

Chapter 2

## Perceptions of people with cystic fibrosis on hospital admissions

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## Abstract

**Background:** In The Netherlands, people with Cystic Fibrosis (CF) are hospitalized in seven Cystic Fibrosis (CF) centers. In general, hospitalization may raise several challenges concerning the patient's psychosocial well-being, before, during and after the admission. The admission of people with CF is complicated, because of segregated treatment and care that aims to prevent hospital-based cross-infection.

**Aims:** This paper is a report of a study of experiences of people with cystic fibrosis with their hospital admission. It evaluates how they perceive their treatment and care and the impact on their social life (school or work).

**Methods:** This article reports on a qualitative study. Data were collected during 2009 and 2010. Nineteen people with CF admitted for more than 5 days in one of the seven Dutch CF-centres participated.

**Results:** The findings are organized into five contexts with themes: Before admission & Arrival (1); Treatment & Care (2); Room & Stay (3); Discharge (4); Social & Societal context (5). The main findings include: patients express a need for enhancing the quality of some treatments, like intravenous injections; patients express normative expectations of healthcare professionals that directly relate to their psychosocial well-being, e.g. they want to be 'seen' and treated as human beings and not solely as patients. They desire segregation policies to be consistent, whilst simultaneously they prefer more flexible segregation guidelines. In general, respondents are satisfied with hospital facilities and dietary possibilities. The study reports on challenges concerning continuation of school activities and work during the admission and after discharge. The paper presents several recommendations for clinical nursing policy and practice.

**Keywords:** hospital admission; psychosocial impact; hospitalization; segregation; patient perspectives; technical competence.

## Introduction

Cystic Fibrosis (CF) is a severe, inherited chronic disease. The incidence of CF varies. In the European Union 1 in 2000-3000 newborns is found to be affected by CF. In the United States the incidence of CF is reported to be 1 in every 3500 births (World Health Organization 2011). In the Netherlands, where some 1350 people live with CF, there are seven multidisciplinary Cystic Fibrosis centres (CF centres) responsible for the treatment and care of people with CF. Supervised by a pulmonologist or a paediatric pulmonologist, a team of specialized nurses, dieticians, physiotherapists, psychologists and social workers treat and care for people with CF.

The advances for diagnosis, treatment and care have improved considerably over the past few decades. Despite this, CF is still a complex disease with a wide variety of symptoms and severity, and an unpredictable course. The number of hospital admissions is expected to rise in the near future as people live longer and require hospitalized treatment. People with CF live longer due to advances in treatment, but the cost is that they require more frequent hospital admissions to manage exacerbations.

Admissions to hospital can have a negative impact upon quality of life and psychosocial well-being. It interrupts a patient's private and social life. The hospitalizations of people with CF is even more complex because of segregation measures which most countries, including the Netherlands, have introduced. People with CF have a high rate of infection with *Pseudomonas aeruginosa*. Research demonstrates that cross infection may occur (Festini et al., 2006; Griffiths et al., 2004; Speert et al., 2002). Therefore, in 2004, Dutch CF-centres introduced segregation policies with a view toward preventing cross infection. People are hospitalized in separate rooms and may leave the room ('outdoor period') only at set times of the day. The literature reports on the negative consequences of segregation for the quality of life and psychosocial functioning of people with CF (Russo et al., 2006; Duff, 2002; Griffiths et al., 2004). Other factors may also influence patients' perceptions of their admission, including the quality of their relationships with nurses and clinicians and the opportunity to have a say in treatment and care. There is a growing interest in improving the quality of life for people with CF in the CF-centres (Stern et al., 2011). However, to date little research has been published in this area (Ullrich & Bartig, 2010; Russo et al., 2008).

We conducted a qualitative study in order to understand how patients perceived these and other areas of their hospital admission. Clinical nurses and other clinical practitioners may benefit from the findings of this study to support people with CF during and after their hospital admission. The findings are relevant to every situation where people are being treated in isolation.

