

Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled

A. H. Graungaard*† and L. Skov‡

*Department of General Practice, Centre of Health and Society, Copenhagen

†Department of Paediatrics, National University Hospital, Copenhagen and

‡Department of Paediatrics, Glostrup University Hospital, Glostrup, Denmark

Accepted for publication 1 May 2006

Abstract

Background Communication with parents who are realizing their child is severely disabled is a difficult task for professionals. Parents are experiencing great emotional stress during the diagnostic process and dissatisfaction with disclosure is widespread. The aim of this study was to investigate parents' reactions when realizing their child's disability, the impact of the diagnosis and parents' ways of coping.

Methods This was a qualitative, longitudinal study, using in-depth interviews with 16 parents of a physically and mentally disabled child who had recently been diagnosed as such. Children's age at inclusion ranged from 1 to 27 months. Half of the children had an unknown diagnosis. Data were analysed using the Grounded Theory method. Results were validated and approved by the interviewed parents.

Results The certainty of the diagnosis was central for parents' experiences. First, the emotional reaction of the parents is highly influenced by the diagnostic process. Second, parents needed possibilities for taking action, and third they found difficulty in coping with an uncertain future. These three themes all related to the meaning that parents ascribed to the stating of a diagnosis. Parents' needs in relation to communication were identified as equality in co-operation with doctors, an empathic professional approach, and the child being seen with possibilities despite his or her disabilities.

Conclusions Parents' process of realization was related to the diagnostic process, and information and communication should be individualized accordingly. Parents wanted to co-operate and they needed possibilities for active coping with their situation.

Keywords

child disability, communication, coping, diagnosis, parent perceptions, qualitative

Correspondence:

Anette Hauskov
Graungaard, MD,
Department of General
Practice, Centre of Health
and Society, 5 Øster
Farimagsgade, Post box
2099, 1014 Copenhagen
K, Denmark
E-mail: a.graungaard@
gpmed.ku.dk

Introduction

Informing and communicating with parents who are realizing their child is severely disabled is a very difficult task, especially in severe or complicated cases. How do modern parents react, what do they need and what circumstances influence the process of information and realization?

For parents, the realization that their newborn child is severely disabled is stressful (Zolnit & Stark 1961; Blacher 1984; Quine & Pahl 1987; Beresford 1994; Case 2001), and it has been found that the initial experiences with health professionals have a major, lasting influence on the parents' ability to cope with their child's condition (Taanila *et al.* 2002; Davies *et al.* 2003).

The communication process between doctors and parents of a disabled child and the satisfaction with the disclosure of the diagnosis have been intensively studied, and it is consistently shown that satisfaction is often low: more than 50% of the mothers are dissatisfied (Quine & Pahl 1987; Sloper & Turner 1993; Quine & Rutter 1994; Pearson *et al.* 1999). Certain factors have been shown to be crucial for parental satisfaction: the time lapse between the suspicion of disability and the diagnosis (Nurse *et al.* 1991; Baird *et al.* 2000), the stating of a certain diagnosis compared with an unknown diagnosis (Quine & Pahl 1986; Quine & Rutter 1994) and whether the doctor giving the information seems sympathetic and understanding in the approach (Quine & Rutter 1994; Davies *et al.* 2003). Generally, parents of a child with Down's syndrome tend to be more satisfied with the disclosure than parents of children with other diagnoses (Quine & Pahl 1986; Quine & Rutter 1994).

To promote higher levels of satisfaction, guidelines have been proposed to facilitate the communicative process (Wolraich 1982; Cunningham *et al.* 1984; Cottrell & Summers 1990; Baird *et al.* 2000); however, as satisfaction is still low, these guidelines may not have been implemented in daily clinical practice (Hedov *et al.* 2002). Parental satisfaction does seem to have increased during the last 20 years (Sloper & Turner 1993; Pearson *et al.* 1999) but although doctors' communicative skills may have increased, many parents still experience a long and exhausting diagnostic process because in 30–50% of children with mental retardation, it is not possible to state a certain diagnosis (Schaefer & Bodensteiner 1992; Curry *et al.* 1997; Hodgson 1998; Daily *et al.* 2000). Baird and colleagues (2000) stated that dissatisfaction with disclosure was related to greater degrees of later self-reported parental depression.

Furthermore, Wharton and colleagues (1996) found that parents who thought the physicians did not understand their needs often also thought that the physicians did not understand their child's needs, and Bradford (1991) found that staff underestimated parents' emotional distress and need for information during admission of their chronically ill child. It has, however, been shown possible to improve parental satisfaction considerably by applying specifically designed procedures and support during the diagnostic process. Dissatisfaction with disclosure of diagnosis is not inevitable as stated by Cunningham and colleagues (1984), even when the diagnosis is unclear (Cottrell & Summers 1990).

Parental reactions are well described in many studies, but mostly in a retrospective design; however, this study was performed while the parents were actually living through the diagnostic process.

