

ORIGINAL ARTICLE

Being affiliated to a cystic fibrosis centre is important for parents' everyday life

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Abstract

Aim: Newborn screening represents a paradigm shift in the treatment of children with cystic fibrosis. This study aimed to explore parents' everyday life experiences from the time of diagnosis and in the following months.

Methods: Narrative interviews were conducted at Aarhus University Hospital, Denmark, with parents (mothers = 15 and fathers = 14) of 15 term-born children with a mean age of 2 weeks (range 1–3.5 weeks). Participant observation and field notes were used to complement interview data. The analysis was inspired by Kvale and Brinkmann.

Results: Three themes were identified. First, on diagnosis, a profound difference in parents' experience was observed depending on whether the diagnosis was communicated by a medical doctor from the cystic fibrosis team or by a paediatrician from another hospital. Second, during the initial meetings and subsequent relationships with the cystic fibrosis team, the knowledge and calmness exhibited by the doctors and nurses were very valuable. Third, regarding everyday life after the diagnosis, most parents described experiencing anxiety and concern for their child's future.

Conclusion: The parents' experiences highlighted essential elements that should be implemented to optimise the patient care pathway as they are fundamental to parents' ability to cope with the new living conditions.

KEYWORDS

cystic fibrosis, narrative interviews, newborn screening, parents' experiences, patient care pathway

1 | BACKGROUND

The widespread implementation of newborn screening represents a paradigm shift in the diagnostic pathway for families having a child diagnosed with cystic fibrosis.¹ Early diagnosis is associated with a significantly improved nutritional status, increased lung function, delayed chronic lung infections and increased survival.² Newborn screening is therefore currently in place throughout the developed world.³

For parents, the diagnosis of cystic fibrosis is often completely unexpected. Being told that your child has cystic fibrosis is generally a very traumatic experience, especially if the child appears healthy, causing parents to disbelieve the diagnosis.⁴ Diagnosing cystic fibrosis under the newborn screening programme calls for a strong focus on the patient care pathway. How best to inform and counsel parents about the screening result has been debated on an international level.¹ The patient care pathway is the patient's journey through the healthcare system.⁵ This is a complex process often

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involving several wards and units.⁵ It is important that healthcare professionals follow the same patient care pathway so that the child and parents experience the process as professionally as possible and without any mistakes relating to the process or any information given.⁶ Introduction of newborn screening for cystic fibrosis seems to have focused mostly on the laboratory part and the screening algorithm. Opposite, the process relating to parenteral information seems underestimated.⁷ This may have serious consequences including unnecessary stress and anxiety for the child and the parents.⁷ Insufficient communication may potentially negatively affect parents' experiences.⁸ Thus, this study aimed to explore everyday life experiences of parents whose children had been diagnosed with cystic fibrosis at the time of diagnosis and in the initial months after the diagnosis was made.

2 | DESIGN AND METHODS

A qualitative study design was chosen. Data were collected through interviews⁹ conducted with parents whose children had been diagnosed with cystic fibrosis during the newborn screening process. We aimed to explore parents' experiences. For this purpose, we adopted a narrative interview approach. Narrative interviews obey a qualitative research methodology that studies lived experiences using stories as data.¹⁰ The approach has been used in various settings.¹¹ We used an interview guide with open-ended questions such as 'Would you like to tell about how it started when your child was diagnosed with cystic fibrosis?' and 'How did you experience getting to the hospital at the beginning of the process?'. These questions were meant to elicit parents' stories as accurately as possible.¹² The interviews were supplemented with field observations during three families' initial consultations at the Centre for Cystic Fibrosis. The observations focused on consultation structure, communication, how a relationship between the parents and the healthcare professional was created, and parents' reactions as observed throughout the consultation.

