the very beginning [when we got the NBS diagnosis]. me and my husband, we were both kind of like what do you [doctors] want to do,what do you think we should do, what do you think we should do, what do you think is best? You guys are the doctors, you know" (mother of a new born infant). Seeking reassurance: Mothers reported that they contacted the health care professional for advice, expertise, reassurance and instructions about caring for their infant: "Once I found out that she possibly could have the CF, I called so many times in the middle of the night. I'm like 'Oh my god, she's breathing really heavy, I don't know if this is right..' There was just a lot of follow-up that came from the hospital that helped.' (mother of one month old infant) One mother found it difficult to approach the health care professional as they regarded her as being overly needy: "What was hard I think in the beginning [was] being new as a parent for one and not knowing	

Study details	Participants	Methods	Findings	Comments
			what was normal for children. and then dealing with the disease, the health care.. The people in health care were somewhat hard to deal with... because I would call a lot because I didn't know, because Iwas so scared, because there was such a fear..I would call the nurse a lot and say 'I don't know if this normal or not, this doesn't seem right.' (Mother of new born infant diagnosed with CF). Confidence in seeking support over time: Parents developed expertise about their child's condition over time, with many becoming assertive and confident advocates: "In the beginning, everything that any doctor ever had to say was gospel. You took that to be the truth, you took that to be the absolute answer. You did not question, that's just the way it was. It took a long time. to get an education within myself. that I needed to question some of the stuff that was going on.. Now I'm not above calling and telling anyone what I think about them or their assessment of my child.. I'm not afraid to ask for what I think Rose needs, and I think that I have certainly evolved in that respect" (parent of child with health problems) Coping with infant with CF (after discharge from hospital): Parents felt overwhelmed when their infant was discharged from hospital: "..It just seemed like everything changed.. It was like there is so much more now to taking care of her, and are we really fit to do that?.. [I]t was just so overwhelming. I mean the first time we went to the clinic they were like well, you have to do this and this. And we met with nutritionists, respiratory therapists and pulmonologists and social workers and you know it was just all so overwhelming, all this stuff we were going to	

Study details	Participants	Methods	Findings	Comments
			have to do. I remember leaving there thinking "how am I going to do all this stuff in one day?' ". (parent of infant diagnosed with CF, after discharge from hospital) Parents seeking information about CF: Some parents felt it was necessary to learn everything about CF immediately after discovering their child had CF: "I'm the kind of person, I'm really proactive, so if I find out about a problem or an issue I want to dive into it and figure out what's the best way to do this, or what should we do? So I want all the information I can get.. I don't just want to be clueless and think, 'Oh she'll be fine, she'll beat the odds.' I want to know the dirty truth. I want to know what these people [with CF] go through so that I know how I can prepare myself and how I can prepare Alexandra". (parent of child with CF diagnosis) Parents did not want professionals to withhold information: ''One problem I have with some doctors is that they talk down to you and don't explain things thoroughly". (Parent of a child with CF diagnosis) Mothers wanted information about CF at a pace that was comfortable for them: ''They had some hand-outs and things...as far as treatment and dietary concerns, you know,'' "But ''there was just too much at that time to absorb, so we [would] look at it a little bit [at a time]..'' (mother of a child with CF diagnosis) Mothers did not want to receive statistical or complicated information about their child's future from the health care professional:	

Study details	Participants	Methods	Findings	Comments
			We had one doctor. and we walked into the room and she sat down and we sat down and she said, 'Having cystic fibrosis is not a good prognosis.' And I sort of thought 'I don't really need to hear this. I'm well aware of what it does.' I didn't really think that was very thoughtful to say to someone while holding their new baby.. This one doctor. could be quite callous. And not really think about how you might be feeling as a parent..[What I needed was] the basics for the moment. You can find out everything else as you go along. It's not necessary to know everything right from the start". (mother of a child with CF diagnosis)	
Full citation Grossoehme, D. H., Filigno, S. S., Bishop, M., Parent routines for managing cystic fibrosis in children, Journal of clinical psychology in medical settings, 21, 125-135, 2014 Ref Id 473660 Study type Qualitative study Aim of the study	Sample size N=25 parents of children with CF Characteristics Parents of children with CF Inclusion criteria Parent with a child at least three months post-CF diagnosis and the child aged between 3 months to 13 years, which has been defined as the period of time when parents may be assumed to bear up to 80% of treatment responsibility Exclusion criteria Inability to speak English	Setting Parents home with telephone interview Sample selection 83 parents were enrolled in the primary study of treatment adherence and completed questionnaires in the CF center. A convenience sub sample of 25 sequentially approached parents were recruited to participate in a telephone interview Data collection Parents participated in a semi-structured telephone interview that included	Themes/categories Support outside of the family system: The presence of an in-home respiratory therapist was identified as a facilitator to creating a daily routine and teaching children about airway clearance techniques. Parent stated "So, a respiratory therapist was able to come out and help with the treatment and that really, really helped a lot and helped to get established and…."	Limitations Aim(s): Clearly reported 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 researchers and the respondents not reported. Data collection: Data collection relied on the semi structured interviews based on previous research. Structure of interview reported. Description of how "themes" were arrived at was discussed in depth. Data saturation and full exploration of theme reported. Ethical approval process reported. Data analysis:

Study details	Participants	Methods	Findings	Comments
To describe parent experiences developing and utilizing CF care routines. Country/ies where the study was carried out USA Study dates Not reported Source of funding Not reported		questions about daily CF treatments. The interview guide created to collect data on general parental coping and spiritual coping. Data analysis Interview transcripts processed using NVivo 10.0. Narrative data were coded and Phenomenological methodolgy was used to guide data analysis.		The analytical process was described with description of themes and categories and use of specific software for processing. No critical review of the researchers' role in the process. Findings/results: Results were presented clearly with output classified into sub themes and categories. (e.g., citation/data and the researchers' own input distinguished). Researchers' role and potential influences in the analytical process not critically reviewed. Overall Quality: Moderate Other information The study did not described the ethical process of research. Study conducted by multiple researchers but the level of consistency between the researchers not reported.
Full citation Hilliard, M. E., Hahn, A., Ridge, A. K., Eakin, M. N., Riekert, K. A., User Preferences and Design	Sample size N=16 adults with CF who consented to participate in the study Characteristics (n=15 (one participant did not complete an online survey)	Setting Interviews were conducted by telephone and by completing an online survey. Sample selection	Themes/categories General information not useful "Sometimes I'll [wonder when] something happens health-related to me, 'Is that normal for everyone or…is that happening to me because I have CF?' And it's hard to find particular sources where I can find that out." (Age 35, Female)	Limitations Aim(s): Clearly reported Aim of the study clearly reported, research method was appropriate for answering the research question Sample selection: Sample selection was clearly reported. The relationship

Study details	Participants	Methods	Findings	Comments
Recommendations for an mHealth App to Promote Cystic Fibrosis Self-Management, JMIR MHealth and UHealth, 2, e44, 2014 Ref Id 405826 Study type Mixed methods study with qualitative content using semi-structured interview. Aim of the study The aim of this mixed-methods study was to involve individuals with CF in guiding the development of engaging, effective, user-friendly adherence promotion apps that meet their preferences and self-management needs.	Age in years, mean (SD) (range): 30.2 (5.9) (21-43) Race, n % : Caucasian 15 (100%) Gender, n, %: female 7 (47%) Marital status, n, %: married/partnered 11 (73%) Education, n, %: college degree or beyond 11 (77%) Work, n, %: full or part time 11 (73%) Inclusion criteria Age 18 years or above, diagnosis of CF, currently treated at the hospital's adult clinic, prescribed at least one pulmonary medication (eg, inhaled mucolytic, inhaled or oral antibiotic therapy, hypertonic saline), and own or use a mobile device (eg, smartphone, tablet) Exclusion criteria Not diagnosed with CF, not prescribed any CF medications, and not a smartphone owner.	Participants were identified from the patient roster of the adult CF clinic at a large, urban hospital in the mid-Atlantic United States. Data collection Participants completed a 30-45 minute semi-structured telephone interview with study staff. A naturalistic inquiry approach was used with open-ended probes. The interviews were digitally recorded and transcribed to facilitate coding and interpretation. Participants were also emailed a secure link to a password-protected Web-based survey to be completed within 2 weeks. Data analysis To identify themes and develop an initial coding guide, five interview transcripts were collaboratively reviewed.	Accessible information: Participants expressed the need for an accessible resource for general information about CF: "Sometimes I'll [wonder when] something happens health-related to me, 'Is that normal for everyone or…is that happening to me because I have CF?' And it's hard to find particular sources where I can find that out." (Age 35, Female) Preference of storage of personal information: Participants preferred central accessible storage for personal CF data/information: "I think that CF can be kind of overwhelming and it's really nice to have one central location to keep important information and data." (Age 34, Female) "Whenever you go to [a] doctor [they ask], 'What's your current list of medications?'…It'd be nice to have the whole history…and then have a place for notes for how well it worked." (Age 48, Female) Communication (with medical team): Participants reported that CF providers may not be responsive if contacted via telephone or email between visits, and would prefer to see the provider in person: "I'm not always in a place where I can call them, so if I can just shoot a text…that would be convenient…If they want me to do something out of the ordinary...I want to [ask], 'How exactly did you want me to do this?' " (Age 23, Male) "In the everyday world [electronic communication] just seems to be replacing talk and conversation and you know, communicating that way, I don't want that to happen [with my doctors]." (Age 35, Female	between the researcher and the respondents clearly reported Data collection: Data collection relied on the semi-structured telephone interviews. Researchers did not justify the use of telephone instead of face to face interviews Data analysis: The analytical process was described in detail. Description of how "themes" were arrived at; saturation of data and exploring all the themes in detail was reported Findings/results: Results were presented clearlyand findings were discussed in detail (e.g., citation/data and the researchers' own input distinguished Overall quality: High Other information The study involves identifying user preferences and design recommendations for an mHealth application to promote CF self-management Mixed methods study (qualitative and quantitative content) Adults with CF

Study details	Participants	Methods	Findings	Comments
Country/ies where the study was carried out USA Study dates Not reported. Source of funding Cystic Fibrosis Foundation Therapeutics.		Two study team members coded the remaining transcripts using the initial coding guide. Discrepancies and coding scheme modifications were resolved through group discussion in an iterative fashion, repeated every five interviews until thematic saturation was reached. A total of 16 interviews were conducted before thematic saturation was reached.	Communication (with family): Participants reported that they would not need another channel of communication with family regarding monitoring adherence: “I would use other more direct messages.” (Age 28, Male) “I would probably continue to communicate with them the way I already do.” (Age 33, Female) Social (support from people with similar experiences): Some people show this as a novel opportunity to network, given prohibitions on face-toface contact “Because people with CF can’t be in the same room as each other,…being able to see someone else with CF is much more profound than just exchanging emails with some anonymous person.” [Age 28, Male] Other could feel discouraged or guilty seeing others doing better or worse than you “I don’t like hearing about CF people that aren’t doing well. I have a hard time distancing myself from it. It’s hard having to filter through all this sadness to get kind of connected with someone.” [Age 26, Female] “I didn't really like it only because some people had it worse than me and if it kind of brought me down because I felt like this is where I'm heading and I just didn't like that…So I don't know if I'd really want to talk to any other people with CF, I don't want to like be depressed.” [Age 32, Male] Social (support for families, partners, caregivers of people with CF):	