## Method

### *Aim of the study*

The aim of this study was to gain an understanding of the experiences and expectations of people with cystic fibrosis regarding their hospitaliza-

tion. With this in mind, the study was conducted in line with a qualitative research approach. The central aim of a qualitative study is to enhance understanding of complex practices (Freeman, 2011)

### Sampling procedure

We strived for maximum-variation sampling: sampling as wide a range of perspectives as possible to capture the broadest set of information and experiences ((Kuper et al., 2008). CF-specialized nurses at the seven CF centres were invited by letter to help recruit respondents for interview. We aimed to include four respondents from each CF centre (28 respondents in total, see criteria in Box 1).

#### Box 1 Criteria for inclusion in the study

Men and women with CF;  
 People with CF admitted to hospital because of a lung exacerbation; whose length of hospital stay is expected to be between 10 days – 6 weeks; and who are in one of the following age groups:  
 children with CF between 12 and 18;  
 adults with CF in the 19 – 25 age range, and 26 years or older.

This study understands 'hospital admission' to mean: the period prior to admission, actual admission, and aftercare. This study focuses on a minimum hospital stay of ten days (this was changed during the inclusion procedure to five days – see 'methods' section).  
 People admitted with intestinal problems were not included in the study.

The nurses recruited people *before their admission*. During the intake conversation by the nurse before the admission of a patient, she explained the purpose and procedure of the research to the patient. Simultaneously, the nurses handed over a written leaflet with procedural information (data collection, analysis and use of the diaries). Some specialized nurses informed us that recruiting respondents was challenging, as they had no time to recruit respondents because wards were understaffed. Next, at the start of the study, only a few potential participants met our criteria due to the relatively expected short admission duration. We therefore decided to change one selection criterion: admissions of 5 days or longer would be included, instead of admissions of 10 days or longer. When patients agreed to participate, the specialized nurse asked them to sign a confidentiality and informed consent form for all collected data (interviews and diaries). Respondents were included in the study between November 2009 and July 2010. The sample comprised 19 respondents.

### Literature search, interview guide and topic list

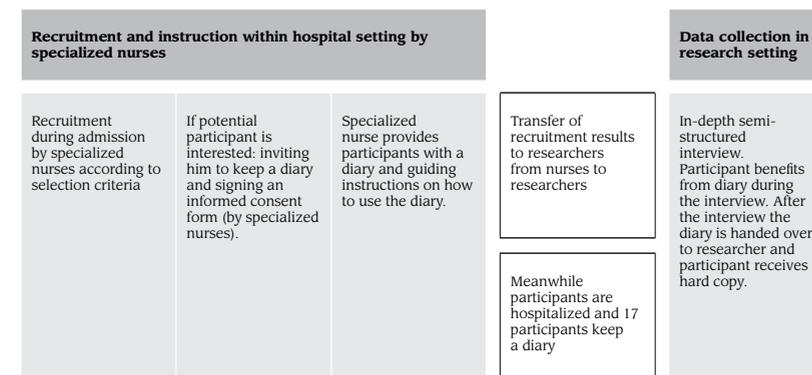
A semi-structured interview guide was developed from an exploratory literature search of several international databases (e.g. PubMed, Chinal and Cochrane Library). The search strings we used consist of terms used to explore CF-patients' experiences with hospital admission, such as 'experiences patients' in conjunction with 'hospital admission' and 'segregation'.

We also studied Dutch sources, both primary and secondary scientific and tertiary literature (e.g. Prins 2010). Empirical scientific studies with a method section are primary sources and other studies without a method section are secondary sources. Tertiary literature concerns non scientific publications, reports and patient information that is relevant to our study. We then conducted a tentative interview. A draft topic list was developed. We also collected self-reported patient characteristics.