2.1 | Study settings and participants

The study was conducted in an outpatient clinic at the Paediatric Centre for Cystic Fibrosis at Aarhus University Hospital, Denmark. Parents whose children had been diagnosed with cystic fibrosis in the newborn screening programme from May 2016 to September 2018 were invited. In total, 16 children were diagnosed; one family opted out and another had twins with cystic fibrosis, leaving 14 interviews (Table 1). Participants were recruited by nurses from the Centre for Cystic Fibrosis. The interviews and field observations were conducted by a trained researcher who did not form part of the multidisciplinary cystic fibrosis team. The interviews were conducted during one of the scheduled consultations at the Centre for Cystic Fibrosis. The parents were encouraged to bring a relative to care for the child during the interview. This allowed parents to focus on expressing their

Key Notes

- Having a child diagnosed with cystic fibrosis is generally a very traumatic experience for parents.
- Information about a possible cystic fibrosis diagnosis must always be delivered by a cystic fibrosis doctor, and parents should receive the diagnosis together.
- The patient care pathway is essential for parents' ability to cope with this serious situation, and their experiences are valuable in the development of patient care pathways.

TABLE 1 Characteristics of participants

Characteristics	N = 15
Gender:	
• Female	9
• Male	6
Age at receiving the screening result:	
• 1 week	3
• 1–2 weeks	8
• 2–3 weeks	3
• 3–4 weeks	1
Received the screening result:	
• At home by a phone call	12
• At another hospital by a paediatrician	3
Went to the 1. consultation at the cystic fibrosis centre:	
• The same day as the phone call	3
• The day after the phone call	10
• Several days after because the child was hospitalised at another hospital	2
At the 1. consultation at the cystic fibrosis centre:	
• Meet the same cystic fibrosis doctor as spoken with in the phone	13
• Meet another cystic fibrosis doctor than spoken with in the phone	2
Cystic fibrosis symptoms when receiving the screening result:	
• Gastrointestinal symptoms; diarrhoea, losing weight, seeming hungry all the time	12
• Seems uncomfortable	1
• No symptoms	2

experiences. Except for one family, both parents ($n = 29$), 15 mothers and 14 fathers, attended the interview. All children were term born with a mean age of 2 weeks ranging from 1 to 3.5 weeks. For 8 couples, it was their first child; for 3 couples, it was their second child; and for 4 couples, it was their third child. After having conducted 14 interviews, the research group agreed that data saturation had been obtained. Adequate variations and sufficient data had been collected

to answer the research question. Furthermore, sufficient in-depth data had been collected to reveal the patterns, categories and variety of the phenomenon under investigation.¹³ The interviews were conducted from March to July 2019 and lasted 45–90 min.

2.2 | Data analysis

The data material was analysed according to the three levels of analysis proposed by Brinkmann and Kvale.⁹ First, the interviews were transcribed and read repeatedly. In the second step, the authors reread the transcripts. During this rereading, they focused on the content of the meaning units, and their interpretations were discussed to achieve a common-sense understanding by searching for patterns and variations in the parents' experiences. The first and second steps were integrated into the *Results* section. The third step consisted of forming a theoretical understanding. In this part of the analysis, relevant theoretical perspectives were included. This level is presented in *Discussion*⁹ (see [Figure 1](#)).

2.3 | Ethical considerations

The ethical principles in the Declaration of Helsinki were followed.¹⁴ Before conducting the study, parents were informed that their participation was voluntary and that they could withdraw from the study at any time without any consequences. Both verbal and written informed consent were obtained, and parents were given time to consider their participation. According to Danish law, this type of research requires no approval from an official research ethics committee (J. no. 221). Data were handled according to the European General Data Protection Regulation.

[Figure 2](#)

3 | RESULTS

The analysis revealed the following three main themes: *receiving the diagnosis; the first meeting in the CF centre; and the new everyday life and the future*. Each theme is described further below.

