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"A qualitative study detailing experiences and needs of support of parents caring for an infant with visual impairment or blindness around the time of diagnosis"

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Title

A qualitative study detailing experiences and needs of support of parents caring for an infant with visual impairment or blindness around the time of diagnosis

Nina Milde (https://orcid.org/0000-0002-5726-4571) (nina.milde@regionh.dk)(linkedin.com/in/nina-milde-08a04a129),[1] Annette Rasmussen,[1] Kamilla Rothe Nissen,[1,2] and Line Kessel (https://orcid.org/0000-0002-9375-1510)[1,2]

[1]Department of Ophthalmology, Copenhagen University Hospital - Rigshospitalet – Glostrup. Copenhagen, Denmark
[2]Department of Clinical Medicine, University of Copenhagen, Copenhagen, Denmark

Corresponding author

Nina Milde
Valdemar Hansens Vej 1-23, Pavillonen, 1. sal
2600 Glostrup
E-mail: nina.milde@regionh.dk
Telephone: +0045 9117 2427
Fax: +0045 3863 4699

Abstract

OBJECTIVE

The whole family is affected when an infant is diagnosed with visual impairment or blindness. We aimed to describe the support needs of parents around the time of diagnosis.

DESIGN

We used a descriptive qualitative method based on the theory of critical psychology and conducted five semi-structured interviews with a total of eight parents of children under the age of two who had been diagnosed with blindness or visual impairment within the last six months. Thematic analysis was used to extract primary themes.

SETTING

The study was initiated within the secondary sector.

PATICIPANTS

Eight parents representing five families caring for a child under the age of two with visual impairment or blindness participated in the study.

RESULTS

We identified three themes 1) Recognition and reactions during the time of diagnosis, 2) Family, network, and struggles and 3) Interaction with healthcare professionals.

CONCLUSION

The single most important lesson for healthcare professionals is to bring hope at a time when all hope may seem to be lost. Secondly, a need to direct attention to families with none or sparce supportive networks. Thirdly, coordinating appointments between hospital departments and at home therapies and reducing the number of appointments to allow parents time to establish a family relation with their child. Parents respond well to competent healthcare professionals who keeps them informed and who sees the child as an individual rather than as a diagnosis.

Strengths and limitations of this study

- We used qualitative interviews, a method that allowed us to gain in-depth insight
- We conducted a thematic analysis to condensate the essential findings
- Due to the choice of method the results of the study have limitations concerning generalizability

Introduction

The whole family is affected when an infant is diagnosed with visual impairment or blindness, and the responsibility for the course of the disease and the subsequently rehabilitation process becomes a substantial part of the family's everyday life (1,2). In general, parents of children with a profound impairment or disability face significant challenge around the time of diagnosis (3,4). The diagnosis is a milestone, which in many aspects outline the prognosis of the disease. Transitioning to being a parent of an infant with a visual impairment or blindness can cause significant stress as parents negotiate the many challenges associated with caring for their child, and the implications of the impairment or disability for their child and family (5). It is therefore essential that the parents receive support and help around the time of diagnosis.

In Denmark, children <18 years of age are registered in The Danish Registry for the Blind and Partially Sighted Children when the child is diagnosed with a visual impairment defined as visual acuity ≤6/18 or significant visual field defect. In addition, children with a hereditary and progressive retinal eye disease are included in the registry irrespective of their visual function at the time of diagnosis. The most important function of the registry is to ensure that the children receive the help needed to be able to manage at home, in school, or at an institution. After registration in the database, every child will be assigned a *vision therapist,* who may help with guidance and counselling in the home, daycare, or school. Optical rehabilitation such as spectacles, contact lenses, magnifying glasses and binoculars will be economical supported.

In Denmark the provision of diagnostic and highly specialized treatment lies within the secondary health care sector, primarily hospitals, whereas the responsibility for other healthcare services, including rehabilitation, lies in the primary health care sector - the municipalities (6). Therefore, patients and parents must navigate between different healthcare sectors in their patient trajectory to get the help they need, which may create unnecessary burdens and delays. This may be of particular concern around the time of diagnosis, which is given at the hospital and the following formal support and help provided by the municipalities, because of a possible delay due to the shift in sectors.