Study details	Participants	Methods	Findings	Comments
			Participants considered social networking to be appealing for family members or partners of people with CF: “I think that support for the family and friends is important…for people who have CF…talking to significant others of people who have CF.” (Age 28, Male)	
Full citation Hummelinck, A., Pollock, K., Parents' information needs about the treatment of their chronically ill child: A qualitative study, Patient education and counseling, 62, 228-234, 2006 Ref Id 473703 Study type Qualitative study with semi structured interviews	Sample size N=20 (sets of) parents of 21 chronically ill children and young people Characteristics Children had chronic conditions which were asthma, CF, diabetes, epilepsy, epilepsy+special needs, leukaemia, other cancers, severe eczema (N=4 with CF). There were 12 boys and 9 girls. They fell into the following age categories: 0-5 years (n=3), 6-10 years (n=12), and 11-15 years (n=6) Inclusion criteria	Setting Details of study methods and recruitment were reported in Hummelinck 2004 study Sample selection Eligible parents were approached consecutively following hospital admission or outpatient clinic attendance at the paediatric department of a district general hospital in the West Midlands. The researcher sent or handed parents a letter with an information sheet and	Themes/categories Parents' need for information (as a means of reassurance) Parents experienced difficulties immediately after diagnosis as they felt confused and frightened when presented with information because they could not find answers to specific questions or resolve anxieties that confronted them: "I felt I was standing outside, watching it all going on, I did not even know...the IV's he was having straight away and I did not even know what that was all about. And they were just pumping all these drugs into him. It was just one injection after the other in, pretty scary actually. You are left on your own in a room, you know. Sitting there, waiting for the next lot of IV's which of course I did not know when that would be. I did not know how many he had to have. It was difficult. " (Mother of a child with CF age 7 years)	Limitations Aim(s): Clearly reported 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 clearly reported Data collection: Data collection relied on the semi-structured interviews. Data collection method was not described in detail and cross referenced to other study for detail information Data analysis: The analytical process was clearly reported. Unclear if saturation of data was achieved. Development of theme was described. No report on

Study details	Participants	Methods	Findings	Comments
Aim of the study To explore the complexity of parents' information needs and how current information provision is evaluated Country/ies where the study was carried out United Kingdom Study dates Not reported Source of funding Not reported	Child's age within range 0-16 years Child suffering from a chronic illness Child's treatment plan includes ≥1 drug to be administered daily for a minimum of 1 week Child living with respondent Each individual parent (as a representative of the child) may only enter the study once Exclusion criteria Respondent(s) lacking English skills Personal reasons (e.g., terminal illness)	reply slip, inviting them to take part in a semi-structured interview. The total positive response rate before and after sending out a reminder letter to non-responders was 31% and 51% respectively (of whom 20 were interviewed) Data collection Semi structured interviews ranged from 45 minutes to 3 hours (average 1-1.5 hours). Detailed information reported in Hummelinck 2004 study Data analysis Data was organised by establishing concepts from the text and subsequently coded, which was refined as the analysis progressed. Emerging themes and hypotheses were continually checked against the data. Interview codes were summarised under relevant categories, which were used to map the range	Parents' reasons for wanting information (as a means of establishing control) Parents wished for more information to feel involved in management of their child's illness and to be able to understand decisions being made. Understanding what was happening helped some parents to cope with the illness and re-establish a sense of control: "I want everything [all there is to know about cystic fibrosis] now. Because then when something arises, you can go [snaps his fingers] 'Right, I recognise that, we have got to do this' or 'I know what that is, we do not need to panic'. We know, we are in control. I think we are in control anyway, but when he's not well...It might not be nice, knowing what might be, but it's better to know. At least you are in control that way". (Father of a child with CF age years) Parents' view on adequacy of information provided Parents of children with CF (that strictly required multidisciplinary care input and secondary care management) reported receiving an 'information overload', particularly at the time of diagnosis (author reported)	transcribing interview, validation or use of qualitative software for processing of information Findings/results: Results were presented clearly and the findings discussed in detail (e.g., citation/data and the researchers' own input distinguished) Overall quality: Poor Other information Study included parents of children with conditions other than CF. Study dates were not reported.

Study details	Participants	Methods	Findings	Comments
		of findings, and associations of themes and explanations for the findings were developed		
Full citation Jessup, M., Douglas, T., Priddis, L., Branch-Smith, C., Shields, L., Arest, C. F., Parental Experience of Information and Education Processes Following Diagnosis of Their Infant With Cystic Fibrosis Via Newborn Screening, Journal of Pediatric Nursing, 31, e233-41, 2016 Ref Id 473728 Study type Qualitative study Aim of the study	Sample size N=10 parents from 7 families of infants with CF (n=7 mothers, n=3 fathers) Characteristics Parents with child having unequivocal diagnosis of CF Inclusion criteria Not reported Exclusion criteria Not reported	Setting Tertiary pediatric hospital in Australia Sample selection Participants were recruited through the CF clinic of a large metropolitan pediatric hospital in Australia. Potential participants were identified from the clinic database and sent an information letter. They were invited to telephone a nominated researcher to register their interest, at which point a convenient interview time was organized. Data collection Data were collected during a single, semi-structured interview lasting about one hour. Guided by a phenomenological intent, these were conversational in style. An interview guide	Themes/categories Personal searching: “I got the initial diagnosis over the phone…. they don’t tell you much. It’s like: “We think she’s got cystic fibrosis and we want you to come in and talk about, and I can see you in two or three days’ time’. And then it’s like: ‘Oh my God,’ and ‘Help, Google!’… People: A team of People: “all very friendly, very positive… really quite a dedicated team.” Likewise: “The people there seemed to want to build a relationship with us straight away.” Such connections were missing in the online world. Too many People: One person's team was another's crowd: “We would just see all these people coming towards us every day and we’d just switch off. We’d go blank … There were just too many people.” “All I can remember is five people in a room watching me cry, feeling like a real goose.” Pumped of People: “They are quite a pumped up team.” “I understand that these guys are so passionate about their job, and I suppose in their eyes it is a little bit more.” Which People: Despite parents often being surrounded by many people, there was a sense of isolation within a crowd, and several felt over whelmed and uncertain regarding who to connect with and of whom to enquire: “I felt quite teary. It was really, really draining …I remember people asking me questions…and I didn’t know who to ask, and I just felt like I was	Limitations Aim(s): Clearly reported 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 researchers and the respondents not clearly reported. Data collection: Data collection relied on the open ended interviews. Structure of interview and topic guide reported. Description of how "themes" were arrived at was discussed. Data saturation determining further sample recruitment was reported. Ethical approval reported. 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:

Study details	Participants	Methods	Findings	Comments
To explore the education needs of ten parents following their infant's diagnosis with CF via newborn screening Country/ies where the study was carried out Australia Study dates Not reported Source of funding National Health and Medical Research Council of Australia CRE grant 515370		was developed, informed by the current literature, team members' experience, and the study objective. This guide was deliberately broad and open-ended in order to encourage participants to recount their experiences from the initial diagnosis phase and the subsequent three-day education period. Data analysis Thematic analysis was used to analyse the data. Transcripts of the interviews were read and analysed individually by all members of the research team, each member highlighting and grouping similar phrases and experiences to synthesize common topics into the identification of themes. Interpretation of the data was then discussed and moderated at regular meetings attended by all.	surviving." One mother recalled: "We came in on the three days. It was sort-of like people came and saw you and then you waited for the next lot of people to come through, and then you waited some more…It was such a nightmare… It was the actual doing, it was terrible." Process: Amount and timing: This presents a challenge when parents have differing requirements. For one: "We were just trying to get everything we could"; whereas for another: "I think at that point for us it was probably all we needed"; and another: "I think the only thing is to ease parents into it." In reality, there is no easy way: "You're given probably more than you want but it's what you need. I don't think there's anything that you could stop or take away from that process. I don't think there is any right way to do it… It's just a process that you have to go through." It is all about confidence and comfort: "You're not ready to hear what'll happen in three years or things like that. You're more ready to hear that stuff once you've found your platform of confidence and comfort." Pragmatics: Numbers and visuals: "We received a sheet … with genetics with some basic pointers about CF… but the very first line on it was the life expectancy for CF… and the number … it's really confronting to have that as one of the first pieces of information." Another vividly remembered: "The first thing you see when you open their website is that 30% of teenagers died from CF … To see that figure is like 'Oh my God.'" and one father explained: 'This is what we got at the time … All we could see, there's a little kid in jail: 'Just one cell mutation can trap you for life'…. It's just awful." Staggered and	Results were presented clearly (e.g., citation/data and the researchers' own input distinguished. Researchers' role and potential influence s in the analytical process not critically reviewed Overall quality: Moderate Other information The study did not described the ethical process of research. Study conducted by multiple researchers but the level of consistency not reported.

Study details	Participants	Methods	Findings	Comments
			practical: "… Just the practical day to day stuff would be great … maybe when the baby is about 6 months, it would be great to have some day to day tips about CF: things to avoid, things to do." Parents could relate to: "Definitely the food …. and then the physio because they are our things to do … the immediate things we needed to do." Several referred to the practical instructions given by the physiotherapist, which represented something they could do. "You know what was terrific was the little physio card that she made up for us…So when we're home going 'What do we do next?' we could go back to the card and check." Format: Format was commented on by all participants, with recommendations from simple fact sheets, to brochures, booklets, DVDs and a map. They needed developmentally relevant information delivered at intervals during their child's first year. "So I think It'd be better to have a booklet day one up to may be six months pre food and then another booklet that's relevant for that time ….Some more of these fact sheets….and use those as a thing to go through with parents over time, rather than overload with information all at once." Relevance: Participants had to be selective of information materials: "We just got a booklet that was produced in America and it wasn't relevant here, and there was so much ambiguity." Reassurance and empowerment: "It would have been a bit more empowering if I'd more information … Because you kind of want parents to become experts." The unknown exacerbated fear: "I think the biggest thing was not knowing what might happen, which gives you a bit of a panic." Knowing included more than hearing about prognosis and care. Parents	

Study details	Participants	Methods	Findings	Comments
			quickly identified that there would be costs to be extracted by time, emotion and dollars: “what they might need in the future so you can save for things.” Hope: “So that’s the most important thing, that optimism is really important for parents.” This was particularly so because it: “…moves you out of a ‘victim’ state to a ‘move on with it’ state.” As one mother declared: “I just wanted to get on with bringing up my baby”. Parents sought information that enabled them to assign their child's position on the ‘severity spectrum’ of CF disease, explained by this father: “I want to kind of put the severity of CF on a spectrum, and then ask: ‘Where does my child fit? Is she worse or better off compared to someone else?’” However, in spite of the best intentions and sources of current information, prognosis evolves and eludes: “I know obviously they can’t tell you for various reasons because they don’t know themselves, but that’s one question that I was asking myself a lot … because we still don’t know.”	
Full citation Jessup, M., Parkinson, C., "All at sea": the experience of living with cystic fibrosis, Qualitative Health Research, 20, 352-64, 2010 Ref Id	Sample size N=8 families with a son/daughter with CF (n=7 people with CF, n=17 parents either as couples or individually) Characteristics Age of people with CF: range: 2-21, average: 10.5	Setting Participants were recruited from a regional CF clinic in Tasmania, Australia. Interviews took place in their homes. Sample selection Purposive sampling. Participants were approached in the first instance by the	Themes/categories Fight for information: "We wanted to know all the details, and there would be things where we would ask the question and they would hedge as if to say, “We really don’t like to tell everybody all those details to start with.” Because we were both biology trained, we just wanted the absolute details . . . it seemed like getting blood out of a stone." (couple of parents) “not just the stuff they want the parents to hear” (one parent who read whatever she could	Limitations Aim(s): Clearly reported Aim of the study clearly reported, research method was appropriate for answering the research question Sample selection: Sample selection was clearly reported and was appropriate for the research question. Data collection:

Study details	Participants	Methods	Findings	Comments
406255 Study type Qualitative phenomenological study Aim of the study To explore the experiences of living with CF Country/ies where the study was carried out Australia Study dates Not reported Source of funding The study was funded by an Australian Postgraduate Award.	Sex of people with CF: 4 males, 3 females At the time of the interview all people with CF were medically stable, not in the hospital nor receiving intravenous antibiotics. Inclusion criteria Person with CF or his/her parents Exclusion criteria Siblings of people with CF	directing nurse. She invited potential participants as they arrived for their appointments. After assent, participants were given information sheets and consent forms and were told that they would be contacted by phone to arrange an interview time. Data collection Data were collected during single, unstructured, conversational-style interviews, which commenced with the participant being invited to tell his or her story. Conversation with younger children was initiated by an invitation to draw. This took place in the presence of their parents, who remained in close proximity. Interviews were conducted in the participants' homes, and were tape recorded and transcribed verbatim. Some parents and the older children with CF	and said that she could recognize the erroneous facts she received from health care professionals) Some parents were "snowed under" by initial information: “blah, blah, blah” (one parent) Fight in the legal arena "Now I don’t know a lot about the legal system, but if I knew what I know now, he wouldn’t be going anywhere, because my lawyer would just make mincemeat out of him. I’ll never forgive him. He didn’t know what he was talking about. He should never have discussed CF because he was just a fool." (parent recalling their initial consultation with a pediatrician)	The authors clearly explained and justified clearly how the data were collected. They also explained that interviews were conducted in the participants' own homes in order to dispel notions of clinical context or interrogation. However, the authors did not discuss data saturation. The relationship between the researcher and the participants was not adequately considered. Data analysis: There was an in-depth description of the analysis process. It is clear how the themes were derived from the data. Sufficient quotations were presented to support the findings. Contradictory data were taken into account. However, there was no critical review of the researcher's role in the process. Findings/results: Findings are explicit and adequately discussed. A colleague with expertise in phenomenology challenged perceived anomalies in the analysis. However, the total number of analysts involved was unclear. There was no respondent validation due to concerns about the research burden on the CF population. Overall quality: Moderate

Study details	Participants	Methods	Findings	Comments
		chose to be interviewed alone, while half of the parents chose to be interviewed as a team. Data analysis The process of explicating the phenomenon began during the initial recounting by participants. Distinct themes were then identified through a process of subsequent reading and rereading of transcripts, listening again to the tapes to verify and to recall subtle nuances. This was informed by a continual turning from the word spoken to the context with a hermeneutic attitude (Walsh, 1996). Interview transcripts were analyzed for recurring themes in light of van Manen's (1990) approach to hermeneutic phenomenology. Therefore, the four lifeworld existentials of space, time, body, and		Other information Ethical approval was obtained from the applicable combined hospital and university research ethics committee. Written informed consent was obtained for all participants, including parental consent for those less than 18 years old. In addition, verbal and observational acquiescence by this group was assured because children were observed for any reluctance or coercion on the part of their parents. Noninvolvement was met with assurance that there was neither obligation nor impact on future care. Other information

Study details	Participants	Methods	Findings	Comments
		relationship were utilized. By analysing the data through the filters of time, body, space, and relationship, distinct themes were identified. This process was underpinned by the awareness of the subtle difference between those themes that van Manen calls incidental and those that are essential and exclusive to the phenomenon under investigation. The authors received feedback from appropriate clinicians on both the participants' contributions and the analysis of them and gave several presentations of the study during its execution in order to verify creditability of the study. Moreover, a colleague with expertise in phenomenology challenged perceived anomalies in the analysis. Transcripts were not returned to		

Study details	Participants	Methods	Findings	Comments
		the participants for comment because of concerns about the research burden experienced by the people with CF. A research journal was undertaken to formalize the reflective process. This consisted of field notes written as immediately after the interview as possible, usually within 30 minutes, plus reflections that were written subsequently and convey a deeper synthesis of impressions.		
Full citation Johannesson, M., Carlson, M., Brucefors, A. B., Hjelte, L., Cystic fibrosis through a female perspective: psychosocial issues and information concerning puberty and motherhood, Patient Education &	Sample size N=17 women selected N=14 women interviewed Characteristics Mean age diagnosis: 1.6 years (range 0.5–5) Mean age menarche: 15.3 years (range 13–18) Mean weight menarche: 20.5 S.D. (range22.5 to 11.5) Mean height menarche: 10.5 S.D. (range 22 to 12)	Setting Women were interviewed at the hospital by the first two authors. Sample selection Women who attended a CF centre in Stockholm were selected for the study. Data collection Data was collected through individual in-depth interviews that lasted 2 hours, and performed by the first	Themes/categories Information provision Pubertal development and fertility: Women recalled that doctors provided information that delay in sexual maturation was related to their CF (authors comment) Women recalled that doctors provided information about problems with fertility: "it was terrible to hear that I might never become a mother" (one participant) "I took it for granted that I couldn't have kids since I knew I would die young" (one participant) Women recalled that they did not talk about it even though they were worried (authors comment)	Limitations Aim(s): Clearly reported 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 clearly reported Data collection: Data collection relied on in depth interviews. Description of data collection method was vaguely described and no information on use of topic guide

Study details	Participants	Methods	Findings	Comments
Counseling, 34, 115-23, 1998 Ref Id 366885 Study type Qualitative study with in-depth interviews Aim of the study To investigate psychological issues concerning puberty and motherhood among CF adult females, to see how they had obtained and conceived information on these matters and how they would like information to be given. Country/ies where the study was carried out Sweden Study dates 1994-1996	Mean age at investigation: 28 years (range 22–34) Organ transplants at investigation: 2 (at 24 and 25 years resp.) Married at investigation: 8 Mothers: 2 Inclusion criteria Diagnosis of CF in childhood (positive sweat test according to Gibson and Cook (>80 mmol cl / l [26] together with symptoms compatible with CF) Monthly visits for clinical evaluation at Stockholm CF centre More than 20 years of age Exclusion criteria Not reported.	two authors, audio-taped and typewritten. Data analysis Data analysis was carried out independently by each interviewer and evaluated by both to obtain a combined interpretation, which was further discussed between authors for final conclusion to obtain reliability and validity of data.	New information about fertility and thoughts about motherhood: Women received information about different methods to overcome their problems to become pregnant by their gynaecologist/CF-doctor (authors comment) Women learned about new methods through general information through the patient association (authors comment) Women experienced mixed feelings about the new information: Some women were positive over new possibility of becoming a mother: "you become more motivated to keep in good shape" (one participant) However, some women were in despair when hearing that they could not become pregnant: "I felt cheated. The gynaecologist said there was no problem because they could help me with insemination, but when I finally met my CF-doctor she said no. She though that my lung function wasn't good enough for a pregnancy. It was a knockout" (one participant) "it was very disturbing that the CF-team should decide whether or not I was allowed to become pregnant" (one participant) Receiving information about puberty and fertility (when, how and who with) When information should be provided: Women reported that they would like information concerning puberty and fertility at 13-14 years age by the CF doctors in a sensitive manner depending on each patient's requirement (authors comment) Older women reported it was important to receive information about possibilities of motherhood to encourage young girls to adhere	Data analysis: The analytical process was not clearly reported. Description of how emerging and overarching themes were reached was not reported, saturation of data was not reported. Insufficient information on the processing of the data or the use of specific qualtiative software. Findings/results: Results were presented clearly supported with quotes and findings discussed in depth (e.g., citation/data and the researchers' own input distinguished) Overall quality: Poor Other information

Study details	Participants	Methods	Findings	Comments
Source of funding Swedish Cystic Fibrosis Association. 'Fo¨renade Liv' Mutual Group Life Insurance Company, Stockholm, Sweden.			to medical treatment and avoid destructive behaviour (e.g., smoking): "It is so hard for man during adolescence. You have to tell positive things so they understand..." (one participant) How information is provided: Women reported that information could be given in smaller discussion groups with CF-girls at the same age, facilitated by two older CF-women (one who had been pregnant, and one who had difficulties to become pregnant) (authors comment) Who should provide information: Women wanted a first visit to a specialist gynaecologist working closely with a CF-team at 16-17 years age (authors comment)	
Full citation Kazmerski, T. M., Borrero, S., Tuchman, L. K., Weiner, D. J., Pilewski, J. M., Orenstein, D. M., Miller, E., Provider and Patient Attitudes Regarding Sexual Health in Young Women With Cystic Fibrosis, Pediatrics, 137, 2016	Sample size N=22 women with CF aged 18-30 years N=16 CF program directors Characteristics Women with CF. CF program directors because of their expertise in CF care and ability to reflect on overall center practices in addition to personal practice. Inclusion criteria Not reported Exclusion criteria	Setting US CF care center Sample selection Sample of women recruited with CF at an accredited adult US CF care center during inpatient or outpatient visits. Thirty potential participants (program directors) were selected based on geographic diversity. Sixteen directors agreed to be interviewed (a 53% participation rate).	Themes/categories Sexual and reproductive health (SRH) is important to discuss in the CF care setting: Patients: "It's always just like you don't talk about it [SRH], it's one of those things that's left to the side, it's […] like they [CF providers] feel it's not as important as everything else, but sometimes it is. I mean, it [SRH] wasn't life or death threatening, but it could've changed my life a lot." Providers: We've been so focused on nutrition and liver disease and lung disease and diabetes, but now that […] quality of life continues to improve, this will be a big issue, a more important issue for everyone." Patient and provider discomfort around SRH is a major barrier to care:	Limitations Aim(s): Clearly reported 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 researchers and the respondents not clearly reported. Data collection: Data collection relied on the semi structured interviews. Structure of interview and topic guide reported. Description of how "themes" were arrived at was

Study details	Participants	Methods	Findings	Comments
Ref Id 469560 Study type Qualitative study Aim of the study To explore the attitudes, preferences, and experiences of patients with CF and CF providers toward sexual and reproductive health care for young women with CF. Country/ies where the study was carried out USA Study dates 2014-2014 Source of funding Not reported	Not reported	Data collection Women with CF completed semi-structured, individual in-person interviews investigating SRH (sexual and reproductive health) care experiences and attitudes toward SRH care in the CF setting. Interviews were structured by key questions and probes intended to guide conversation. All interviews were audio-recorded and transcribed. Thematic saturation was reached after the 13th interview. For program directors, semi-structured, individual phone interviews, exploring attitudes toward SRH care, timing and content of SRH discussions, and potential barriers and facilitators to female CF SRH care. Interviews were audio-recorded and transcribed. Thematic saturation was reached after the eighth interview.	Patients: "Sometimes women are afraid to speak up and they keep these things [SRH issues] personal to them… and might feel uncomfortable." Provider: "I think the number 1 [reason] is that a lot of the younger women are …embarrassed, especially because I'm a middle aged man, they're just a little embarrassed to bring it up." "You do what you're comfortable with. I'm not good at fielding questions about sexuality, so I probably don't bring it up as often as I should." Educational resources coupled with standardized provider discussions would facilitate SRH care: Patient: "Sometimes, if people were to feel uncomfortable… maybe be given a pamphlet. Or some papers that have Web sites that you can, you know, go on… or maybe there would be an online thing where you can actually ask questions, kinda like be anonymous because maybe some people are embarrassed." Providers: "…a concise booklet that was […] very accurate [with] all the different [SRH] subjects at a comprehensive level. Because some [patients] probably don't necessarily want to talk about it in the clinic, but … we could provide accurate information to them that they could access at their own convenience." Patients: "It's [SRH discussion] important. And, sometimes, [the CF provider] may have to be the initiator in these kinds of, you know, issues. Sometimes women are afraid to speak up and keep these things personal to them…and they [patients] might feel uncomfortable. The doctor should say, 'Hey, is there something – anything we could discuss about, you know, sexual development or things like that or pregnancy?'	discussed. Data saturation and full exploration of theme reported. Ethical approval process not reported. 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 (e.g., citation/data and the researchers' own input distinguished. Researchers' role and potential influences in the analytical process not critically reviewed. Overall quality: Other information The study did not described the ethical process of research. Study conducted by multiple researchers but the level of consistency between the researchers not reported. Findings cannot be generalized to all CF care providers (ie, those who are not directors).