Theme	Self-understanding <i>The researcher tries to formulate what the participant seems to perceive as the meaning of his own statement</i>	Common-sense understanding <i>The meaning may be a broader frame of understanding leading to a critical view about what has been told regarding the content</i>	Theoretical understanding <i>A theoretical framework is used when interpreting statements</i>
Receiving the diagnosis "I am sitting there alone and I do not know shit and I am told that they know nothing about the disease so they cannot tell me anything about it and we must not google. Already there I think, will she die now, what happens"?	I'm alone and understand nothing and am told that they cannot tell me anything and that we must not google. I think, she dies, what happens	How parents are informed about their child's diagnosis is of great importance for their ability to cope with the situation. Information about a child's serious diagnosis should be given to both parents and requires professional patient continuity of care with specialists who can provide comprehensive information	Receiving neonatal screening results from a healthcare professional who is not a CF specialist and therefore unable to answer the parents' questions about the disease has been shown as having undesirable consequences ¹⁸
The first meeting in the CF centre "It was a special feeling that we drove down here with the idea that our whole world had broken down and it was all death and misery - and then we drove home and thought completely differently".	We drove to the hospital and had it like our whole world had broken down, everything was dead and devastated and when we drove home, we just thought completely differently. It was a special feeling.	After receiving the screening result at phone, parents must be offered a consultation at the CF centre in a short time to carry on an adequate information about the possible diagnosis by CF specialists	A patient care pathway that ensures specialist care is helpful for the family's ability to cope with the situation ^{16,19}
The new everyday life and the future "Even though we can see that the staff is very busy, we have the experience that there is all the time for us that we need."	Although the staff is very busy, we find that they have all the time we need	Parents experience that they get all their needs covered in the consultation	Healthcare professionals' attitude and ability to adapt to parents' needs are essential. ^{20,25}

FIGURE 1 Example illustrating the analysis process with self-understanding, common-sense understanding and theoretical understanding

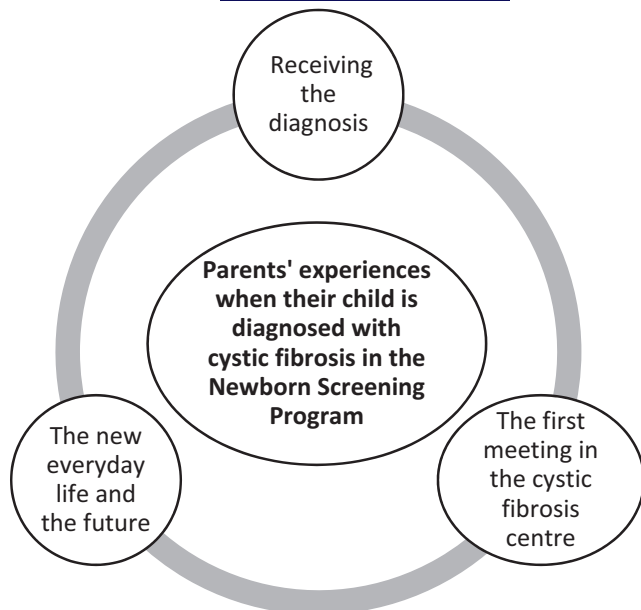


FIGURE 2 Three themes illustrating the parents' experiences when their child is diagnosed with cystic fibrosis in the newborn screening programme

3.1 | Receiving the diagnosis

When parents received the screening result, their child was 1–3.5 weeks old. The parents of 10 newborn infants received the screening result by telephone at their home. Two parents received the phone call at work. The parents of three newborn infants received the result while at another hospital where their child was hospitalised. A clear difference in the parents' experiences was observed depending on whether the diagnosis was communicated by a physician from the cystic fibrosis team or by a paediatrician from another hospital. All parents expressed how their world changed at that moment. Although most parents were unaware of the disease, they understood its severity. Some of the parents assumed that the issue would be serious because they were given an appointment on the day of or 1 day after they had received their screening result. Others expected that the issue would be serious because they were given an appointment at a hospital located far from their home. A father explained this as follows:

I also thought that it must be very severe since we have to go all the way to Aarhus and that they cannot see us at the hospital near us. (Father 8)

During the first phone call, the parents were given brief information regarding the neonatal screening results, including the possible diagnosis of cystic fibrosis. Where possible, this was then followed up by a second phone call after a short period of time to ensure that both parents had received the information. Two fathers who received the message while being alone at work expressed the trouble and pain they experienced when they had to inform their wives about their children's possible diagnosis. As one of the fathers described:

I had to cry it out for myself beforehand.