The relation between the certainty of the diagnosis, parental experiences and coping strategies is not well described. Is it possible to improve parental satisfaction and hence their ability to cope with their new life situation? What are the parents' overall needs during the diagnostic process and does this relate to the actual cause of the disability? What is the *meaning* of a diagnosis for parents during the process of realization? The concept of meaning is used in the sense of 'perception of significance' as defined by Park and Folkman (1997).

The purpose of this study was to elucidate the experiences of parents of a severely disabled newborn child in relation to the diagnostic process and bringing the results into a coping perspective. We used the definition of coping by Lazarus and Folkman (1984) as 'The constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person'. They describe coping as consisting of two different strategies: problem-focused coping, which is 'coping that is directed at managing or altering the problem causing the distress' and emotion-focused coping, which is 'coping that is directed at regulating the emotional response to the problem'.

Parental coping efforts are discussed in relation to parents' experience of actual clinical practice and clinical implications are considered. This article is part of a qualitative, longitudinal interview study of the use of coping strategies and mobilization of resources among parents of a severely disabled newborn child.

In this study, the term 'severely disabled' is used about an individual with severe physical and mental disabilities.

Methods

Design

Longitudinal interview study of 16 parents (eight couples) of severely disabled children. All parents were interviewed in depth twice. The first interview was aimed to be arranged within 3 months of disclosure of the disability and the second interview 2 years later. The results presented in this article are the conclusion of the analysis of the first set of interviews and the findings were subsequently validated during the second set of interviews.

Data sampling

The participants were recruited in co-operation with the doctors in the neuro-paediatric department, the neonatal ward and

the department of clinical genetics at the National University Hospital Copenhagen, Denmark, after approval from the local ethical committee. Oral and written information was given to all parents. After written consent was received, appointments for the interviews were made.

All parents of 11 suspected severely disabled children were invited to participate. Inclusion criterion was: parents of children with inborn severe mental and physical disabilities that had been recently diagnosed. Exclusion criteria were: parents living apart, parents of foreign origin (because of language difficulties), parents with psychiatric diseases, parents under age and parents of a previous child who was disabled.

Three couples refused to participate: one couple because they had twins and were too busy, one couple because only one of the parents felt stable enough to participate and one couple did not respond to the inquiry. The children's age ranged from 1 to 27 months at time of inclusion, the majority being 1–10 months. The major characteristics of the child and the family are listed in Table 1.

Data collection

AG conducted semi-structured in-depth interviews separately with each parent. An interview guide (Kvale 1996) was used which included the main themes of: parents' perception of the diagnostic process and disclosure, parents' ways of managing practical and emotional demands in the initial phase, parents' perception of their child, parents' perception of the consequences for their future life and parents' ways of mobilizing resources. The first interview was conducted between 1 and 9 (mean 3.5) months after the disability was diagnosed or strongly suspected and the second interview 2 years after the first interview. All parents agreed to participate in both interviews. The parents were interviewed in their homes, except for one couple still in the hospital with their child. The interviews were 1.5–2 h in duration.

All 32 interviews were audiotaped and simultaneously recorded on minidisk. All were transcribed verbatim, in full, by AG or a secretary. All names, places, diagnosis and other identifiable data were changed or presented in an anonymous form.

Table 1. Characteristics of the interview families

Sex of child	Age at interview	Siblings	Diagnosis	Symptoms	Parental education
Male	2 months	First child	Unknown	Severely impaired interaction, severe developmental delay, hypotonia, epileptic seizures. Normal feeding. Died 22 months old	Both parents higher education
Male	4 months	First child	Unknown	Impaired interaction, tube feeding, >100 seizures daily, dystonia	♀: higher education student ♂: further education
Male	8 months	First child	Infantile spasms	Delayed motor- and mental development. Normal feeding. Hypotonia	♀: further education ♂: higher education
Male	10 months	First child	Unknown	Delayed motor- and mental development, relatively strong interaction. Normal feeding	♀: vocational training and higher education student ♂: vocational training
Female	1 month	First child	Lissencephali	Normal feeding in the neonatal period, then tube-feeding, developed severe dystonia, died 10 months old	Both parents higher education
Male	8 months	First child	Lumbar meningo-myelocele	Cerebral shunt, normal interaction, able to sit by himself	♀: higher educational student ♂: higher education
Male	27 months	Sister 5 years old	Wolf-hirschhorn syndrome, diagnosed 18 months old	Delayed motor- and mental development, feeding difficulties. Epilepsy. Hypotonia. Heart disease, operation scheduled	♀: higher education ♂: further education
Female	1 month	Sister 30 months old	Down's syndrome	Normal feeding. Heart disease, operation scheduled	♀: further education ♂: unemployed

All citations have been approved by the parents. AG collected additional data relating to demographic conditions, medical investigations and diagnostic status from the hospital's records of the children.