Study details	Participants	Methods	Findings	Comments
		Data analysis Interview transcripts were analyzed through an iterative process of coding to identify themes. 1 initial set of codes for patient participants and 1 for providers were developed. By using a consensus coding approach, the coders reviewed their coding, discussed any discrepancies, and defined any new codes. A senior co-investigator (EM) adjudicated any differences in interpretation. ATLAS.ti 5.0 (Scientific Software Development GmbH, Berlin, Germany) was used to facilitate data management and coding.	” Providers: “[T]here’s definitely not a systematic approach. I think for us it’s very provider-dependent. It seems for our adult and adolescent providers, it’s part of what they’ve been trained to do…I think our paediatricians aren’t quite as systematic with it or as astute with how to approach it.” “I think one way [to improve SRH care provision] is to have clear transition topics that are brought up on a regular basis that need to be addressed. So that it [SRH] becomes a more routine part of annual visits and potentially even quarterly visits; it’s just part of the issues that need to be addressed with regularity. So, regularity becomes familiarity.” Women with CF prefer early, open-minded SRH discussions initiated by the CF team: Patients: “[SRH] was brought up in school when I was in 4th or 5th grade, so I was probably 9…I think between 8 and 10, depending on if puberty is starting, I think you should be informed.” “Honestly, for me, the easiest thing would be to just start [SRH discussions] young and have it be an expectation. We walk in here and know that people are going to talk to us about bowel movements, that’s just part of what we know is gonna be asked. So, if you start [SRH discussions] at a young age, I think it just becomes part of the routine and it doesn’t become as uncomfortable as it would be.” “I think that they should start talking about something to do with it [SRH] at a younger age. So then when you grow, and hopefully continue to see the same doctor as you grow up, you feel comfortable with that doctor and discussing the rest of the topics.” “I just think it would be good for the doctors to bring [SRH] up more because…when I was	

Study details	Participants	Methods	Findings	Comments
			younger, I never even thought to say anything about it. And then, by the time I was old enough, it was well past the age…of needing concern."	
Full citation Kirk, S., Milnes, L., An exploration of how young people and parents use online support in the context of living with cystic fibrosis, Health Expectations, 19, 309-21, 2016 Ref Id 473757 Study type Virtual observational study (Netnography or online ethnography) Aim of the study To explore how online peer support is used by young people and parents to support self-	Sample size 97 participants on young patient discussion forum and 182 participants on parent's discussion forum Characteristics Young adults with CF and parents Inclusion criteria Not reported Exclusion criteria Not reported	Setting Virtual. Based on discussion in online forum. Sample selection All postings made to the young people and parents over a random 4-month period Data collection Those relating to fundraising and non-CF issues (for example, favourite television programmes). Data analysis The discussion threads were downloaded into Word documents and imported into NVivo for analysis. The data were coded using an inductive grounded theory approach to identify themes and patterns emerging from the data. Through the constant comparison process, data were grouped	Themes/categories The online culture: communication styles and community While parents mainly used the site to seek specific advice or emotional support, young people use d it as a social networking site. "hey Tina welcome back! how did you get on with the exams? i'm good thanx, back on the IV's in June. how are you?" "aww i'm gd. on my Iv's atm. halfway there! yay! a week is too long though. i feel like pulling the needle out! glad to hear you're feeling good. i think i need a bronch to! havent had one in ages and sometimes you can just tell you need one! now is one of these times! (but don't tell the doctor!" Although the groups were a place where negative emotions could be expressed, it appeared that there were boundaries to this. Indeed, the online group was not always seen as being an appropriate place to discuss certain experiences and feelings: "This is a short post. I ashamed to say I often feel the same (perhapes manage it a little better though). I dont want to open up on this subject on here though. Feel free to email me on XXX" (Parent)	Limitations Aim(s): Clearly reported Aim of the study clearly reported, research method was appropriate for answering the research question Sample selection: Sample selection was clearly reported. Whether the sample is genuine representative of the CF population is unclear and it was based on a single online discussion forum. Data collection: Data collection relied on the discussion thread. Structure of study and topic guide not reported and might not be applicable as this is not a qualitative study. Description of how "themes" were arrived at was unclear or whether data saturation reached. Data analysis: The analytical process was described but was inadequate in description. No critical review of the researchers' role in the process. Use of NVivo for analysis Findings/results:

Study details	Participants	Methods	Findings	Comments
care in relation to CF. Country/ies where the study was carried out UK Study dates Not reported Source of funding NIHR's Health Services & Delivery Research programme, UK.		into codes and over-arching themes	Managing treatments Group sought advice and support about how to manage different treatments and therapies. "Have you tried going swimming together just the girls in yr family make exercise fun and then when she has done it go and have lunch together or buy her a treat, That has worked with my son 13." "We used to use straws – blowing cotton wool balls across the kitchen table – actually our physio who has retired showed us this one – it was great fun when we all joined in as a family. " Managing emotions Group discussion provided an outlet for parents and young adults to express their emotions. "Hey, You are certainly not alone! I think everyone with CF has felt like tha sometimes. I know for a fact I hve felt like why do I bother but I tend to do it when i'm well bcoz i cant see any difference when i take my tablet sna if i miss them but I've learnt now that i have to do my nebs and stuff" Managing identity Some parents tried to validate their identity and to justify that they were good parents	Results were presented clearly under different themes with generous use of quotes. Researchers' role and potential influences in the analytical process not critically reviewed. Overall quality: Moderate Other information As this is a virtual observational study of discussion thread, challengers and oppurtunities were discussed.. Ethical issues around online discussion is controversial and was addressed.

Study details	Participants	Methods	Findings	Comments
			"my daughter is 15 now but i remember like it was yesterday going through the stuff u r now and to be honest u sound like a great mum and my only advice is a mum knows best just listen to your heart and u wont go far wrong." Managing support from services and health-care professionals Participants advised parents to take an assertive stance and question medical decision making. "I just wanted to say that I think your attitude towards your son's care is fantastic. I know a lot of parents struggle to stand up to/question medical staff (including my mum when I was younger) so it's great that you have already managed to gain the confidence to do it when your son is still at such a young age."	
Full citation Lang, L., Duff, A. J., Brownlee, K. G., Introducing the need for lung transplantation in children with cystic fibrosis: parental experiences, Journal of Cystic Fibrosis,	Sample size N=8 parents of children with CF Characteristics Parents of children refered for lung transplant treatment. 7 female and 1 male. Age range = 35-50 years Married = 7, divorced = 1 Age of children with CF = 3-16 years	Setting Participants' home Sample selection 10 families of children undergoing lung transplant were asked to participate (mean time between referral and interview was 3 years and 4 months). Eight participant agreed. Data collection	Themes/categories Role of information in relation to lung transplantation Most of the participants thought information helped them to prepare: Distressing but facing reality Although upsetting, many parents felt discussion helped them face the reality of the situation (author's comment) "I wanted to be told everything (e.g. assessment criteria, procedures, complications and outcomes, including statistics, quality of life, drug-side effects and long-term progosis".	Limitations Aim(s): Clearly reported 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 participants was not reported. Data collection: Data collection relied on the semi-structured interviews. Description of data

Study details	Participants	Methods	Findings	Comments
4, 259-62, 2005 Ref Id 473773 Study type Qualitative study with semi-structured interview Aim of the study To recruit the view of parents of children with CF on their actual experience, of how the flow of information should be managed and how the process of initial introduction by the refering centre could be improved Country/ies where the study was carried out UK Study dates No reported Source of funding	Inclusion criteria Not reported Exclusion criteria Not reported	Participants were interviewed at home via telephone there responses being transcribed verbatim at the time. Data analysis Content of transcript were analysed using well-validated qualitative research tool (Content Analysis). Coding and category identification were undertaken by two independent researchers and then aggregated with 90% inter-rater agreement	"Information makes you more aware and perpared" "I would have liked more information" Others were reluctant: "I didn't want information" "I didn't really want to deal with it" "Having the informatoin is depressing" Gradual introduction and support by the CF team A gradual and informal process of discussing CF and treatment options prior to crisis-point was recommended as a means of preparing and supporting families more effectively. (author's comment) Having a good relationship with the clinician introducing and discussing LTx was seen as essential. Parents felt the process would also be less formal and less distressing if the CF nurse, who knew the family and who had perhaps been previously emotionally supportive, was central to this. (author's comment) Availability of information, format and timing The majority of parents thought information was crucial to preparation, suggesting various formats (e.g., written material, videos, personal accounts, specific transplant group meetings and counselling). Parents wanted information at different times, either as soon as possible or when LTx became an option for their child. Therefore, it seems beneficial to have information available for parents to access as and when they wish.	collection method was vaguely described although validated qualitative research tool was used. Data analysis: The analytical process was reported vaguely. Description of emerging and overarching themes was reported, but saturation of data was not reported. Coding and category identification by two independent researchers suggest reliability of findings Findings/results: Results were presented clearly. Discussion of the finding was limited and cross reference to citation/data and the researchers' own input was not adequately presented Overall quality: Moderate Other information

Study details	Participants	Methods	Findings	Comments
Not reported			Referring for assessment When the time for lung transplant referral arrived, parents wanted to meet with the Consultant, the majority wanting to know all the facts at this point in order to make a decision. Some participants "only wanted to know the positive aspects" Several stated that following such discussions, they forgot some of what was said and said they "wanted written, bullet-point information or FAQs to refer back to". The majority of parents also wanted their partner/spouse to be involved. Parents felt that their child's age and ability to understand and make their own decision were important factors determining the extent to which their child was involved initially.	
Full citation Macdonald, K., Greggans, A., 'Cool friends': an evaluation of a community befriending programme for young people with cystic fibrosis, Journal of Clinical Nursing, 19, 2406-14, 2010 Ref Id 369281 Study type	Sample size N=17 participants of which n=10 were children or young people CF or their parents, n=3 were befrienders, n=2 play therapists, n=2 education liaison personnel Characteristics Age of people with CF: 8-18 FEV1: 27-101% Inclusion criteria Inclusion criteria for hospital and educational personnel: to be involved closely with the	Setting Setting of the befriending scheme: the Butterfly Trust Setting of the interview for children and parents: their own homes. Sample selection The Butterfly Trust approached all families in the befriending programme and sought permission for the researchers to contact them. Telephone contact was made and	Themes/categories Experiences of befriending Befrienders were mostly young people who were in transition between education and employment. Continuity in befriending with young adult with CF (befriendee) was thus difficult: Parent of a 16 year old befriendee: "They'd be better if the lassies were a wee bit older, ken they're away on holiday, I dunno what age, she can only be in her 20s, changing jobs, its months since we've seen her." Befriending – what's good about it? Befriending was seen as helpful by both parents and young adults. Young adult of 15 years was happy in the company of befriender	Limitations Aim(s): Clearly reported 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 researchers and the respondents not clearly reported. Data collection: Data collection relied on the semi structured interviews. Structure of interview and topic guide reported. Description of how