### Data collection

A total of 19 in-depth interviews were held around two weeks following discharge from hospital. The interviews were conducted by the first and third author separately and took between one and a half and two hours. During the interviews, the researcher asked questions related to the predefined topics and participants were invited to share topics that were not explicitly addressed by the researcher. To increase rigor as a method of triangulation, on admission, participants were given a notebook and asked to use it as a diary. They were informed about the purpose of the diary and that would be handed over to the researchers afterwards. The notebook contained a brief guide with questions (e.g. Can you write something about how you experienced your first admission day? How did you experience your contact with the nursing staff?). The diary-instructions stressed that we were interested in experiences with the *current* admission. Participants were not obliged to use this notebook, and if they didn't they were still included in the project. In total, 17 respondents actually kept a diary. Two respondents did not – they did not have enough time, or they found the writing itself difficult. During the interview participants benefited from their diary. The diary functioned as a personal 'reminder' of the admission experiences and this increases rigor. After the interview, the diary was handed over to the researcher (with consent). All interviews were digitally recorded after consent and transcribed verbatim by a research assistant. In order to check our interpretation of the interview, the respondents received a printout of our interpretation and asked whether they recognized it, or wanted to change or add anything (member check).

Figure 1: Overview of recruitment and instruction procedure.



## Data analysis

The transcripts and diaries were analysed thematically and simultaneously according to a content analysis approach, a technique for making replicable and valid inferences from texts to the contexts of their use (Krippendorff, 2004). The texts were divided into fragments, and fragment labels (codes) were assigned (open coding). Codes were then assigned to categories, and the categories from several transcripts were related (axial coding).

**Table 1:** Example of content analysis

1st level	2nd level	3rd level	4th level
<i>Fragment transcript</i>	<i>open coding</i>	<i>category</i>	<i>axial coding</i>
Just before I left for the hospital, I heard that my neighbours' eight-week-old baby was suffering from CF. We are very close to our neighbours and this meant I couldn't just go and visit my neighbours anymore. That really hit me right before I was admitted. I am pretty down to earth, but that really got to me.	Hard time coping with news of baby with CF. Good contact neighbour. Events before admission.	Other people with CF and limitations in contact.	Impact of segregation Social contacts

## Quality procedures

Internal validity is enhanced by conducting member checks with respondents and (reflexive) peer debriefing by the authors of this article (Mays & Pope, 1996; Reeves et al., 2008). The analysis was conducted by the first three authors. The role of the last two authors was to critically reflect on the interpretations of the first three authors. By combining several data collection methods (triangulation by interviews, diary, literature search), the validity and reliability were enhanced; triangulation makes it possible to detect data in-congruencies. 'Thick descriptions' of the study context and meanings endowed to experiences enhance the transferability of the findings, i.e. the possibility of translating the themes to other socio-cultural contexts (Kuper et al., 2008).

## Ethical considerations

We aimed for informed consent, anonymity, respect for privacy/confidentiality and transparency. It appeared that the project did not need to be submitted to an accredited Dutch Medical Research Ethics Committee (aMREC) for approval because the study did not concern medical research or any form of invasion of the study participant's integrity. We worked with informed consent forms, and participant names were not used in any of the research reports.

## Results

### Participants

A total of 19 respondents with the following characteristics participated:

**Table 2:** Respondents characteristics (n=19)

Nr. Resp	Gender	Age	Situation at home	Admission to adult / children's ward	Regular admission involving I.V. antibiotic cure	Perception of condition: 1. 'normal' 2. 'controllable' 3. 'distressing**
1	M	40	Living together	A	yes	3
2**	F	17	Lives with parents	C	yes	3
3**	F	17	Lives with parents	C	yes	2
4	F	39	Married	A	yes	3
5**	F	41	Lives with parents	A	yes	3
6	F	31	Single	F	yes	3
7	F	18	Lives with parents	A	no (last admission 9 months ago)	2/3
8	M	14	Lives with parents	C	yes	3
9	M	29	Lives with parents	A	yes	2
10	F	18	Lives with parents	C	yes	2/3
11	F	14	Lives with parents	C	no, 3d admission to hospital	3
12	F	50	Married	A	yes	3
13	M	37	Planning to live together	A	yes	3
14**	F	26	Living together	A	no, 3d admission?	2
15	F	33	Single	A	yes	3
16	M	50	Married	A	yes	3
17	F	21	Lives with parents	A	yes	Recently transplanted
18	M	45	Married, with children	A	yes	3
19	F	36	Widow, partner passed away, cause of death: CF	A	Partner was admitted to hospital several times	

\* Perception of health (Lowton & Gabe, 2003):

**Re 1.** 'normality' as not requiring hospitalisation for CF, or being in employment without needing any more sick leave than a 'healthy' person (p.297). Normality also included having an active social life.