Data analysis

AG conducted a Grounded Theory (Glaser & Strauss 1967; Strauss & Corbin 1998) analysis on the first set of interviews using the steps of: *open coding* by identifying central themes and concepts, the *axial coding* of identifying properties and dimensions of each central theme and at the same time exploring theoretical codes such as causes, conditions, consequences and processes (Glaser 1978) and the final *selective coding* of finding patterns and relationships between themes, properties and dimensions to form a conceptual theory that contains explanations and predictions of the experiences and behaviour of the population under study. During the second set of interviews, these findings were validated with the parents in order to validate the theory and its applicability in the different diagnostic situations.

Every step of analysis was validated with the full interview material, as all interviews were reread, and recoded several times. Parts of the interviews were co-coded with the supervisor and differences and disagreements were adjusted. All interviewed parents were asked to comment on a written draft of this article, and all were invited to a session with an oral presentation of our findings and asked for feedback. All the results were approved by the parents, who added valuable information, and parents responses were validated with the supervisor who was attending the meeting.

Results

Results are presented in the following order: (1) main finding (core category); (2) main themes with properties; (3) emotional

and cognitive dimensions; (4) coping strategies; (5) content of main themes; (6) parental needs.

Main finding

The main finding is that parents' experiences and coping possibilities when realizing that their newborn child is disabled are strongly influenced by the nature of the diagnostic process and the certainty of the stated diagnosis. This core category is called:

'Diagnosis: searching for certainty' and it refers to the central influence the diagnosis and thereby the diagnostic process had on parents' experiences of both emotional themes such as perception of the future, realization of the child's condition and the perception of the child, as well as on more concrete themes such as the information and communication with doctors, and the experience of hospitalization.

The impact of the diagnosis on parents' experience of their child's condition is illustrated in two citations (see Box 1).

Main themes

Five main themes (listed in Table 2) were identified as being of central importance in parents' experiences and they all related to the core category of diagnostic certainty.

The core category of the searching for certainty was found to relate to and influence all other main themes. The main themes were also interrelated in many different aspects, as appears in the following sections.

Dimensions

The emotional and cognitive contents of the core category were identified and are illustrated below by four dimensional scales. All parents related to these dimensions, but with different strengths and variability (Fig. 1).

Box 1

As the parent, I still have the impression that, I can see he is having some physical seizures, but I can also see something completely different inside him. Something that you can't see when you just enter the room for ten minutes and talk a little to the parents and prescribes some drugs. I have the impression that he will recover, and that sooner or later he will show normal EEGs. This is how I feel, but it might be a kind of hope you hang on to when the case is unclear. (Anton, father of child with an unknown diagnosis)

On the second day, when we got the message, it was actually nice to get certainty, after that awful night, it really helped me a lot, and I think it actually made me feel a little more on top of things. (Claus, father of child with a severe certain diagnosis)

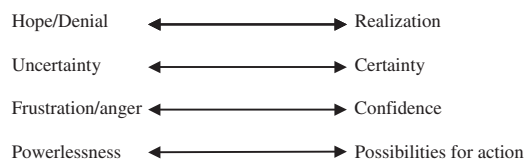
Table 2. Main themes and content

Main theme	Content (properties)
Creating future images	Shattered dreams, uncertain prognosis, creating new future images, emotional strain of uncertainty, gender views of future horizons, next child
Identifying possibilities of action	Powerlessness, collecting information, doing everything possible, alternative medicine, regaining control, retaining hope, training and stimulation
Perceiving the child	Deficits vs. potentials, case or child, diagnosis credibility, recovery possibilities
Communicating with health professionals	Satisfaction, setting, timing, level of information, communication style, co-operation, gender, hope conflicting with information
Implicit expectations of the healthcare system	Diagnosis and cure, fight for the child, physical and structural conditions, human errors

Box 2

... and then a couple of weeks passed where we were in the paediatric ward and nothing happened really. Tests were done, and the situation was put on hold. He was having daily seizures and we did not feel that anything was happening at all. (Anton, father of a child with an unknown diagnosis)

Well, people are different and ... some of them you communicate better with, than others. The first doctor we met we felt very confident with, and we felt that he made his message clear and that he did it as well as he could. (Carla, mother, about the doctor disclosing a very severe diagnosis)

**Figure 1.** Emotional and cognitive dimensions.

Parents of a child with an unknown diagnosis typically fluctuated much more between the poles of all scales than parents of children with a certain diagnosis such as Down's syndrome, or microcephalia.

These fluctuations strongly influenced parents' satisfaction with information, their process of realization and their coping efforts during the diagnostic process. It is also noteworthy that the father and the mother of a child were not always at the same point on the emotional scale at the same time, which also complicated communication.

Citations illustrating the frustration-confidence scale (see Box 2).

Coping strategies

Many different coping strategies were identified in this study.

We found problem-focused coping strategies such as collecting information, learning new skills, controlling the

health professionals' actions and decisions, investigating alternative medicine and training possibilities, and seeking second opinion.

Emotional coping strategies were identified as: retaining hope, creating future images, ignoring the seriousness of the condition, seeking social support, concentrating on possibilities in the child, evaluating beliefs and identifying positive aspects.

These strategies appear in the following results and examples.

Content of main themes*Creating future images*

Parents' realization that their future dreams and expectations would have to change because of their newborn child's disabilities was painful.