Study details	Participants	Methods	Findings	Comments
Qualitative logitudinal pilot study Aim of the study To evaluate the impact of a community youth befriending programme on a group of young people with CF and their carers. Country/ies where the study was carried out UK Study dates Not reported Source of funding Not reported	people with CF involved with the study. Exclusion criteria Not reported	then following verbal consent a visit was arranged to discuss the research and complete consent forms. Data collection Children and parents were interviewed individually (or together, according to their wishes) in their own homes. All interviews used a semi-structured format, with a topic guide. Half of the families were interviewed twice; once near the beginning of the befriending relationship and again if their befriending experience had extended to one year after the first interview. The three befrienders were interviewed via a focus group. Individual semi-structured interviews were conducted with the play therapists and education liaison personnel. Data analysis	"it's what I expected, going out having a wee bit of a laugh and when I come back my dad says I'm always happier than when I left home." Young adults understood that having a befriender took the pressure of parents. "when they first asked me if I wanted a befriender, I just wanted to go through it myself, saves my mum and dad having to do all that stuff." Parents also recognize that their children might share their emotion with befriender when they sometime struggle to share with parents. "… this is one of the reasons that the befriender … plays a role in it … that builds up a sort of friendship with (son) … that if he's got any fears like that, hopefully he'll speak tae the befriender." Befriending – what's not so good about it? Criticism of befriending was around the continuity. Young adult was unhappy about the lack of continuity "Don't know what happened to the first one……I thought it was me…. I could never get in touch with her. Parent shared the same concern "I feel let down and (son) has been let down because he was getting close to her." Befrienders also faced challenges in building and boundaries of the relationship "…It can take a while to get to that stage, I'm now totally comfortable with (child), we can talk about anything…"	"themes" were arrived at was discussed. Data saturation and full exploration of theme not reported. 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 and quotes for robustness of findings. Researchers' role and potential influences in the analytical process not critically reviewed. Overall quality: Moderate Other information The study described the ethical process of research. Study conducted by multiple researchers but the level of consistency between the researchers and rigour of the process reported.

Study details	Participants	Methods	Findings	Comments
		Each interview was tape recorded and field notes recorded immediately after the interviews. Framework model previously reported in the literature was used to build a matrix of themes and codes from the four sets of data (children, parents, befrienders, others). Separate lists of themes, categories and concept maps were constructed for each participant group and peer reviewed by the second researcher to ensure congruence of findings.	"He doesn't understand why he can't come to my house, or I can't bring my child along and neither do I." Befrienders were also concerned about their lack of knowledge when discussing with parent or young adult about CF. "I would like more training about CF, the parents talk to you in jargon you don't understand – what's IV's?"	
Full citation Miller, A. R., Condin, C. J., McKellin, W. H., Shaw, N., Klassen, A. F., Sheps, S., Continuity of care for children with complex chronic health conditions: parents' perspectives,	Sample size Parents of 47 elementary school-aged children Characteristics Parents of elementary school-aged children with spina bifida, Down syndrome, attention-deficit/hyperactivity disorder, Duchenne muscular dystrophy or cystic fibrosis Inclusion criteria	Setting Most families (44 of 47) were interviewed in their homes, while three were interviewed at the hospital at their request. Sample selection Purposive sampling strategy to recruit parents or primary caregivers of elementary school-aged children. Participants were	Themes/categories Relational and informational continuity and their significance: Parents' believed that knowledge of the child, according to parents, developed through relationships with a consistent set of service providers, both in and outside of medical settings. "You need to see the regular faces, because they're the ones you feel at least know your child best," the mother said. "They know the history," the father added, "so you feel they have the whole story."	Limitations Aim(s): Clearly reported Aim of the study clearly reported, research method was appropriate for answering the research question Sample selection: Sample selection was clearly reported in detail including the process of recruitment of participants. The relationship between the researchers and the respondents not clearly reported.

Study details	Participants	Methods	Findings	Comments
BMC Health Services Research, 9, 242, 2009 Ref Id 473866 Study type Qualitative study Aim of the study Parent's perspectives on continuity of care for children with complex chronic health conditions and to identify the salient factors in the experience of, and factors contributing to, continuity in this population Country/ies where the study was carried out Canada Study dates Not reported Source of funding	Not reported Exclusion criteria Complex, multi-factorial clinical profile	contacted through specialized hospital clinics, physicians' offices, and patient support and advocacy organizations. These conditions were selected as representative of chronic conditions of childhood that have a significant and varied impact on child and family functioning and require a wide range of services. Data collection Semi-structured, open-ended interviews conducted by a trained member of the research team. Parents were encouraged to provide a spontaneous narrative about the various service providers with whom they and their child interacted over time, starting with their earliest contacts. Questions and probes were designed to provide an opportunity for parents to discuss how they perceived and experienced a	"It's nice when relationships do develop, you know. Kate knows the nurses [in the cystic fibrosis clinic] and she likes them, and ... she's not scared when she goes down there. Those faces are familiar to her, and if she is sick, it's not scary, it's not somebody she doesn't know." Continuity and communication: Parents identified communication as an integral feature of positive experiences of continuity of care. "I believe that's what [continuity] is. It's a relationship. A relationship is formed on communication, you know, and that's all that's happening between a doctor and patient, for example ..." Management continuity: seamlessness versus compartmentalization: Parents described high standards and even excellent management continuity provided by groups of service providers based in one location. "Most of her stuff is [cystic fibrosis] stuff and then there's the hearing thing, but that's not a doctor thing, that's more of a rehabilitation, audiology, speech therapy, and that kind of thing. The two aren't really related, except when her delayed language might interfere with what a child her age can do in terms of their own care, because you can't really explain it to them." Parents working to ensure continuity:	Data collection: Data collection relied on the semi structured interviews. Structure of interview process reported but no information on use of topic guide. Description of how "themes" were arrived at was discussed. Data saturation and full exploration of theme reported. Data analysis: The analytical process was described with description of themes and categories and use of specific technology. No critical review of the researchers' role in the process. Findings/results: Statements of the findings are clear. Reasoned and adequate discussion of the evidence. Researcher did not the credibility of their findings (e.g. triangulation, respondent validation). Overall quality: Moderate Other information The study did not describe the ethical process of research although ethical approval obtained. Interview conducted by single researcher but the level of consistency and accuracy not reported.

Study details	Participants	Methods	Findings	Comments
BC Medical Services Foundation and Michael Smith Foundation		number of aspects of their child's care Data analysis Interviews were transcribed and field notes were imported into ATLAS.ti for data management and anlysis of themes. Interview data underwent two major stages of coding and analysis. Some codes were developed inductively given their repeated appearance in the interviews; others were derived deductively based on the Reid and Haggerty continuity model.	Parent state that lack of continuity in management required parents to take initiative. "It was chaotic and frustrating, and nobody seemed to know what they were doing, and nobody was calling the specialized clinic at the Children's Hospital to find out what should be done...." Parent limiting continuity: Parent sometime want to limit or control the flow of information between different agencies. "I don't want them to send [reports from the hospital] to the school. The school doesn't need to know until I think they need to know, and then I can tell them." Systemic and organisational barrier to continuity: Parent reported lack of coordination between different organisations. "To me, it was like you were cut off from life. You turn six, that's it. You're gone. When they do it from zero to six, they coordinated. They stayed on top of it, they tell you what they need. As soon as they get into the school system ... I'm not even sure who coordinates it then."	
Full citation Roehrer, E., Cummings, E., Beggs, S., Turner, P., Hauser, J., Micallef, N.,	Sample size N=15 n=5 children n=5 adolescents n=5 adults Characteristics	Setting Sessions were conducted at the participant's residence whenever possible. Sample selection	Themes/categories Pre-pilot themes Awareness of symptoms and peer support: Participants expected that they would become more aware of their symptoms by being in the pilot.	Limitations Aim(s): Clearly reported Aim of the study clearly reported, research method was appropriate for answering the research question

Study details	Participants	Methods	Findings	Comments
Ellis, L., Reid, D., Pilot evaluation of web enabled symptom monitoring in cystic fibrosis, Informatics for health & social care, 38, 354-65, 2013 Ref Id 333172 Study type Qualitative study with semi-structured interviews. Aim of the study To evaluate a pilot trial of an information system conceptualised and developed to assist people with CF, and their families, to enhance their skills and communication in relation to self-management for their condition.	Males=10; Females=4 Target recruitment age range: 0-10 years; 12-17 years; 18 years onwards Actual recruitment age range:19 months- 5 years; 11 years-14 years; 21 years-52 years Inclusion criteria Children, adolescents, and adults with CF. Exclusion criteria Not reported.	Participants were identified through attendance at one of the Tasmanian CF clinics. Recruitment was through random selection of participants in three groups to allow comparison within each age range group in their interaction and use of MyCF website. Data collection Data was collected at pre- and post- pilot, and sessions conducted in a structured manner. Data analysis Thematic analysis was used to analyse data. Codes were developed and similar themes grouped together.	Expected benefits included peer support for participants and parents (authors comment). Post-pilot themes Expectations: Participants reported that their expectations had been met by the pilot, but expected more interaction with the health care professional and peers (authors comment) Use of diary (MyCF website): Participants reported that using the diary daily was too great a burden (authors comment). Impact of negative and positive perspectives of MyCF website diary: Participants reported that there was no change to their management of CF as a result of using the diary (authors comment). However, Participants also reported that they felt a greater sense of involvement in their treatment, better understanding of symptoms (authors comment). Some participants felt that the diary was not useful or was limited (e.g., in times of illness).	Sample selection: Sample selection was clearly reported. The relationship between the researcher and the respondents not clearly reported Data collection: Data collection relied on the semi-structured interviews. Description of data collection method was described but limited in information provided Data analysis: The analytical process was reported. Description of emerging and overarching themes was reported, but saturation of data was not reported. Findings/results: Results were not presented clearly. (e.g., citation/data and the researchers' own input distinguished). Not supported by appropriate quote Overall quality: Low Other information The study looks at participant preferences (pre- and post-pilot) upon web-based use of a diary for managing their CF.

Study details	Participants	Methods	Findings	Comments
Country/ies where the study was carried out Australia Study dates June 2011 to September 2011. Source of funding Tasmanian Community Fund grant.				
Full citation Tipping, C. J., Scholes, R. L., Cox, N. S., A qualitative study of physiotherapy education for parents of toddlers with cystic fibrosis, Journal of Cystic Fibrosis, 9, 205-11, 2010 Ref Id 366981 Study type Qualitative study	Sample size N=11 n=5 physiotherapists n=6 parents of children or young people with CF Characteristics Age of children or young people: 2 to 16 Other characteristics not reported Inclusion criteria Physiotherapists were included if they were involved in CF care and education at Monash Medical Centre. Parents were included if they if they had a child with CF between 2-16 years of age and were involved with the CF	Setting CF clinic at Monash Medical Centre. Sample selection Participants were identified and recruited through purposeful sampling by the clinical co-researcher from the CF clinic. A variety of participants (in terms of age and gender) was used to gain a broader understanding of people experiences. Focus group sample size was determined based on the literature, which suggested 6–12 participants per group.	Themes/categories Physiotherapy treatment “I asked to see the physio at the time... it was just impossible to try and keep someone of that age still for 20 min to half an hour to finish the treatment... he started telling us about doing some bubble games” Physiotherapy education “They gave us a video as well, really outdated ... I didn't think it was the greatest video but anyway it was a bit old fashioned.” “I think firstly in that first week we felt information overload... to be told like especially with the physiotherapy...that you've got to do this every single day for your child's life it's just overwhelming.” Connectedness with health care professionals "I think they view it as a test if you ask them to demonstrate. Because often that first time that you're doing the education it is so	Limitations Aim(s): Aim of the study clearly reported, research method was appropriate for answering the research question. Sample selection: The recruitment strategy was appropriate for the aims of the research, because a variety of participants (in terms of age and gender) was used to gain a broader understanding of people's experiences. However, given that all the participants were from the Monash Medical Centre, the results obtained in this study may not be generalised to different CF population groups, for example families who are