(Father 1)

Most parents were also given the doctors' mobile numbers. Several parents called the doctor later in the day. They described this as absolutely crucial in helping them deal with the troubling message that their child probably had cystic fibrosis.

Prior to receiving the national screening results, none of the parents had any concerns for their child. Only two parents had heard of cystic fibrosis before. All parents were told not to refer immediately to online cystic fibrosis sources, because most of the information available, especially about treatments, was outdated. However, this did not stop them from researching online, and all mentioned having read about the average 42 years lifespan of patients with cystic fibrosis and having experienced this as a terrible piece of information. The families admitted to another hospital explained that it had been an extremely painful experience for them to receive their screening result. According to the affected parents, the information they received about the significance of their result was limited. This was a very frustrating experience. One mother expressed this as follows:

I am sitting there alone and I know nothing, and I was told that they also know nothing about the disease, so they cannot tell me anything about it and we must not Google. Now I'm thinking, will she die now? What happens?

(Mother 2).

3.2 | The first meeting in the centre for cystic fibrosis

All families except one met with the doctor they had spoken to on the phone. Three families visited the hospital the same day and ten families on the following day. Retrospectively, most believed this was an appropriate timescale and that it gave them some time to start coming to terms with the information and make practical arrangements such as taking care of siblings. All families were asked if staying in the hospital for a few days would be helpful. One family agreed and stayed in the hospital's family house. The field observations revealed that the parents who had spoken with the doctor on the phone had already developed some relationship because of the severity of the conversation. A nurse specialised in cystic fibrosis also participated in the consultations and in conversations with parents. Both the doctor and the nurse adopted a structured approach to helping the parents take in all the information they provided. This included repetition of the phone call where the screening algorithm and genetic context were explained to the family. The use of visual artefacts and long breaks in the dialogue with the parents were also key elements in the structured approach. In the field observation, it was observed that parents asked if an error might have occurred. The doctor would then show them the test results on the computer, which allowed

them to see the civil registration number. This helped them accept that a diagnosis of cystic fibrosis was a possibility. All but three children had symptoms of cystic fibrosis, which was described as an essential issue in the process of accepting the diagnosis. One mother explained it as follows:

When we got him on the scales and he still had not put on weight, I thought, okay, something is happening here and began to realise that maybe what they are telling us is true.

(Mother 13)

The consultations lasted approximately 2h and were very intense in terms of dialogue and information shared, but at the same time characterised by tenderness and caring for the family. The knowledge and calmness displayed by the doctors and nurses were of utmost importance to parents. Most families said that they did not want their children to be admitted to the hospital at their first consultation in the Centre for Cystic Fibrosis when they were informed about the illness. Retrospectively, most believed that they made the right decision. This was exemplified by a couple where one father was in full agreement when his wife said:

We were exhausted that we had to drive so much, but we were happy to be home. We would rather be at home.

(Mother 3)

Two families believed that it would have been helpful for them to be admitted to the hospital because they were in shock and needed to cope with a large amount of information. Overall, most parents expressed some signs of relief after the first consultation because they felt well informed and perceived that the Cystic Fibrosis Team had the situation under control. This made them feel hopeful about the future. A father expressed this with a sigh of relief:

It was a special feeling that we drove down here with the idea that our whole world had broken down and it was all death and misery, and then we drove back home and thought completely differently.

(Father 7)

3.3 | The new everyday life and the future

After the first consultation at the Centre for Cystic Fibrosis and while the diagnosis was being verified, the families had multiple consultations depending on their child's condition. These consultations were held approximately 2–3 times a week for the first few weeks and then at longer intervals. Parents received the necessary education regarding treatment and care at the Centre for Cystic Fibrosis. The child needed to visit the Centre for Cystic Fibrosis every 4 weeks

from that point onwards. If the child was unwell, more frequent visits were scheduled. At the first consultations, the families were introduced to the multidisciplinary team. Most parents described experiencing anxiety and concern for their child's future. Their thoughts ranged from seeing the child as healthy and having some challenges to wishing that their child had never been born. As one mother expressed while crying:

I must honestly admit that I would wish she had died at birth, but this is because of all the procedures she has to undergo.