I just feel that we have so much to give (crying) and I have always looked forward so much to my life together with my husband. I was so happy, while I was pregnant. I looked forward to life so much, also because I had such a happy childhood, and wanted it to be the same for my children. I just think living is so many wonderful things, and it is so sad if he can't experience the same thing ... (still crying). (Anna, mother of a child with an unknown diagnosis)

The unexpected uncertainty about the future was exhausting for all parents realizing their child was disabled.

The quest for a diagnosis and thereby a prognosis originated mainly in the quest for 'knowing' what the future might bring when the common dreams of normality were shattered.

I need to have some (future) pictures . . . I have been on the Internet, and seen a 12-year-old boy with the same diagnosis, standing up looking happy . . . It is important for me . . . I find the uncertainty hard . . . (Claus, father of a child with a known diagnosis)

The creation of a new future image might be realistic, positive illusionary or even a 'worst case' image. Most parents' altered their view of the future pictures frequently, or even created more than one picture at a time. Sometimes this possible future was so frightening and uncertain that parents preferred to limit their views of it as illustrated in Fig. 2.

I don't want to feel depressed and sad every single day, when we don't know what it is . . . so I prefer to have a good time, and then wait and see, maybe there will be a time when things are not so good, but then I will take it as it comes. (Anna, mother of a child with an unknown diagnosis)

We found a gender difference concerning the length of the visualized future. Fathers tended to need a longer future perspective and a firmer idea of what the future might bring. Mothers were more likely to concentrate their mental energy on caring for the baby, breastfeeding and other normal parenting duties, as well as mentally strengthening the child with their energy. After the initial phase of shock, they could not afford to spend mental energy on fear and despair. This sometimes cre-

ated distance between the parents and also complicated communication with the health professionals.

The question of having more children was of major concern to all parents.

I think if we weren't able to have any more children, it would be a major crisis . . . it means a lot to me, to have a normal child . . . because I think it is a good drug . . . it would strengthen me and thereby my relation to my first child. (Claus, father of a child with a known diagnosis)

This concern also influenced the need for an aetiological diagnosis, in order to predict the risk of the next child being affected.

To many parents, a sibling was imagined to be a source of stimulation for the disabled child, and a way of providing security for the disabled child when the child grew up and the parents eventually died.

Identifying possibilities for action

When realizing that the newborn child was severely disabled and initially also often suffering from life-threatening conditions such as seizures or respiratory problems, parents experienced a strong feeling of powerlessness, and an overwhelming uncertainty of what life would bring. The feeling of powerlessness forced the parents to try to act, to try to do something, anything, not just to sit and watch (Box 3).

The parents' desperate search for a diagnosis was often triggered by the hope that if they received a diagnosis, they might be able to do something for their child.

We hoped that if they managed to find out what it is, then it would be possible to do something for him, I believe, we wanted to do something for him – what could we do? (Frans, father of a child with a very late diagnosis)

Often the need to act was described as a way of not giving up hope, and necessary for the parents to hang on to in their present emotional condition.

If hope disappeared, you might as well close the world. (Bo, father of a child with an unknown diagnosis)

It was of major importance to the parents to know within themselves that everything possible had been done for their child, inside and outside the formalized health system. They felt responsible for securing this by checking up on the doctors,

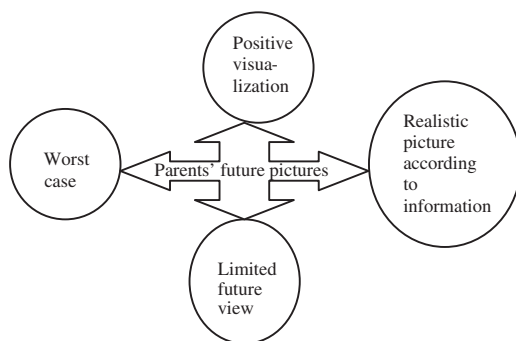


Figure 2. Parents' future images.

Box 3

It (the seizures) hurt us as much as it did him . . . It has been terrible to watch . . . you get frustrated because you can't do anything, and you can't help him in any way, you feel totally powerless . . . totally powerless as a parent. (Anton, father of a child with an unknown diagnosis)

I feel calmer inside, because I know that we tried that also . . . and you know somehow I got the feeling that we have to try everything possible, everything that can be done . . . it feels worse just to sit and be unhappy . . . I can't do that, I have to do something because otherwise . . . (Beate, mother of a child with an unknown diagnosis)

asking for second opinions, reading scientific literature, seeking alternative treatment methods such as healing, Chinese medicine and the Doman training method:

Now science has had its chance to figure out what is the matter with our son and they are treating his seizures . . . but it isn't enough for me . . . now they have given up a little at the hospital, so now we try to go somewhere else, to see what they can do. (Anton, father of a child with an unknown diagnosis, visiting healers)

The use of alternative medicine was often not disclosed by the parents so as not to offend their physician.