Study details	Participants	Methods	Findings	Comments
Aim of the study To identify factors that impair the delivery and retention of physiotherapy education for parents of children with CF and factors that impair effective physiotherapy treatment in the home environment. Country/ies where the study was carried out Australia Study dates Not reported Source of funding Not reported	clinic at the Monash Medical Centre. Participants who fitted the study criteria and who appeared to the clinical co-researcher to be appropriate to interview as they would be willing to discuss the difficulties and challenges of having a child with CF. Exclusion criteria Participants were excluded if they did not speak English or were under 18 years of age.	Sample size for the interviews was determined by completing interviews until theoretical saturation of data was reached. Data collection One focus group of paediatric physiotherapists (1 h duration) and 6 semi-structured interviews of parents (25–55 min duration) were conducted guided by interview maps. Focus groups and interviews were digitally recorded and transcribed. The focus group and the first interview were conducted by an experienced facilitator, whilst the subsequent interviews were conducted by the principal researcher under the guidance of the experienced facilitator. Data analysis Grounded Theory principles were applied in the analysis. Each participant was	overwhelming" (from physiotherapists focus group) “I don't have any problem with people trying to tell me how to improve things. So yeah we thought it was really valuable.” Social support “I wasn't coping very well… the physio was very good. I don't know why, but for some reason I think the physio part of Cystic Fibrosis, not only is it huge because of what it does, I just think it's huge in terms of support. We just asked them so many questions … I've placed my baggage on them and they've taken that really well.” Family can be perceived as supportive by some people: “At the time we also had a bit of support unit with my mum and sister in law there and they were taught [physiotherapy techniques] as well for back up and a bit of emotional and moral support for me.” Or unsupportive by others: “My husband who is an angel, he is fantastic, he also wasn’t 100% support[ive] in that manner, he left most of it (physiotherapy) for me”	managed through different health care networks, thus limiting external validity. The relationship between the researcher and the respondents was not clearly reported. Data collection: Data collection was clearly reported, including the number of interviews, data saturation and the use of an interview map and digital recording. However, the authors did not explain why they chose a focus group for the physiotherapists and interviews for parents. Data analysis: The analysis process was described in detail, including details on how categories, sub-categories and themes were developed. Sufficient quotations were presented to support the findings. However, there was no mention of contradictory data and researchers did not critically examine their own role, potential bias and influence during analysis and data selection. Findings/results: The findings were explicit. Data analysis was completed independently by two researchers to enhance credibility. Moreover,

Study details	Participants	Methods	Findings	Comments
		assigned a code number and pseudonym for transcription and quotation. The audio and transcribed versions of data were reviewed multiple times to capture the full impression of the data. Line by line analysis was then completed to identify categories. The relationships between the categories were explored to develop sub categories and themes. Key quotations were identified and reviewed with the audio data for accuracy. The researchers met to discuss the emerging themes and were in agreement with themes and categories. Data analysis was completed independently by two researchers. The coding process was completed numerous times by each researcher to ensure clear development of		participants were asked to review the emerging themes and comment on their accuracy. There is adequate discussion of the evidence which takes into consideration studies with contrasting findings as well as studies with similar findings. Overall quality: Moderate Other information Ethics approval was obtained from the Southern Health and Monash University Ethics committees. All participants were required to give written informed consent. The authors noted that they outlined data collection and analysis clearly in order to allow completion of a similar study in other population groups. The authors also noted that by having children of participants spread across a wide age range they addressed recall bias of parents. Other information

Study details	Participants	Methods	Findings	Comments
		themes. Quotations were used to validate and reinforce key themes. Participant members were asked to review the emerging themes and comment on their accuracy.		
Full citation Tluczek, A., Koscik, R. L., Modaff, P., Pfeil, D., Rock, M. J., Farrell, P. M., Lifchez, C., Freeman, M. E., Gershan, W., Zaleski, C., Sullivan, B., Newborn screening for cystic fibrosis: parents' preferences regarding counseling at the time of infants' sweat test, Journal of Genetic Counseling, 15, 277-91, 2006 Ref Id 366982	Sample size N= 33 families Characteristics Families of infants with abnormal newborn results (8 with CF confirmed after sweat test) Inclusion criteria Not reported Exclusion criteria Not reported	Setting Qualittative interviews in families' homes and it lasted about 1 hr Sample selection Families were recruited from CF Centers during appointments for diagnostic sweat tests following abnormal CF NBS results. All participants provided written consent for this study. Data collection Semi structured interviews conducted by the principal investigator or 3 research assistants trained to conduct qualitative research. When both parents participated, they were interviewed together. Data analysis	Themes/categories Implication for child who is CF carrier Mother of carrier infant: "I think probably for his future. What is it going to mean for (him) when he gets married and has his own kids? How is that (being a CF carrier) going to play a role? How do we tell him about all this and explain it to him so that he understands? And I think more of how is it going to affect him then us, now? How in the future is it going to affect him?" Straight answers Father of carrier infant: "The lady who dealt with us, she didn't beat around the bush. If you ask her an open question, she would give us a straight answer to the best of her ability, and I appreciate that very much." Use simple language Mother of carrier infant: "We like to know that he does or he does not have this, instead of using all these big, giant words that make your head swim. It is confusing because one (test) could be a good thing that he's negative, another one could be a bad thing that he's negative." Information from a specialist Father of carrier infant: "It's a comparison between somebody who's a specialist in that area (genetic counselor), to somebody who, you	Limitations Aim(s): Clearly reported Aim of the study clearly reported, research method was appropriate for answering the research question Sample selection: Sample selection including process of recruitment was clearly reported. The relationship between the researchers and the respondents not clearly reported. Data collection: Data collection relied on the semi structured interviews. Structure of interview and topic guide not reported. Description of how "themes" were arrived at was discussed. Data saturation and full exploration of theme reported. Data analysis: The analytical process was described with description of themes and categories. No

Study details	Participants	Methods	Findings	Comments
Study type Qualitative study Aim of the study 1) understand parents' perceptions about genetic counselling received while awaiting their infant's sweat test results; 2) identify conditions that may affect the quality of their experience; 3) develop a model for genetic counselling under the conditions of new born screening (NBS) using CF as a prototype for NBS programs using gene technologies Country/ies where the study was carried out USA			know, is the initial person that you visit (primary care provider) and they don't have the expertise in that particular area ... the genetic counselor was more qualified, more prepared, and more comfortable." Wanted detailed explanation about CF before Sweat Test Results Father of carrier infant: "I want all the information. That way I know what I'm waiting to hear about. So it's not this black box that I don't know anything about and when I find out.. I think it was good that we had the information ahead of time. And, in fact, we were even seeking it out." Probability of CF diagnosis Mother of carrier infant: "She told us, based on the information she could see, there was a pretty low percentage, it was a very low percentage that, you know, this test was going to come back high (abnormal). And we felt pretty good after that, that, you know, we were going to be able to know for sure, and, and that it was going to be a good result, and we can put it behind us." Genetics of CF Mother of carrier infant: "She had the tools ...She started drawing out to show us 'if one of you is a carrier and one isn't,' ...she explained our chances of our child having the disease ...She had the statistics to back up what she was telling us. She could show us mathematically."	critical review of the researchers' role in the process. Findings/results: Results were presented clearly with appropriate use of quotes to support the findings (e.g., citation/data and the researchers' own input distinguished. Researchers' role and potential influences in the analytical process not critically reviewed. Overall quality: Moderate Other information The study did not described the ethical process of research or the ethical approval. Study conducted by multiple researchers but the level of consistency between the researchers not reported.

Study details	Participants	Methods	Findings	Comments
Study dates 2002-2004 Source of funding National Institute on Diabetes,Digestive,and Kidney Diseases and by the National Institute for Human Genome Research (R01 DK34108–16) and National Institute of Child Health and Human Development (K23HD42098-01)				
Full citation Tluczek, A., Orland, K. M., Nick, S. W., Brown, R. L., Newborn screening: an appeal for improved parent education, Journal of Perinatal & Neonatal	Sample size Unclear. N=193 parents of 100 infants diagnosed with CF (N=16), who were heterozygous Cystic fibrosis-Carrier (n=34), diagnosed with congenital hypothyroidism (N=23), or had normal screening results (N=27). Characteristics	Setting Interviews were conducted in parents' homes when infants were between 6-12 weeks of age. Sample selection Parents were recruited from 4 medical centres (paediatric primary care or specialty care clinics) in Wisconsin, USA. Convenience sampling was used to	Themes/categories Parental knowledge of new born screening: Fathers were more likely than mothers to be uninformed about new born screening, and obtained information from their wives, or by their infants' abnormal results: “We didn't know anything about the testing at all and then they called us a week after he was born saying that we need you to bring him in.”(mother, CF group) Misinformation: Parents reported that they had very little knowledge of NBS, and the lack of information increased emotional reactions to abnormal	Limitations Aim(s): Clearly reported Aim of the study clearly reported, research method was appropriate for answering the research question Sample selection: Sample selection was unclear and it was mixed population with other chronic diseases. The role played by the researcher in sample selection was not clearly reported.

Study details	Participants	Methods	Findings	Comments
Nursing, 23, 326-34, 2009 Ref Id 366985 Study type Qualitative study with semi-structured interviews. Aim of the study To learn how parents were informed about new born screening and to obtain their suggestions for improving the process of educating parents about new born screening. Country/ies where the study was carried out USA Study dates Not reported. Source of funding National Institute on Diabetes, Digestive and	The sample was primarily of white European Americans (94.4%), and married couples (80%). Parents' age ranged from 18-59 years. Infant genders were equally divided. Inclusion criteria Families qualified for inclusion if their infants were less than 6 months and had an abnormal NBS in the State of Wisconsin and subsequent testing showed the infant to have (a) cystic fibrosis (CF group), (b) congenital hypothyroidism (CH group), (c) one CF mutation, considered to be a CF carrier (CF-C group), or (d) a normal NBS and healthy (H group). Exclusion criteria Infants with serious comorbid diagnoses or who were more than 8 weeks premature were excluded.	recruit parents on the basis of their infants' NBS results and subsequent diagnostic testing. Data collection Data was obtained through semi-structured interviews as a part of a larger research project conducted by the principle investigator (PI) or specially trained assistants. Interviews lasted for 20-30 minutes. All interviews were audiotaped and randomly checked by the PI. Data analysis Data was analysed by coding of the transcripts. Data was analysed for themes, labelled with descriptive codes, categorised by similarities in themes. Thematic codes were compared for differences or similarities based on participant's group membership. Codes and categories were reexamined and	results. They also expressed confusion about testing procedures: "They did not inform me in the hospital that 'we're doing the NBS'… . I had to ascertain when it was actually done because I was concerned, having some difficulty understanding the results. Which then begs the question 'why didn't I know when the NBS was done?' I think at the very least I should have been informed." (mother, CF group) Improving the educational process: Parents of infants who had abnormal results expressed the need for emphasis of the significance of NBS from health care providers to all new parents: "Make sure that they know how important it is. I mean it might not be important to the people who come out with perfectly healthy babies, but for people like us what a difference it made." (mother, CF group) Timing of parental education: Parents expressed that they would like NBS information at the hospital, at the time of the heel prick, or during pregnancy, in advance of parenthood, in the form of a pamphlet. However, one parent expressed that this information was not appropriate during labour or at the time of delivery: "In the pregnancy, explain 'when your child is born we're taking some of the blood and sending it here. Here's a pamphlet about what they're screening for." (father, CF group) Verbal and written communication: Parents expressed that there was a need of improved verbal and written information about NBS, what the test would involve and why the test was being done.	Data collection: Data collection relied on the semi-structured interviews. Description of data collection method was reported. Data analysis: The analytical process was reported in detail. Description of emerging themes was reported, but saturation of data was not reported. Direct and summative content analysis performed. Codes and categories were re-examined to ensure validity of the findings. Findings/results: Results were presented clearly. Findings were adequately supported with quotes and discussed in detail. (e.g., citation/data and the researchers' own input distinguished) Overall quality: Moderate Other information The population included parents of infants with: (1) a CF diagnosis, (2) one CF mutation and therefore CF carriers (CF-C), (3) congenital hypothyroidism (CH), and (4) normal screening results (H).