**Re 2.** Respondents have an attitude of 'controlling' their health and this requires a considerable effort. Generally speaking, starting intravenous (IV) antibiotics marked a change from the perception of 'normal' health to one of health as a controllable state (p. 301).

**Re 3.** 'health as distressing' involves daily disruption to work, social relations and hopes for the future as a result of the effects of emerging chronic illness (p. 306). Respondents are concerned about their health. IV is no longer as effective as it used to be, other solutions are sought (e.g. port-a-cath or PICC-line). People consider the transplant option.

\*\* Respondents 2 and 3 were interviewed in the presence of their parents. Respondents 5 and 14 were interviewed in the presence of their spouses.

Number of Respondents	Gender		age			Regular admissions		Perception of health			
	M	F	≤ 18	19-40	≥ 41	Yes	No	1	2	3	N/A
19	6	13	6	9	4	16	3	0	5	12	2
100 %	32%	68%	32%	47%	21%	84%	16%	0	26%	63%	11%

Most respondents have been admitted to hospital several times in the past (84%). This made it possible for them to compare different admissions (and may enhance the quality of the data).

Most respondents were admitted on a regular basis (16 out of 19 respondents). Respondents of all seven CF centres are included. There are more females than males. A possible explanation for this may be the challenges we have met when including respondents as mentioned in the 'sampling' section.

### Contexts and themes

The following five contexts with themes were identified:

Figure 2: Contexts and their themes

Context: Before admission & arrival	Context: Treatment & Care	Room & Stay	Discharge
<ul style="list-style-type: none"> <li>- Theme: uncoordinated care</li> </ul>	<ul style="list-style-type: none"> <li>- Trust in medical and nursing performances</li> <li>- Quality of information, communication and contact with health care providers</li> <li>- Acknowledgement of self expertise</li> <li>- Consistency of segregation policies</li> </ul>	<ul style="list-style-type: none"> <li>- Freedom</li> <li>- Hospital facilities</li> <li>- Daily routine</li> </ul>	<ul style="list-style-type: none"> <li>- Discharge</li> <li>- Transition home</li> </ul>
Social and societal context (family, partner, friends, colleagues, classmates)			

We now describe the context and themes that emerged. Table 3 illustrates each context with one or more relevant quotes.

Table 3: Themes and illustrative quotes

Quote no (respondent)	Context	Respondent quote
1 (10)	Before admission & arrival	I get there around eleven in the morning, but only get my antibiotics at seven in the evening. I get someone to come with me, and my Dad takes time off, but it's a real pain when the doctor doesn't come until late.
2 (5)	Treatment & Care	In the middle of the night, half past five, or six, it was still dark (...) I felt I had to watch: 'Are they doing this the right way?'
3 (7)		Yes, I... and then I get my antibiotics, and think to myself: "Here I am on a drip, but what else am I doing here?" I don't see anyone else at all. I'm all on my own.... yeh... (...). A nurse comes along every now and again to look at the drip, and then she's gone again. And I'm just lying there.....
4 (13)		If you've got CF then you've really got to keep an eye on yourself and see whether things are OK or not. Because of course when they examine you they can see all sorts of things, but not everything, so you've really got to say how you're feeling, and I said I wasn't happy with things, and also because I'd been treated several times but it had never really worked.
5 (13)		I'm pretty sure my old doctor would have said: 'Prevention'... And also because that's what I'd said.... there comes a time after a while when you know your body so well. (...) and I think they didn't really have a good idea of what was going on...
6 (2)		I really don't understand why we have to do a lung test so early. It's not right in the morning, it gives the wrong idea. A bit of a waste of money. But they don't do anything else, there's no time. I did tell them once, but you know what it's like....
7 (12)		I sometimes do it myself, and they say (...) "come on, you can do it, even when it's finished" [the nurses]. "Yes, that's right." And then they [trainees] see what I'm doing ... and they come over to me and say "You really shouldn't be doing that yourself." "No, but I'm allowed to (do) it myself; go and ask the nurses.... they know I do it myself."
8 (9)		There is a segregation policy, but they do tend to turn a blind eye a bit. It all depends who's here with CF. It's really up to the adult CF patients themselves, and there are people who couldn't care less and then the nurses should really say, 'we do have rules for that kind of thing you know.'
9 (4)		The segregation policy really isn't up to much. There you are all shut away and that's not good for you... you have to get better but you can't do anything apart from walk from the bed to the door and back again. (...) We used to go and stretch our legs and walk quite a way, but we can't do that any more. It doesn't particularly help you get better.
10 (14)	Room & Stay	Meals were fine, there they come with a trolley in the morning and afternoon. Of course the food's much better at home, but it really wasn't too bad at all.
11 (1)	Social & societal context	You suddenly get really pissed off. My girlfriend and me. Yes, that's what happens. All people with CF do that. About anything, is pure frustration.
12 (3)		It's really difficult to concentrate, because there's things happening all the time. I once put up a sign saying 'I'm busy'.
13 (14)	Discharge	Only when I left I didn't see any of the nursing staff to say goodbye to, that's a bit weird. And when I got home I realised I'd still got my wristband on.