The parents' fear of the possibility of realizing in the future that they had failed their child and that they had not done their best also added to their need to act:

The worst case is if you don't . . . if you in some years ask yourself 'why didn't we try this or that' we won't take that risk . . . so everything needs to be tried. (Bo, father of a child with an unknown diagnosis)

When it became obvious that the child was disabled and a cure was not available, all parents in the study engaged in considering what else could be done for their child. Stimulation and exercising with the child was a matter of great concern. This was where most parents experienced a possibility to do something for their child. The parents felt uncertain whether the training offered by the healthcare system and social system was enough and often felt a lack of support in their own efforts to stimulate their child.

After we started to exercise him ourselves, and he has progressed, then it is like getting back into life . . . we are in a completely different process now. We are able to do something for him, we can see it helps. He has become

happy and it is opening something up . . . (Frida, mother of a child with a certain diagnosis)

Perceiving the child

Most parents indicated a troubling difference between themselves and the doctors in the perception of the child. Parents often focused on their child's possibilities where doctors described the child in terms of disabilities. Parents experienced this as a misinterpretation of their child, and that their child was treated more as a case than an individual. This complicated the communication between doctors and parents of children with both certain and uncertain diagnoses as illustrated in Table 3.

The parents saw the child as an individual with possibilities and not an individual with only disabilities, but in the medical terms used by doctors a disabled child's condition was described by symptoms, often by its lack of abilities and this is also the case in medical literature, which parents often read.

It is nice when somebody who just meets her, and thinks she is just fantastic, and that she can actually do several things . . . That they see her as a child with potentials. Because right from the start she was looked on as very ill by the doctors, when they did their daily rounds and looked at her . . . And that's strange because she looks quite normal, except for a very small head. (Carla, mother of a child with a severe known diagnosis)

The parents' perception of the child was influenced by the diagnosis. With a certain diagnosis, the parents were better able to perceive the child as disabled.

When there was no diagnosis, the perception of the child was more changeable, often dominated by 'but he looks so normal' and 'positive visualizations' about the future. Most parents did not have a medical background, and found it very difficult to

Table 3. Perceptions of the child

	Doctors' perception of the child	Parents' perception of the child
Child with a diagnosis	Doctors inform of which disabilities will be or might be the consequence of a certain illness or syndrome The child's diagnosis is described by its lack of abilities. Deficits = areas of concern	Parents realize that their child is disabled, but they are aware of its potentials Potentials = areas of concern
Child without a diagnosis	Doctors try to define the child's condition because of lack of abilities which is seen as a symptom Basic perception of the child is based on disabilities	Parents want to see potentials. They realize disabilities gradually. Basic perception of the child is based on possibilities

accept that the finding of several concurrent symptoms indicated a permanent, disabling condition.

Yes, that is the way I see him. I don't see him as a sick little one, sitting in a wheelchair, and not able to do anything by himself. I see him as a little boy, running around, happy and well. (Bo, father of a child with severe disabilities but unknown diagnosis)

Communication with health professionals

The parental satisfaction with the diagnostic process was strongly related to the certainty of the diagnosis and to the duration of the diagnostic process.

In a few cases, the disclosure of the diagnosis was experienced as a single specific occasion. However, most often disclosure consisted of a series of tests, appointments with doctors, results of the tests and then more tests, where the diagnosis or presumed diagnosis of the child was discussed with the parents several times. This is what we have termed 'the diagnostic process'.

In this period of uncertainty, hope, despair and different statements from different experts, information is of utmost importance to parents, who often ended up very frustrated and mistrusting the health professionals.

... for a very, very long time they suspected that he had a mitochondrial disease, but it turned out that he didn't, ... But with mitochondrial diseases things almost always go downhill quickly, so for two months we were convinced that we had a child who was dying. (Frida, mother of a child with a very late diagnosis)

The experience of and satisfaction with the diagnostic process also depended on the setting of the information, the timing of the information and the level of information related to the parents' readiness for information.

My husband wasn't there at the time (when I got the message), he had spoken to the doctor while I was in the bathroom ... it was all so confusing at the time, but what I found terrible was, I would have thought that if I was going to have such a message, I would have had a private room to get the message in, and that there would have been enough time, I remember his (the doctor's) mobile phone ringing, so he didn't have time to finish, so we only got half messages all the time, and then there was another patient in the room, and a child crying, and nurses coming in. It was quite difficult to show feelings when others were around ... (Elise, mother of a child with a preliminary diagnosis)

There were two dominant parental expectations related to communication and information: empathy and equality in co-operation. Parents expected that the health professionals engaged in their situation with the ability to feel the impact their words were having on the family's life, and to let it show.

When this was the case, parents were satisfied with the information and the way it was given, even when the diagnosis was serious.

The doctor came to examine her, and he examined from head to toe, and he did it in a very nice way, I think he communicated really well ... And then he finished with an ultrasound scan, and I asked him if he would assume that she would not develop normally, and he answered 'yes'. (Claus, father of a child with a certain diagnosis)

Parents also expected to be co-operating partners with the doctors, as their active participation in the diagnostic process was an important acting possibility. They felt a main responsibility for the treatment of their child, and wanted to be acknowledged as the experts on their specific child. When this

expectation was not reciprocated by the doctors, it was a source of many parental frustrations.