This qualitative study sets out to describe the support needs of parents caring for an infant with visual impairment or blindness around the time of diagnosis, with the purpose of elucidating potential uncovered need for support and help.

Materials and Methods

We used a descriptive qualitative method based on the theory of critical psychology to explore the experiences and needs of families to infants under the age of two with newly diagnosed severe visual impairment or blindness. We were interested in understanding the family's lived experiences within their social context (7,8).

The parents were recruited from the Department of Ophthalmology at Rigshospitalet, Denmark in relation to appointments in the clinic or by phone or e-mail. The main criterions for participation were 1) to be a parent of a visually impaired or blind infant under the age of two, 2) learning of the diagnosis within the past 5 -6 months and 3) the child should be in The Registry for the Blind and Partially Sighted Children. This timespan was partly chosen because most are diagnosed in the early years, and partly due to the authors experience of this timespan being particularly vulnerable.

We excluded families of children with severe systemic comorbidities that could interfere with the child's development at the time of the interview to keep a strong focus on the impact of visual impairment or blindness.

Parents were informed on the study and given an information leaflet. If they agreed to participate, contact information was exchanged, and a meeting was arranged.
All invited parents agreed to participate, and there were no dropouts during the study. Parents were interviewed one time only.

The study was performed using a semi-structured interview guide (online supplementary file 1). The interview guide was intensively discussed and revised in collaboration between all authors of the study. The interview guide included the following themes: (1) The first phase; from the first suspicion about a problem to the meeting with healthcare professionals (2) The meeting with the hospital; the process of investigating the reason for concern leading to the receiving of the diagnosis (3) From the hospital to the municipality, establishing contact to the vision therapist (4) Everyday life and the future; the experience of everyday life and expectations to the future and finally (5) Closure; room for final comments. The themes followed a chronological logic and inherent in every theme was a focus on the support and help offered and wanted.

The same two researchers were present for all interviews. Interviews could be performed in the homes of the families or at the hospital according to parents' preferences. Interviews were audio recorded and transcribed at a later timepoint. Interviewer 1 (NM) was responsible for conducting and transcribing the interviews. Interviewer 2 (AR) ensured that all aspects of the interview guide were covered by the interviewer and that potential uncertainties or vague/misleading answers were resolved during the interview. Data was organized by two of the authors using a category scheme and thereby interpretated using a thematic analysis and resulted in a total of three themes (9).

The data sample was characterized by in-depth material, since data collection continued until redundancy and saturation was achieved (9). Informants were assigned a code to provide anonymity and confidentiality. When referred to in the text, informants are identified by a code: I:1 [informant number], Mother or Father, 1 [age of infant].

Before the beginning of each interview, the informants received written and oral information about the study and that study participation was voluntary and that consent could be withdrawn at any time point. Informants signed an informed consent form (online supplementary file 2).

Patients and/or the public were not involved in the design, conduct, reporting, or dissemination plans of this research. Ethical approval of the project was not required according to Danish regulations (10). The study followed the tenets of the Helsinki Declaration (11).

Results

We interviewed eight parents (five families) of infants under the age of two diagnosed with a visual impairment or blindness. Four out of five interviews were conducted in the homes of the families, one was conducted in the hospital in connection with the family coming in for a routine examination (Box 1). The interviews were completed between May 2021 and January 2022 (this period lasted longer than expected due to the covid-19 pandemic). The interviews lasted approximately 1-1.5 hours, resulting in approximately a total of 80 pages of transcribed text. An overview of the interviews is presented in Table 1.

Table 1.