### **Themes related to the time before admission and arrival on the ward**

The main theme in this context concerns: uncoordinated care. Respondents are not satisfied with their first day of admission. After arriving on the ward, they have to wait a considerable amount of time before starting treatment. Most respondents said they had to wait about six hours. They find this annoying (quote 1, Table 3), it makes them tired, and may also put a strain on people who are accompanying them.

Apart from emergency situations, patients do not understand why they are sometimes admitted on a Friday, just before the weekend. Antibiotic treatment does continue over the weekend in Dutch hospitals, but apart from that, additional treatment e.g. physical therapy, is seldom provided.

### **Themes related to treatment and care**

Four themes found in the context of Treatment and Care, concern: (1) trust in technical performances by staff (2) quality of information, communication and contact (3) acknowledgement of self expertise and (4) consistency of segregation policies.

Firstly, respondents have experienced situations where they have been given intravenous antibiotics that they have a sensitivity towards (e.g. in the case of allergies). Respondents experience this to be a medical error, because their files contain information on their medication sensitivity. They concluded that professionals didn't inform themselves thoroughly. This causes distress, even at night when some respondents watch the antibiotic drip very carefully (quote 2, Table 3). Patients experience pain when their veins are frequently punctured. They believe this pain could be avoided if someone with more experience were to do it (e.g. an anaesthesiologist). They often ask whether an anaesthesiologist can insert the intravenous line, but they often feel that no-one really listens to them. The respondents who have been given a venous access device, such as a Port-a-Cath or PICC line, were positive about their device and the provision of antibiotics by professionals.

Secondly, patients have several criteria for evaluating meetings with clinicians, nurses and other health-care professionals. The level of equality they experience in the relationship and the amount and nature of the attention they experience, is important. Respondents also value the accuracy and personal relevance of the information they are given, and the way practitioners communicate with them. Our findings demonstrate that this is not always the case. Above all, people value human contact. Most respondents explicitly mention their desire to be seen as a unique human being, instead of as a case. People experience this notion of humanity in situations where there is humour and friendliness, for example. Despite the fact that nurses and physicians are relatively easy to contact, people with CF believe that the quality of the contact needs to be improved. This relates to the quality of information and also the quality of 'attention' that professionals give (quote 3, Table 3). Segregation has consequences for social contact and etiquette, such as handshaking. Both adults and children feel stigmatized if professionals do not introduce themselves according to social norms. They feel the need to be treated in the same way as other people, and this includes shaking hands.