But it would be easier if we had cooperation with the professionals, instead of this fight to get their attention . . . to try to break through the shell of professionalism. It is like: I am the expert and you are the ones who don't know anything . . . (Bo, father of a child with an unknown diagnosis)

The gender of the parent seemed to influence the way information was received and the level and type of information required. Fathers (or men) tended to need more intellectual possibilities for understanding and coping with the situation, asking especially for written and scientific information, while mothers (or women) could not integrate this type of information in the initial phases.

And then I persuaded her (the nurse) to photocopy an article from some medical journal that described this disability, and I read it. It wasn't very funny reading, but it helped a lot, to know what kind of game we are in here . . . and I could see that this article wasn't something that my wife would like to read in any way. (Dan, father of a child with known diagnosis)

A difficult aspect in the counselling process was that the parents' need to retain hope often conflicted with the paradigm among doctors of providing enough information to secure that the parents were fully informed and realized their situation. Often parents doubted the doctors' words or skill, especially in difficult diagnostic processes where realization might be a very prolonged process.

As the situation is now, it is very reassuring, because we can't really see any difference from him and any other 10-week-old baby. The difference might get bigger in time, but this gives us time to slowly get used to the situation, and I think that's quite healthy . . . (Anton, father of a child with an unknown diagnosis but with severe symptoms)

Implicit expectations of the healthcare system

When their child developed symptoms, most parents expected the doctors to be able to find a cause and a treatment. These were some of the implicit and often unconscious expectations that most parents had, and the lack of fulfilment of these expecta-

tations led to serious frustration and distrust, and the feeling of powerlessness increased.

And then we did everything we could to try to get the doctors to figure it out . . . Because pretty quickly we thought they were such amateurs, because it was completely random, what they were testing for. Different doctors were doing their rounds and then they thought: wonder what this may be? We wanted them to find out what was the matter with him . . . And I remember it as two months of pushing them: come on and find out for Christ's sake . . . (Frans, Father of a child with a much-delayed diagnosis)

A difficult diagnostic process was often experienced as a 'fight for the child', a fight for the doctors to do the investigations quickly, and to retain the doctors' interest in that specific child.

When parents' expectations of the diagnostic process and the physical conditions related to hospital admission were met, they were sometimes satisfied, even though the stated diagnosis was serious.

It was really good (being admitted to the hospital), first of all it was very nice that we had a private room, and my husband could stay with me . . . and it was a good process where we slowly found our own feet again, and recovered from the first shock until we got a new daily routine in the hospital and became able to take care of everything ourselves. (Carla, mother of a child with a known diagnosis)

Most parents, who were admitted to the hospital with their child for a long period in relation to a difficult diagnostic process, experienced human- and system-related errors, for example: lack of communication, uninformed doctors and nurses, medication errors and lack of sufficient observation of their child. This added to the feeling of uncertainty and powerlessness connected with the lack of a certain diagnosis, and distrust was often expressed as a consequence of even minor incidents. Parents often expressed uncertainty whether the staff was able to care adequately for their child, and they felt they had to do it themselves all the time (see Box 4).

Parental needs

Parents expressed needs that were related to practical arrangements, emotional relations, and content of information and communication as listed in Box 5.

Box 4

It was our frustration with it all I think, it was also frustration with our own situation, and it was maybe stupid to blame it on the staff, but actually I think there was a really good reason for that, and I also think it helped, because before that, blood samples had been lost because the nurse had forgotten to label them, and I simply can't have that. (Anna, mother of a child with an unknown diagnosis)

Box 5

Parents' wishes and needs in communication

- equality in co-operation between parents and physicians
- an individual and specifically designed information strategy
- an empathic and personal approach
- treatment of the child as a child not a case
- consideration of the child's possibilities despite its disabilities

Discussion

We identified three different major causes of the importance of diagnostic certainty. The first is that the emotional reaction of the parents is highly influenced by the diagnostic process. Second is the necessity of a possibility of doing something for the child, and third is the difficulty of coping with an uncertain future, which is mediated by creating new future images. These three major causes all refer to the meaning that parents ascribe to the stating of a diagnosis.

The parents' use of coping strategies was found in our study to be strongly related to the diagnostic certainty, which is consistent with other findings. Taanila and colleagues (2002) found that in families defined as low-coping families all children were diagnosed very late, but in high-coping families obvious aetiology was found in most of the children. It is important to note that both kinds of coping strategy are most often applied concurrently or in the same situation (Lazarus & Folkman 1984) and that coping is not necessarily a conscious process, despite the word 'strategy' being used. In addition, it is not always possible to reduce stress in circumstances such as those in our study; consequently, the word 'effort' might be more appropriate in this situation. It is shown that active coping strategies are important to the well-being of parents caring for a disabled child (Beresford 1994; Starke & Moller 2002; Taanila *et al.* 2002). It is a dominant finding throughout our data that the emotional stress of having a child with disabilities was greatly reduced if the parents found a way to do something for the child. When there was a diagnostic uncertainty, it was often difficult for the parents to find an acting possibility and consequently what they could do was to try to facilitate the diagnostic

process. This was done by the parents seeking information, doing their own research and urging doctors to perform the testing as quickly as possible. Starke and Moller (2002) found that dissatisfied mothers were more likely to seek information than satisfied mothers, and their motives were more often to control the actions of the professionals.