Overview of interviews

Interview	**Parents present at the interview**	**Number of children in family**	**Family structure**
Interview no. 1	Mother and Father	2	Cohabiting
Interview no. 2	Father	2	Cohabiting
Interview no. 3	Mother and Father	3	Cohabiting
Interview no. 4	Mother	1	Single parent
Interview no. 5	Mother and Father	3	Cohabiting

At the time of the interview four out of five children were under the age of one year. These children were taken care of at home by a parent on parental leave. One child, age 1.5 years, attended daycare with normal sighted peers. For the families with more than one child, the child with the impairment, was the youngest sibling.

Recognition and reactions during the time of diagnosis

The concern about a potential visual impairment presented itself in different ways for the parents and with a variety in timespan with a median of one to two weeks after the birth. In some cases, the parents were the first to notice something different about the eye or the periocular area. In other cases, it was a health nurse that raised concern, e.g. due to lack of eye-contact, involuntary eye-movements, or abnormal physical appearance of the eyes or periocular area.

Whether it was the parents or the health nurse who first articulated concern this immediately entailed a both shocking and overwhelming experience: *"We had an appointment right away, and my world totally collapsed. I am a single mother, but I have tried, it has been a very long process"* (I:6 [informant number], Mother, <1 [age of child]).

Moreover, learning the child had a visual impairment brought out reminiscence of losing the possibility of maintaining a worthy life. As a mother of a blind infant explained *"Well I just think that we were pretty sure of that our life would end (...). That is, we are going to have an infant who can't do anything at all, because of his blindness. Well, none of us have any experience with blind people at all, and to us, it was just like saying, nothing matters anymore, and then just let him be"* (I:1, Mother, <1).

This quote sums up a thought raised by all the parents, how the impairment would impact the life of their child, which possibilities would they have for maintaining a worthy life, e.g. would the child be able to obtain an education and be independent as adolescent or adult. All parents expressed concerns about how the impairment would impact the family for example the possibility for parents to maintain their job, having to move etc. elevating potential stressors: *"Will one of us never return to our job, can we afford to stay in our house, are we going to rethink moving one more time (...). When so many things happen at one time, things we don't have to worry about right now, then I just think things stumbles a little bit"* (I:2, Father, <1).

Additionally, the diagnosis initiated a process where the families had to accept the loss of a healthy child, and to rethink and reorganize their expectations of the family to be by seeing the family in a new, unknown, and different light: *"So, one might say, that he has overcome a lot of things, and I hope that things are* *moving in the right direction. I'm doing what I can to help him in the best possible direction"* (I:6, Mother, <1).

Common for all the parents was that once the possibility of an impairment was raised everything happened quickly which on one hand made the situation even more overwhelming and extreme, but on the other hand also made the parents feel safe, as expressed in the following quote: *"You can say that the process in itself is extremely overwhelming, and because everything happens so quickly, just makes it even more devastating. But it was also a good thing that things moved quickly. (…) One can't just sit and wait around when you have been told that you child is blind or have cancer, then you just have to get going, right"* (I:1+2, Mother & Father, <1).

Six out of eight parents described being given the diagnosis also emphasized a general concern of what might else be wrong with their child, leaving them in a heightened preparedness for handling a sudden emergency: *"I saw that my baby is not fine, so that is like hard, and it is very difficult to accept that. And still it's fear all the time, will he have other problems"* (I:4, Mother, <1). For all parents this concern had a interconnectedness to the concrete diagnosis of their child which had embedded a risk of associated comorbidities that could present at a later stage: *"Then you also realize that glaucoma also is a concept that you have to relate to, and obviously that is something that we are really afraid of her [daughter] getting"* (I:3, Father, 1).

When asked what support and help would have been most helpful at the time of diagnosis, parents indicated that they wanted reassurance of everything ending well: *"If I were to say it face-to-face, then I would say, that even though things right now seem completely hopeless, then everything is going to work out. Well, it will get better, and try to stay calm. It's some really skilled people that are working with your child right now, and they know what they are doing, and they are doing everything possible to help"* (I:3, Father, 1).