A third theme concerns the acknowledgement of self expertise. Many people with CF have become experts when it comes to their body and

health. They also have clear opinions about what they need from a medical and technical perspective. They would like to see their experiential knowledge acknowledged. The majority of adult respondents seem to believe they themselves are partly responsible for their treatment and care (quote 4, Table 3). For example, one male respondent had surgery for a pneumothorax and had to recover in intensive care. He asked to be treated with preventive antibiotics, but his physician did not agree (quote 5, Table 3). The fact that patients need to have a say in treatment and care also applies to technical procedures, e.g. measuring lung function. Patients prefer their lung function to be measured in two different ways: with and without bronchodilators. (It is usually the case that only bronchodilators are used.) Several respondents stress the importance of timing; they believe measuring the lung function in the morning does not give the right reading because they need time to 'wake up' and so the results are biased (quote 6, Table 3). Despite these remarks, there have been no policy changes. One respondent negotiated certain privileges for her medical care with the nursing staff, but trainee nurses do not always accept this (e.g. quote 7, Table 3).

Lastly, a theme in the context of Treatment and Care concerns 'consistency of segregation policies'. Most young respondents (<18 years) see segregation policies as acceptable. However, adult patients report inconsistencies surrounding segregation policies at the centres, and on how segregation was put into practice on the wards (quote 8, Table 3). These inconsistencies are confusing, and they would like to see clarity on this matter. Respondents believe that some CF centres take a flexible stance: people with CF should be able to decide for themselves whether or not to follow segregation guidelines. For most adult patients the negative consequences of segregation outweigh the positive effects. They believe that the chance of being infected by another patient is relatively slight. Only a handful of patients are genuinely concerned about cross-infection.

### **Themes related to the context room and stay**

An important theme related to room and stay concerns 'freedom'. Most patients feel locked up and their freedom restricted. They believe segregation has a negative impact on their recovery because they can't be mobile or be in contact with other people (quote 9, Table 3). The time set aside to leave their rooms is not acceptable. Respondents are disappointed when at the last moment they learn they are unable to go outside because a fellow patient just left his or her room.

Respondents reported on their experiences with the availability of rooms, room facilities, including facilities for visitors, design and atmosphere of the room, meals and hygiene. Generally, they are satisfied with these aspects of their room and stay. They appreciate the digital facilities available, such as a laptop and wireless internet. This enables them to be connected to people in the outside world. People are also positive about the menus, but would like to decide themselves when their meal is served (quote 10, Table 3).

### **Themes related to social context and participation in society**

Themes related to this context, concern: (1) flexible visiting hours (2) integration of school and work.

Respondents are satisfied with flexible visiting hours. They generally experience considerable support from their families and friends. Some respondents report that their intimate relationships undergo a few difficulties (quote 11, Table 3).

Young people need more time to do their homework for school. According to them, the daily schedules when in hospital do not really take sufficient account of that (quote 12, Table 3).

Most adults have a part-time job and experience support from their colleagues. However, a few people find returning to work a challenge and have to catch up without any extra support.

### Themes related to discharge

Respondents are satisfied with the procedural aspects of their discharge. However, they would like to be able to say goodbye to nurses and other staff when they are discharged (quote 13, Table 3).

Treatment will often be continued at home, and the hospital pharmacy often prepares medication for this. However, some people have to wait up to eight hours before they can get their medication.

## Discussion

The findings raise four main subjects of discussion. The people of this study articulate:

- 1) a need to have more control and better communication concerning their treatment and care;
- 2) a need to share decisions about segregation;
- 3) that they appreciate the quality of instrumental and technical skills;
- 4) that they experience challenges posed by social obligations, such as work and school.

This study has shown that people with CF wish to have more control in their treatment and care. A small number of respondents (n=3) actually felt they were in control of their treatment and care in the relationship with the care providers. The need for control is all the stronger because of the erratic way in which CF develops. People with CF, together with care providers to some extent, identify the priorities for their particular situation. They develop not only the patient's experiential, empirical knowledge, but often also intensive and long-term relationships with professionals. Patient compliance acquires a different meaning in this context, compared with the extent to which people with CF 'obey' instructions on treatment and care, or follow segregation guidelines. Compliance is therefore determined in dialogue. Following Meichenbaum's & Turk's example, we use the term 'adherence' (1987) or dialogic compliance: an active and voluntary involvement of the patient based on collaboration, in which the patient and the professional work jointly towards a desired outcome (adherence). In the context of this study, this means that decisions are made jointly and responsibilities are allotted through processes of shared decision making at various times during admission, such as the intake interview as conducted by nurses (Elwyn, 2010). Linked to this process of shared decision making, patients articulate specific normative expectations. These expectations inform us about what