(Mother 5)

The parents also experienced many challenges in their everyday lives after the diagnosis. One of these challenges was rooted in a lack of understanding from their environment, that is family and friends, employers and the public system. A father perceived it as follows:

It is a kind of a challenge when it is a hidden disease... just to use hand sanitizer...even my mother, she forgets it sometimes as she has a healthy grandchild at same age.

(Father 8)

The parents described cystic fibrosis as a hidden disease because their child would seem relatively unaffected by cystic fibrosis despite many hours of daily treatment. This made it difficult for their surroundings to understand the severity of the disease. This caused parents immense pain and made them feel lonely because no-one understood the severity of their situation. This lack of understanding of their child's disease prompted most parents' fundamental fear of losing their child. A mother explained this expressing despair:

I started rejecting him a little because I was afraid of getting too close to him shortly after which he might die.

(Mother 4)

All parents highlighted the importance of being affiliated with the Centre for Cystic Fibrosis, particularly the cystic fibrosis specialists. This gave them a great sense of security and spurred them on to drive for several hours to the centre when needed. The staff's calmness, care and unique insight into the significance of the disease for families' everyday life were pivotal in this process.

The strong relationship between parents and permanent staff helped produce a necessary focus on caring for the children and was essential to parents. The parents who received the screening result from healthcare professionals who were not specialists in cystic fibrosis experienced long-lasting emotional consequences. The parents' experiences were highly influenced by the way they were informed about the diagnosis and less so by their child's conditions

and the fact that he or she was admitted to hospital. A despairing mother noted as follows:

I have dealt with the fact that she is sick, but the way it was told, I cannot get over it.

(Mother 2).

Finally, their opportunity to connect with the Centre for Cystic Fibrosis anytime was crucial. Several parents spontaneously described their experiences with the staff who had time to answer their questions and talk about everyday life, thoughts and feelings. As one father expressed:

No matter what we have needed to talk about, they have taken the time; either the doctor or the nurse.

(Father 11)

4 | DISCUSSION

The findings of this study underpinned the impact that the diagnosis had on parents and revealed that the patient care pathway was essential to their ability to cope with the diagnosis. Furthermore, the interviews showed how strong their memories were of that first telephone call informing them about the diagnosis of cystic fibrosis. These findings confirm those of previous studies^{15,16} where all participating parents recalled particular experiences regarding the diagnosis, including the information given, the doctor's attitude and their own thoughts and emotions, as well as the realisation that their life had now changed. The study by Jedlicka-Köhler¹² was conducted before newborn screening for cystic fibrosis was possible. Previously, children with cystic fibrosis were diagnosed by symptom presentation and the most typical pre-cystic fibrosis diagnoses were asthma and pneumonia.¹⁷ However, the parents' experiences when receiving the diagnosis in many ways seem similar to those reported in the present study despite the fact that the treatment and prognosis are totally different today. This emphasises the importance of conducting telephone conversations and first meetings with the highest level of professionalism as this appears to significantly affect parents' coping abilities. It is therefore evident that the initial phone call must be handled by a specialist in cystic fibrosis.

A severe childhood disease arouses strong emotions. These emotions include anxiety, shock, grief and feeling out of control, and the manner in which a diagnosis is given influences these emotions.¹⁶ Hence, this factor should be seriously considered. In the present study, the cystic fibrosis doctor attempted to provide information about the possible cystic fibrosis diagnosis simultaneously to both parents. This was done by offering a second phone call. At the first phone call, the diagnosis was given to one parent only. However, the interview shows that occasionally the other parent was also present. This calls for reflection and underscores that the cystic fibrosis

specialist should initially ask whether the other parent is present and advise the parent to turn on the speaker on the phone. Moreover, parents were allowed to contact the doctors in order to ensure that they were not left alone with the news of the diagnosis. In line with results from our study, Chudleigh et al.¹⁸ showed distress in both parents when only one parent received the possible diagnosis, and the parents therefore could not support each other.¹⁸ As part of the patient care pathway, parents should be allowed to support each other in the best possible manner; therefore, ensuring that both parents receive the screening result together appears to be the optimal method.