Information-seeking is a widely used problem-focused coping strategy and has consistently been found to have a positive effect as a coping strategy (Beresford 1994; Pain 1999; Taanila *et al.* 2002).

When applying the 'perception of significance' definition of *meaning*, it appears from the results that the meaning parents ascribed to the stating of a diagnosis was related to a search for coping possibilities in order to reduce the immense stress that all parents experienced. The importance and consequences that parents ascribed to the stating of a diagnosis was not always realistic in a medical sense. It contained parents' subconscious expectations that if the doctors identified the diagnosis, it would mean some restoration of basic human needs as future predictability and a possibility to personally influence and control the situation.

Although communication between parents and health professionals has been extensively discussed over several decades (Wolraich 1982; Pearson *et al.* 1999), there is still evidence of central problems as experienced by the parents, and it is also likely that parents are becoming increasingly informed and insisting on an extensive involvement in their child's condition (Case 2001).

The parents' needs for communication as shown in our results are consistent with other findings that parents prefer a proactive and individualized service provision (McConachie

Box 6

Situation-related

- Consideration of what kind of process the parents are going through, in relation to the diagnostic certainty
- Planning of information strategy from the first evidence of disability
- Thorough consideration of timing, setting and level of information
- Consideration of the parents' actual state of realization
- Reflection on parents' coping efforts and how to support positive coping strategies
- Focus on the child's abilities, and not only on its disabilities

System-related

- Implication of information and communication guidelines for different diagnostic situations
- Evaluation of the clinical implication by feedback from parents
- Supervision and evaluation of the involved health professionals

1994; Case 2001), and these needs match recommendations for good practice on disclosure of the diagnosis of cerebral palsy (Baird *et al.* 2000), but as Cottrell and Summers (1990) stated 'It cannot be stressed enough that breaking bad news is a process which may continue for years rather than a one-off event'. Our findings in this study indicate that the parental process of realization is relating to the course of the diagnostic process and the nature of diagnosis, and consequently this process has to be taken into account in information and communication.

Methodological considerations

By using a qualitative method in investigating this complicated and highly emotional situation, we aimed to give the parents' feelings and words immediate access to data.

The limitations of the study were due to the unbalanced representation of interviewees in terms of educational level, socio-economic status and geographical localization. This was due to the urban localization of the hospital, and, in some cases, to our exclusion criteria. The socio-economic conditions are mentioned in only one study as creating a significant difference in parental satisfaction, showing a higher possibility of dissatisfaction in mothers with a non-manual background (Sloper & Turner 1993). We did not find any differences related to socio-economic background only, in our data.

The exclusion of parents of foreign origin may have a major influence on our results, because many reactions may be culture-based, and would be worthy of a separate study. The validity of the findings was secured by using the Grounded Theory method, which is a method where findings are closely related to data. Furthermore, the coding was validated by the two

authors co-coding some of the interviews. Finally, the findings were validated with the interview persons themselves, who all have had the possibility to comment on the findings.

As the interviews were performed during the process of realization, the risk of recall bias was reduced.

Conclusion

Parents engaged in a wide range of different coping strategies to reduce the stressful feelings, and the use of different coping strategies was influenced by the certainty of the diagnosis. To parents, the stating of a diagnosis had a specific meaning in order to regain predictability and control in life and to provide them with active coping strategies.

The communication between health professionals and parents during the diagnostic process was of great importance, and seemed to influence the way parents coped with their new life with a disabled child. In most cases, there were many points of dissatisfaction and criticism from most parents.

Some proposals for the clinical implications of these findings are listed in Box 6.

Communication and information in this situation is a very difficult task, but improvement will have a substantial potential to increase parental satisfaction and coping abilities, and thereby improve quality of life in families with severely disabled children.

References

- Baird, G., McConachie, H. & Scrutton, D. (2000) Parents perceptions of disclosure of the diagnosis of cerebral palsy. *Archives of Disease in Childhood*, 83, 475–480.