the patient expects that should be done by whom and how. For example, respondents report their wish for these relationships to accommodate their 'humanity', their 'entire' story, and the 'person behind the patient'. These findings are in line with earlier studies of people with CF and guidelines for care (e.g. Walters, 1990; Kerem et al., 2005).

The need to 'have a say' in treatment and care also applies to segregation policies. This study demonstrated that adult respondents were dissatisfied with the segregation policy, and felt that the disadvantages (limited freedom and human contact) outweighed the benefits (preventing infection). Their experience can be attributed to inconsistent enforcement, conflicting information about the risks involved, and patients' wish to retain control over their own lives. From a patient's perspective, more clarity on the risks is required. A formal patient education program regarding the transmission of infectious agents is suggested. Studies on shared decision making confirm the need for clear information, or, where there is a lack of information, the willingness of nurses and clinicians to address uncertainties (e.g. Elwyn, 1999).

A third subject for discussion is the finding that people with CF do not always have confidence in the technical expertise of care providers, such as nursing staff, junior physicians or ward doctors. This is particularly true when it comes to inserting an intravenous line, or changing antibiotic drips. According to patients, professionals such as nurses should be proficient in a range of skills, including technical competences. Other research confirms this: according to a literature review conducted by Rchaidia et al., 'knowledgeable and skilful nurses were seen as those having great experiential knowledge and technical competence' (Rchaidia et al., 2009, p.16). Their systematic review demonstrated that good nurses were aware of their professional limitations: they would know when to call in a doctor or a psychologist to offer psychosocial support. According to people with CF, this is not always the case.

The findings show that experience with work and school is diverse. Whereas one respondent enjoys considerable support from colleagues, another is obliged to make up for lost time on return to work. Further research is desirable in order to increase our understanding of this subject. Other studies have shown that people with CF have a variety of problems in striking a balance between care and work (e.g. Demars et al., 2009). Few studies focus on how patients view hospital admission and work. Almost all the young people with CF in this study had problems keeping up with their homework. Even though all CF Centres have special facilities for school, children with CF in our study could not find enough time or freedom from distraction to keep up with their schoolwork. Relatively little research has been carried out into the impact of admission on school and school performance. Further research is warranted.

Before the paper concludes with some implications for policy, it reflects on the limitations of the study. A small amount of respondents has been admitted to different CF centres in the past and this may have influenced the findings. Comparison of admission over lifetime and between centres may have positive and negative effects. It may have provided the evaluations of participants with more depth and nuance, yet, we do need to reckon with projection of former experiences on the current admission. Next, the study consisted of a relatively small sample of respondents. Despite this, the study

gives a clear idea of the major themes that people with CF have to cope with surrounding their hospital admission. As demonstrated, the themes complement and enrich former studies. We would recommend a supplementary quantitative study in order to shed light on what the findings from this study mean for relatively large groups of people with CF. The findings of this study could serve as input for developing a survey or questionnaire.

## Relevance to clinical practice

We conclude with the relevance for the clinical nursing practice. Clinical nurses have an important responsibility in communicating of cross infection procedures. This should be part of routine standard care. In addition, nurses could be advocates of themes like shared responsibility for segregated care. In order to invite patients to help decide about segregation, clinical nurses need to have the necessary communication skills to address uncertainties, explore and set expectations. This implies that a sufficient amount of time should be given to consultation and the exploration of what segregated care *means* for a patient and the impact of it for one's well-being. Furthermore, this relates to the wish of respondents for relationships that accommodate their 'humanity'. Nurses could safeguard the basic needs of patients in order to provide care from basic values like listening, being responsive and sharing responsibilities (Tronto, 1999).

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### Chapter 3

## What cardiovascular patients have to say about psychosocial support

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