Receiving neonatal screening results from a healthcare professional who is not a cystic fibrosis specialist has been shown to have undesirable consequences. This is so because non-specialised staff lack the necessary knowledge to answer the parents' questions about the disease.¹⁸ Our findings supported the importance that the initial call was made by a cystic fibrosis specialist. This may impact the parent's future relationships with healthcare professionals.¹⁸

Another critical issue concerns the period from the first phone call to the result of the confirmatory test. This period was extremely stressful and characterised by uncertainty for parents, an uncertainty that should be minimised.¹⁸ Our findings highlighted that it is essential that the phone call is made only if the family may be offered an appointment at the Centre for Cystic Fibrosis within the following days. This observation is in line with the findings of Rueegg et al.¹⁹ In the present study, the participants expressed how the cystic fibrosis teams gave them '*all the time we need*'. This is essential in supporting parents who have had a child diagnosed with cystic fibrosis because cystic fibrosis is a rare disease about which only a few healthcare professionals have sufficient knowledge and ability to support the family in the initial phase. Dialogue is the focal point of the relationship between parents and healthcare professionals. Dialogue should therefore be set within a framework of healthcare workers to build a foundation for future collaboration, as argued by Kitson et al.²⁰ Therefore, the first meeting is extremely important as it underpins the need for a professional, well-designed patient care pathway. A consistent statement in the present study referenced the doctors' and nurses' considerable knowledge and calmness, which meant a great deal to the parents. This is in line with conclusions reported by other studies, underscoring that families should be referred and receive information about the diagnosis by cystic fibrosis specialists.^{7,18,21}

Parents receive a considerable amount of treatment information, such as the potential requirement for nutritional enzymes. Research shows that parents who were informed of the cystic fibrosis diagnosis often received more information than they could take in.^{15,16} For some families, this is probably a challenge. In our study, most families felt well informed. Furthermore, findings from this study demonstrated the benefit of having a consistent structure for the first consultation, including the conversation and information provided. The use of structure, repetition, use of visual artefacts and long breaks allowing parents to raise questions may explain why

most parents experienced some relief after the first consultation. This structure was maintained during the following consultations.

Our findings support not only that information regarding the possible diagnosis should be given by a cystic fibrosis specialist but also that the patient's care pathway should be planned in close collaboration with a cystic fibrosis centre. Additionally, the screening result should be given to both parents at the same time. Finally, if the child is hospitalised at another hospital, the cystic fibrosis doctor should initiate a virtual consultation with the parents when the diagnosis is given.

4.1 | Strengths and limitations

One of the strengths of this study was that all but one parent of children who had been diagnosed with cystic fibrosis in the study period were included. Only parents from one of the two cystic fibrosis centres in Denmark were included in the study, which may potentially limit the generalisability of the findings. Some cultural circumstances may be relevant to consider, which may limit the generalisability to other countries. However, the result from our study is similar to the findings of other studies,^{22,23} supporting that our results are likely relevant to other countries. To address this limitation, we have presented the transferability of our research and provided rich descriptions in order to allow readers to make transferability judgements themselves.²⁴

5 | CONCLUSION

Our findings illustrated that the initial conversation is important and that the manner in which screening results and their consequences are delivered is fundamental to parents' ability to accept and cope with the diagnosis and come to terms with their new living conditions. These initial steps form the basis for a long relationship with the cystic fibrosis team. The team's considerable knowledge and calmness are of pivotal importance to the parents and their journey of receiving professional treatment. The parents highlighted that being affiliated to a cystic fibrosis centre was very important for their everyday life as parents to a child who had been diagnosed with cystic fibrosis.

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CONFLICT OF INTEREST

None.

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