- Beresford, B. A. (1994) Resources and strategies: how parents cope with the care of a disabled child. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 35, 171–209.
- Blacher, J. (1984) Sequential stages of parental adjustment to the birth of a child with handicaps: fact or artefact. *Mental Retardation*, 22, 55–68.
- Bradford, R. (1991) Staff accuracy in predicting the concerns of parents of chronically ill children. *Child: Care, Health and Development*, 17, 39–47.
- Case, S. (2001) Learning to partner to partner, disabling conflict: early indications of an improving relationship between parents and professionals with regard to service provision for children with learning disabilities. *Disability and Society*, 16, 837–854.
- Cottrell, D. J. & Summers, K. (1990) Communicating an evolutionary diagnosis of disability to parents. *Child: Care, Health and Development*, 16, 211–218.
- Cunningham, C. C., Morgan, P. A. & McGucken, R. B. (1984) Down's syndrome: is dissatisfaction with disclosure of diagnosis inevitable? *Developmental Medicine and Child Neurology*, 26, 33–39.
- Curry, J. C., Stevenson, R. E., Aughton, D., Byrne, J., Carey, J. C., Cassidy, S., Cunniff, C., Graham, J. M., Jones, M. C., Kaback, M. M., Moeschler, J., Schaefer, G. B., Schwartz, S., Tarleton, J. & Opitz, J. (1997) Evaluation of mental retardation: recommendations of a consensus conference. *American Journal of Medical Genetics*, 72, 468–477.
- Daily, D. K., Arding, H. H. & Holmes, G. E. (2000) Identification and evaluation of mental retardation. *American Family Physician*, 61, 1059–1067.
- Davies, R., Davis, B. & Sibert, J. (2003) Parents' stories of sensitive and insensitive care by paediatricians in the time leading up to and including diagnostic disclosure of a life-limiting condition in their child. *Child: Care, Health and Development*, 29, 77–83.
- Glaser, B. G. (1978) *Theoretical Sensitivity*. Sociology Press, Mill Valley, CA, USA.
- Glaser, B. G. & Strauss, A. (1967) *The Discovery of Grounded Theory*. Sociology Press, Mill Valley, CA, USA.
- Hedov, G., Wikblad, K. & Annerèn, G. (2002) First information and support provided to parents of children with Down syndrome in Sweden: clinical goals and parental experiences. *Acta Paediatrica*, 91, 1344–1349.
- Hodgson, S. V. (1998) The genetics of learning disabilities. *Developmental Medicine and Child Neurology*, 40, 137–140.
- Kvale, S. (1996) *Interviews. An Introduction to Qualitative Research Writing*. Sage Publications, Thousand Oaks, CA, USA.
- Lazarus, R. S. & Folkman, S. (1984) *Stress, Appraisal and Coping*. Springer Publishing Co., New York, NY, USA.
- McConachie, H. (1994) Implications of a model of stress and coping for services to families of young disabled children. *Child: Care, Health and Development*, 20, 37–46.
- Nurse, A. D., Rohde, J. R. & Farmer, R. D. T. (1991) Ways of telling new parents about their child and his or her mental handicap: a comparison of doctors' and parents' views. *Journal of Mental Deficiency Research*, 35, 48–57.
- Pain, H. (1999) Coping with a child with disabilities from the parents' perspective: the function of information. *Child: Care, Health and Development*, 25, 299–312.
- Park, C. L. & Folkman, S. (1997) Meaning in the context of stress and coping. *Review of General Psychology*, 1, 115–144.
- Pearson, P., Simms, K., Ainsworth, C. & Hill, S. (1999) Disclosing special needs to parents. Have we got it right yet? *Child: Care, Health and Development*, 25, 3–14.
- Quine, L. & Pahl, J. (1986) First diagnosis of severe mental handicap characteristics of unsatisfactory encounters between doctors and parents. *Social Science and Medicine*, 22, 53–62.
- Quine, L. & Pahl, J. (1987) First diagnosis of severe handicap: a study of parental reactions. *Developmental Medical Child Neurology*, 29, 232–242.
- Quine, L. & Rutter, D. R. (1994) First diagnosis of severe mental and physical disability: a study of doctor-parent communication. *Journal of Child Psychology and Psychiatry*, 35, 1273–1287.
- Schaefer, G. B. & Bodensteiner, J. B. (1992) Evaluation of the child with idiopathic mental retardation. *Pediatric Clinics of North America*, 39, 929–943.
- Sloper, P. & Turner, S. (1993) Determinants of parental satisfaction with disclosure of disability. *Developmental Medicine and Child Neurology*, 35, 816–825.
- Starke, M. & Moller, A. (2002) Parents' needs for knowledge concerning the medical diagnosis of their children. *Journal of Child Health Care*, 6, 245–257.
- Strauss, A. & Corbin, J. (1998) *Basics of Qualitative Research*. Sage Publications, Thousand Oaks, CA, USA.
- Taanila, A., Syrjälä, L., Kokkonen, J. & Järvelin, M. R. (2002) Coping of parents with physically and/or intellectually disabled children. *Child: Care, Health and Development*, 28, 73–86.
- Wharton, R. H., Levine, K. R., Buka, S. & Emanuel, L. (1996) Advance care planning for children with special health care needs: a survey of parental attitudes. *Pediatrics*, 97, 682–687.
- Wolraich, M. L. (1982) Communication between physicians and parents of handicapped children. *Exceptional Children*, 48, 324–329.
- Zolnit, A. J. & Stark, M. H. (1961) Mourning and the birth of a defective child. *Psychoanalytic Study of the Child*, 16, 523–537.