Study details	Participants	Methods	Findings	Comments
Kidney Diseases National Institute of Child Health and Human Development		refined to assure the descriptive, interpretive, theoretical, and evaluative validity. Finally, the frequencies were tabulated for each descriptive code and category across study groups. The PI cross-checked 20% of the coded data to assure at least 95% consistency among coders and checked all tabulations for 100% accuracy.		
Full citation Whyte, D. A., Baggaley, S., Rutter, C., Chronic illness in childhood: A comparative study of family support across four diagnostic groups, Physiotherapy, 81, 515-520, 1995 Ref Id 406577 Study type	Sample size N=4 families with a child with CF Characteristics Not reported Inclusion criteria Age of child: 4 years in 1993 Gender: male and female mix Parents: one single-parent family in the group if possible Severity of CF: At least one year after diagnosis; the illness not in a terminal stage Exclusion criteria	Setting Not reported (hospital setting?) Sample selection Convenient sample of four families were identified from hospital outpatients clinics living within 20 mile radius of hospital Data collection Data was collected through two interviews, one with the mother (only notes taken) and the second interview was conducted with both	Themes/categories Diagnosis of CF: Mothers reported variation of diagnosis of CF of their children and the stress of when they found out their diagnosis: "My husband and I were completely traumatised at first and only kept going on adrenalin for the first year. Now I grieve for the baby I wanted and didn't get. However, we still love Jane" (mother of infant diagnosed at birth) "we were told that she might die when she was in her teens-I shall always remember the doctor saying that, and the effect it had on us" (mother of an infant diagnosed at 15 months age, who had symptoms of loose stools) Informal support:	Limitations Aim(s): Clearly reported 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 not clearly reported Data collection: Data collection relied on the semi-structured interviews. Description of data collection method was very limited. No information on use of topic guide or the process to cover all the themes reported.

Study details	Participants	Methods	Findings	Comments
Qualitative study with semi-structured interviews Aim of the study To increase understanding of the needs of families caring for children with chronic illness To investigate the continuity, effectiveness and acceptability of care from the parents' perspective To identify commonalities and differences in the response of families to chronic childhood illness across four diagnostic and prognostic categories To inform the design of a questionnaire suitable for a large-scale survey of a	Not reported	parents (tape-recorded). A free flow of conversation was established around the areas of research interest although a schedule suggesting questions that should be addressed was included. Data analysis Interview transcripts were analysed and 28 major categories were identified. Hardcopies were made and analysed in detail alongside the interview transcripts.	A mother of twins with CF found that the help she received from the community support scheme was not helpful: "The help I got was not the same as help from the family. if only my mum had been around...we do miss a granny figure" Support groups: Some parents found that joining support groups was helpful, and parents considered volunteering to work with families who were newly-diagnosed with CF: "I would like to work with newly-diagnosed families. I needed much more help with the emotional side of things during the whole of the first year" (mother of a child with CF) Professional support (support at home, at school, and continued support and reassurance): Families considered the hospital as a primary source of professional support, for problems with their child adhering to physiotherapy: "the new physiotherapist came out to get the message over. 'If you won't let mum do it, someone else has to come'" (mother of a child with CF) Mothers reported that learning about physiotherapy in hospital was helpful: "we do it three times a day mostly-on different parts. We do front and back in the mornings, sides at lunch time and tops in the evening. We learnt that in hospital, it was helpful" (parent of a child with CF) Mothers reported that the visit of the physiotherapist to the school was helpful: "the physiotherapist went to the school and told them all about CF, and that helped the	Data analysis: The analytical process was not reported in detail. Description of methodology of emerging and overarching themes was not clearly reported, and saturation of data was not reported. Findings/results: Results were presented clearly (e.g., citation/data and the researchers' own input distinguished. Limited discussion of the results/findings. Overall quality: Low Other information Cystic fibrosis was one of the four groups of chronic diseases included in the study.

Study details	Participants	Methods	Findings	Comments
families caring for children with chronic illness Country/ies where the study was carried out United Kingdom Study dates January 1993-March 1994 Source of funding University of Edinburgh Development Trust			teachers to understand Rachel's problems" (mother of a child with CF, at school) Mothers reported that continued support from the physiotherapist was helpful in crisis situations: "I wasn't coping and I went to the hospital before my appointment was due and I just broke down in tears. The physiotherapist was very good, and said it wasn't a unique situation, and that I was coping well. I was happy that I had spoken to someone about it-it helped" (mother of a child with CF) Communication: Parents reported that there was a breakdown of communication between hospital and the community team that occurred on several occasions regarding changes in prescription: "communication between the hospital and the GP seems to have gone out of the window-John had his drugs changed and on-one told us, so the prescription was left lying" (parents of twins with CF)	
Full citation Widerman, E., Communicating a diagnosis of cystic fibrosis to an adult: what physicians need to know, Behavioral Medicine, 28, 45-52, 2002 Ref Id 367005	Sample size N=36 men and women diagnosed with CF. Male (N=15) and female (N=21) Characteristics Mean age of participants was 39.7 years (SD 10.6, range 20-69 years) Mean age of diagnosis was 26.5 years for men (SD 6.7) and 29.2	Setting Interviews were conducted face-to-face for participants (N=16) living within a 300-mile radius of the author's university, and by telephone (N=20) for other participants. Sample selection Participants were recruited by the author placing notices in CF	Themes/categories Information at diagnosis Diagnosis and communication For individuals suspected of CF, their physicians told them not to be concerned as they would probably test negative: "[My doctor] decided to have me tested for CF...He said, 'Don't worry, you're too old'. It can't be, blah, blah, blah, blah. And it came back positive. So they did it again. And it was positive again" (46 year old woman) Communication of diagnosis by physician	Limitations Aim(s): Clearly reported 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 clearly reported Data collection: Data collection relied on the semi-structured interviews. Data collection

Study details	Participants	Methods	Findings	Comments
Study type Qualitative study using semi-structured interviews Aim of the study To determine the extent to which the needs and issues of the CF adult are addressed by existing bad news and paediatric CF recommendations, and to develop and present recommendations to supplement them Country/ies where the study was carried out USA Study dates Not reported Source of funding Cystic Fibrosis Foundation	years (SD 8.5) for women Mean age of diagnosis was 9.9 years, SD 8.87, range 4 to 29 years) 50% of participants were married, or had a partner 75% participants attended or graduated from college 36% participants were employed full time Inclusion criteria Men and women in the US who had received a diagnosis of CF at 20 years age or older. Exclusion criteria Not reported.	patient publications, posting notices on a CF consumer list serve, and distributing flyers at selected CF centres in order to ensure diversity in gender and time since diagnosis (>3 or <3 years). Participants were continued to be recruited until no new perspectives emerged during data collection. Data collection Semi structured interviews, either face-to-face (n=16) or by telephone (n=20). Participants were asked to describe and reflect on their experiences when they received their diagnoses. Issues, experiences, and emerging themes were identified. Case notes were made from each interview. Data analysis Data were analysed by considering each individual's story and related case notes, highlighted words, experiences and	Physicians were tentative in communicating a positive result to the patient, as a result, participants reported that their initial diagnosis interview left them confused and questioning whether they actually had CF: "OK you tested positive for CF, but we wanted to make sure you really have the illness. So, therefore we are going to forward you another clinic for confirmation" (Participant's comment) Searching for information At first mention of CF, participants searched for information: "I immediately went to the library the next day and looked up CF. And, everything said you were going to die by the time you were 16. And here I was 40". Content of information at diagnosis: Physicians provided information about CF in even, unemotional, but not uncaring, tones: "[The doctor] was able to convey [the diagnosis] in such a manner as to keep me from getting overly excited about it". (Male participant diagnosed with CF previously) Participants reported that they were given educational materials during the diagnosis interview but they were directed to parents of young children and did not address issues associated with adult diagnosis: "I want to know about adult stuff. I want to know what to look for in symptoms, hints to better activities now, not to think I am going to die soon so often". (male participant) Directional or action-orientated content: Physicians provided information and answered questions, but the overall impression they communicated was one of doing something in	method was appropriately described Data analysis: The analytical process was reported but was unclear on use of analytical software. Authors' interpretation was checked independently. Unclear if saturation of themes was achieved Findings/results: Results were presented clearly (e.g., citation/data and the researchers' own input distinguished) Overall quality: Moderate Other information

Study details	Participants	Methods	Findings	Comments
and Solvay Pharmaceuticals		interpretations that were essential to the diagnosis experience. Data was reduced to identify essential characteristics and establish themes and categories. Interpretations were verified further for consistency.	response to the diagnosis, of taking control (authors comment) Life expectancy: Participants wanted to know how long they could expect to live and whether being diagnosed as an adult was associated with longer life expectancy (authors comment) Impact of CF: Participants wanted to know how CF would change their lives (whether they could or should have children), and what to expect in the future (authors comments) Questions about CF: Participants wanted to know what treatments would be effective, and signs to look out for as indicators of their health status, and if their symptoms could be controlled: "I wanted to know everything" (participants comment) Some participants questioned why they were diagnosed with a paediatric condition, why they had not experienced symptoms, and how many others are diagnosed as adults (authors comment) Participants were confused about what questions to ask at the time of diagnosis: "Because how can you ask questions about something you know nothing about? First you assimilate the disease, then you question it" (female participant) "I was confused. I didn't know what to ask" (male participant) What to do after diagnosis: Almost all participants asked about what they should do next:	

Study details	Participants	Methods	Findings	Comments
			"What do I do now?" or "how do I care for myself?" Coping with CF: Participants wanted to know how to have a "normal life" , and how to cope with CF emotionally, in addition to keeping their lifestyle patterns (e.g., job, exercise, travel) (authors comment) Support at diagnosis Participants preferred CF physicians as their primary source of treatment, information and support (authors comment) Most participants reported that they were satisfied with how the diagnosis was communicated to them either face-to-face or by telephone. Participants reported that they appreciated physicians who were optimistic, supportive, "straightforward", compassionate, and took their time in giving the news (authors comment) Participants reported that they reacted in a positive manner when their questions were answered, and given information about CF, as well as positive messages to promote hope (authors comment) Participants appreciated privacy, having other professionals available and a "warm" atmosphere (authors comment) Some participants expressed that their emotional needs were not met, and did not receive sufficient information, and were treated impersonally, and that they would have liked more privacy (authors comment) Recommendations made by participants: Participants expressed that physicians should consider the effect that a diagnosis of CF will have on patients and should appreciate that	

Study details	Participants	Methods	Findings	Comments
			learning of CF turns lives "upside down". They also felt that physicians must communicate with the patient in a way that acknowledges differences of experiences and learning of CF on an individual basis. Physicians should keep up to date about late CF diagnosis and have age specific educational materials at diagnosis (authors comment)	
Full citation Widerman, E., Knowledge, interests and educational needs of adults diagnosed with cystic fibrosis after age 18, Journal of Cystic Fibrosis, 2, 97-104, 2003 Ref Id 367006 Study type Quantitative and qualitative study Aim of the study To address evidence gap about the actual and self-perceived knowledge of	Sample size N=130 adults diagnosed with CF after age 18 Characteristics Male and female adults diagnosed with CF after age 18 Inclusion criteria Not reported Exclusion criteria Not reported	Setting Participant's home. Sample selection Notices posted on CF-related web pages, in CF newsletters, and through notices sent to CF centers with adult programs. To volunteer, individuals had to respond to an email address contained in the notices. 175 questionnaires were mailed to eligible male and female. The response rate was 74.3% (130) and represented: the continental US (92); the UK (5); Scandinavia (23); continental Europe (4); and other nations (6). Data collection	Themes/categories Evaluation of information provided at diagnosis Materials: Participants said most information materials were non specific and was not helpful with their particular concern. A women wrote "I got a booklet from the CF Foundation listing the median age of survival as 21. I was diagnosed at 24!" A man lamented, "None (of the materials) addressed social, economic, psychological, or political issues and obstacles." Some participants wanted information explaining their generally good health statuses and/or their atypical symptoms. A 39-year-old woman related, "My problems are associated with my sinuses and nasal cavity.... Much information did not know how to correctly treat this aspect of the disease." Another participant recalled, "We were given two books, but only one little paragraph really applied to me." Caregivers: Participants said that care givers should offer more information and show empathy. A 31 year-old woman wrote:"'Doctors need to have more information available. I had 15 min	Limitations Aim(s): Clearly reported Aim of the study clearly reported. Research method was not the most appropriate for answering the research question. Qualitative semi structured interview would have been better. Sample selection: Sample selection was unclear. The need for international sample solicited through email was not justified. Data collection: Data collection relied on the postal questionnaire with open ended question. Survey instrument described. There was no theme or topic guide or report of data saturation. Data analysis: The analytical process was poorly described and involved grouping information based on frequency.

Study details	Participants	Methods	Findings	Comments
people diagnosed with CF as adults in order to inform the development of educational materials for this sub-population and to guide caregivers in educating them. Country/ies where the study was carried out International Study dates Not reported. Source of funding Solvay pharm aceuticals, Belgium.		Data collected through pre-designed postal questionnaire and had both fixed response and open questionnaire for quantitative and qualitative information. Data analysis Grouping and counting responses to open-ended questions and assigning importance to them according to frequency of mention. Not all participants responded to all questions, but in most cases fewer than four cases were missing. Missing data were not included in analyses.	counsel with my diagnosis and that was it. I would call with a question. They would answer, but otherwise I have been on my own for information. It's scary to have a bomb dropped on you and then it's like here, deal with it." Another young woman recalled, "My physicians gave me no information. I actually supplied them with articles and I have continued my self-education once I realized that physicians often do not keep up on the literature." A 51-year-old man diagnosed 2 years previously said, "The concern for my emotional health by the medical professionals was almost non-existent." A 37-year-old male simply wrote, 'It seems like care is lacking.'	No further analysis of the qualitative information. Findings/results: Results were presented clearly but qualitative data was under-reported compared to quantitative data. Output were classified into sub-themes and categories. Researchers' role and potential influences in the analytical process not critically reviewed. Overall quality: Poor Other information Ethical approval not reported. Was sponsored by pharmaceutical company.
Full citation Widerman, E., The experience of receiving a diagnosis of cystic fibrosis after age 20: Implications for social work, Social Work in	Sample size N=36 participants with cystic fibrosis (male=15 & female=21 Characteristics Participant's age ranged from 20-69 years with a mean age of 28 years. Time since diagnosis ranged from 4 months to	Setting No reported Sample selection Participants recruited through newsletters or flyers. Purposive sampling was done according to time since diagnosis to ensure the exploration	Themes/categories Craving for information Timing of information Participants showed their frustration, as they wer not given information at time of diagnosis (authors' comment) Format	Limitations Aim(s): Clearly reported Aim of the study clearly reported, research method was appropriate for answering the research question Sample selection: Sample selection was reported. The relationship between the

Study details	Participants	Methods	Findings	Comments
Health Care, 39, 415-433, 2004 Ref Id 474153 Study type Semi-structured qualitative study Aim of the study This study explores 1) the experience of receiving diagnosis of cystic fibrosis after age 20 & 2) adult's self-expressed educational and support needs, interests and preferences following a diagnosis of cystic fibrosis Country/ies where the study was carried out USA Study dates Not reported	29 years. Approximately 50% of them were married and in professional occupations, 75% attended or completed college, and almost approximately 33% worked full time outside of the home. Inclusion criteria Men and women living in the US who had received a diagnosis of cystic fibrosis at age 20 years or over. Exclusion criteria No reported	of cystic fibrosis experiences at different points in the illness trajectory in different individuals Data collection 20 telephone and 16 face to face interviews ranging from 45 minutes to 2 hours. A semi structured interview guide was developed for efficient collection of data. Data analysis Transcripts from interview and case notes from researcher were used for interpretation and for development of individual themes. To determine the accuracy of themes in capturing the experiences, participants were asked to comment on the developing themes. Similar themes were grouped together and data reduction done by eliminating repetitions. Themes were subdivided based on gender and self - perceived illness severity.	Participants said they were given information addressed to a paediatric audient. Few adult materials were available: "It seems there is not enough information for me to reseach on my own out there. I want to know about adult stuff" (man recently diagnosed with CF) A woman wanted directions on how to do chest percussions; she was given a booklet with illustrations of an infant (authors' comment) Content: general information, rather than illness-specific Participants were not particularly interested in biomedical descriptions of CF, or even in instructions on self-care (authors' comment). "We need more on everyday stuff" (man recently diagnosed with CF) A woman lamented her CD education involved "technical things" and "nothing about what life would be like". (woman diagnosed with CF as adult) Wanting sympathy Moderate or seriously ill participants admitted feeling self-pity and wanting sympathy, particularly from family members and caregivers (authors' comment). "Once in a while, I'd like someone to feel sorry for me" (woman diagnosed with CF as adult) Participants said they envied and resented the concern of the public for CF "poster children". But because CF is not outwardly apparent in most adults, participants felt their families, friends and coworkers understimated its impact (authors' comment).	researcher and the participants was not reported. Data collection: Data collection relied on the semi-structured interviews. Data collection method was vaguely described and needed further information on development of interview guide. Data analysis: The analytical process was reported but was unclear on use of analytical software. Authors' interpretation was checked independently which improved validity. Unclear if saturation of themes were achieved Findings/results: Results were presented clearly and discussed in detail (e.g., citation/data and the researchers' own input distinguished) Overall quality: Moderate Other information Ethical process not reported.

Study details	Participants	Methods	Findings	Comments
Source of funding Not reported				
Full citation Hodgkinson, R., Lester, H., Stresses and coping strategies of mothers living with a child with cystic fibrosis: implications for nursing professionals, Journal of Advanced Nursing, 39, 377-83, 2002 Ref Id 367043 Study type Qualitative study with semi-structured interview. Aim of the study To explore current stresses and coping strategies used	Sample size N=>100 (sampling cohort of mothers of children with CF) n=17 mothers interviewed Characteristics Maternal: Age ranged between 24-48 years Educational level: no GCSE, 4/17; GCSE/O level, 6/17; A levels/equivalent, 4/17; Degree, 3/17 Employment status: unemployed, 10/17; part-time employment, 6/17; full-time employment, 1/17 Family type: nuclear, 15/17; single parent, 2/17 SES: class I, 4/17; classII, 6/17; class IIIM, 3/17; class IV, 2/17; class V, 2/17 Children with CF: Age ranged between 2-13 years	Setting Interviews were conducted at the participant's home. Sample selection The sampling frame of this study was the cohort of over 100 mothers of children with CF attending the regional Birmingham (England) Children Hospital cystic fibrosis clinic. Data collection All semi-structured interviews were performed by RH, a third year medical student studying for an intercalating degree at Birmingham Medical School. Interviews lasted between 30 and 65 minutes. All interviews were audiotaped and fully transcribed. Interviewees were	Themes/categories Coping with CF (social support): Mothers found support from various sources including family, partner, friends, CF liason nurses and their primary health care team (authors comment) Mothers identified friends as an important source of support because they could talk about other things than CF: "If I visit my friend who lives round the corner, we don't sit there talking about S, you know, we can have a gossip and just things like that. CF isn't the centre of the conversation all the time, which like, it shouldn't have to be" . Relationship with health professionals (support from health care professional, nurse specialist, primary care) Most mothers considered recognition of responsibility for caring for a child with CF during consultations with nursing and medical healthcare professionals to be important and encouraging as well as achieving a mutual relationship with the healthcare professional: "He will always, without fail, give you praise…and he'll say Wonderful specimen mother. Well done, keep it up, wont you, you're doing marvellous', and it's what you need". Many mothers turned to nurse specialists for support and advice, and was critical in interpreting information and aiding understanding of treatment and compliance:	Limitations Aim(s): Clearly reported 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 clearly reported Data collection: Data collection relied on the semi-structured interviews. Data collection method was appropriately described, including saturation of themes Data analysis: The analytical process was reported, but not in detail. Transparency of analysis was ensured by using two independent researchers who compared and extracting evidence from the transcripts. Saturation of themes was described in the data collection section. Findings/results: Results were presented clearly (e.g., citation/data and the researchers' own input distinguished

Study details	Participants	Methods	Findings	Comments
by mothers and to identify roles and strategies that nursing professionals could extend or adopt to support them and families of children with CF. Country/ies where the study was carried out United Kingdom Study dates January to May 2001. Source of funding Not reported.	Gender: female, 9/21; male, 12/21 Hospital stay in past year (number of stays): 0 stay, 7; 1 stay, 7; >2 stays, 3 Mean number of children with CF/household: range 1-3 Hospital visits in past year: range 5-21 GP visits in past year: range 0-4 Inclusion criteria Mothers of children with CF who attended the regional Birmingham Children Hospital CF clinic. Exclusion criteria Mothers of children who had been diagnosed within the previous 12 months and families known by the clinic nursing staff to be undergoing a period of crisis.	assured that any potentially identifying features would be removed from the transcripts. Themes were identified and developed from reading and re-reading transcripts. Themes were further refined and clarified using the Framework analytic approach. Interviews and analysis were conducted concurrently and continued until no new themes were emerging and data saturation was felt to be complete. Data analysis A grounded theory approach was used for data analysis. Ideas were read and compared and searched for disconfirming evidence during the analysis. All interviewees were also sent a copy of the primary analysis,	If we do have any worries or concerns [we] just contact the hospital straight away…we never bother going up to the doctors, we always just contact S, she's one of the nurses". Mothers reported that there was a need for a more involvement in their childrens treatment as their role was limited: "Well basically he [GP] just writes prescriptions for us…he hasn't played a big part in the cystic fibrosis part of it". Communication: Mothers described themselves as a conduit between the GP, practice nurse and specialist clinic as well as reporting poor communication in terms of co-ordinating drugs and change in treatments (Authors comment) Mothers reported that the primary care team's unfamiliarity with CF drugs, which contributed to distrust of primary care advice: "The GP says-'what do you normally have?' and it's sort of, well it would be nice if they could tell me what they think". Mothers felt that they could not escape discussions about CF with their health care professional, even if they had gone for unrelated problems: "I'm very aware if you need to go to the surgery that there must be this big label in my notes that says Child with CF. You could go with aningrown toe nail and it would be down to C, you know, you can never have a problem of your own, it'll be you're depressed becauseof C. I'm thinking, you know, I've lost, I'm never S, I'm never, I'm always C's mum".	Overall quality: Moderate Other information Mothers of Children with CF

Study details	Participants	Methods	Findings	Comments
		asked to comment on the themes and concepts, and these were then considered and incorporated in the subsequent phases of the analysis.		