<u>Family, network, and struggles</u>

Support from family and friends was perceived as crucial for relief and relaxation in everyday life. Support from family and friends was provided in many ways, ranging from conversations to practical assistance e.g. babysitting older siblings in relation to visits to the hospital. *"But we have a close relationship to both sets of grandparents, so I just think that he [big brother], the days where we had to go to the hospital, he was at his grandparents, and that was something he thought of as quite awesome"* (I:1, Mother, <1). Not all parents had close relatives nearby and they reported a lack of support and help from relatives, also leaving them with having to manage on their own, and not having anyone to share their burdens and griefs with: *"He was crying all the time, like first 3-4 months, like no, he would not allow me to take a little break. He was not sleeping, and dad working at days, and girls also disturb so much, and nobody in this country, like you know, when you are tired you can see all the windows look like everybody is happy, but you are not"* (I:4, Mother, <1).

Likewise, four parents also reported that even though they had someone to share their burdens with, they also felt responsible for not hurting the other person with their grief so as to protect the ones nearest even though the parents were hurting themselves. *"Well I have had some friends, that I have talked to, and then off course my mother who are so connected to us, but it can also be very hard at times when it's one that you are very close to, because she has also been very sad and sad on my behalf. (…) But the thing with all the time protecting one another, and with my mother in this situation, where I haven't turned so much to her"* (I:6, Mother, <1). The same form of protection of ones nearest in times of grief are also experienced between spouses: *"Like my father was dead, my mother was dead (…), and I'm alone. I don't have any brother or* *friend closely where I share. I can't share with my wife, I know she is the mother, she has more, if I share something, then we fall down"* (I:5, Father, <1).

To be able to share and process the hard feelings associated with having an infant with a visual impairment or blindness, six out of eight parents expressed a general need for professional emotional support for instance conversations with a psychologist. However only one out of eight had seen a psychologist. Reasons for not seeing a psychologist included long waiting lists, difficulties getting a referral and that it's not free of charge. Most parents had considered the possibility of connecting with other parents in the same situation but had not established any contact. Only three parents had engaged (virtually) with parents of children with the same diagnosis: *"I have found a network of people who have children with the same diagnosis or have the diagnosis themselves in USA. Talking with someone who has older children, of what to expect of the future, that was what I needed the most"* (I:7, Mother, <1).

All the parents reported having experienced *struggles* after becoming parents to an infant with an impairment. The parents defined struggles as having to secure the right support and help for their child and family: *"I just think, that when you have an infant that is a little bit different than the rest, then you will experience some struggles. And that just requires an enormous amount of effort, a lot I would say. And maybe especially concerning the blindness, because no one really knows what to do"* (I:1, Mother, <1). One couple experienced having their claim for compensation for loss of earnings rejected, which made them file a complaint to their municipality. In the meanwhile, a local newspaper interviewed them about their point of view of the situation resulting in a sudden change of event: *"After 2-3 days we were called in for a new meeting (...), and are told that we now are granted compensation for loss of earnings"* (I:3, Father, 1). Not all parents experience receiving/being granted those services that they apply for, as a father explained: *"I have requested the municipality almost 20 times, but they refuse me clearly, and school refuse me clearly; we don't give you, we don't give you anything"* (I:5, Father, <1).

Interaction with healthcare professionals

After been given the diagnosis the parents experienced having to attend to a considerable number of appointments both in the hospital at different departments such as the ophthalmological, genetic etc. moreover they also had appointments in their own home with a vision therapist, health nurse, physiotherapist etc. The parents estimated that they would have 2 – 3 visits every week at hospital or home in the first 5 – 6 months after diagnosis. Appointments were experienced both as reassuring and calming but also as a stressor in everyday life as they had to coordinate visits at different places and timepoints: *"I just had to say 'Hey try and listen to this, we have been at the hospital several times a week, I'm not able to cope with more or having to adjust to more things. It's not because you don't want to, but you just have a lot on your hands, both having to handle the emotional challenge of having an infant with an impairment, but also handling all the practical aspects of everyday life"* (I:6, Mother, <1).

In relation to these appointments the parents also describe a feeling of being responsible for coordinating the course and bringing messages from one specialist to another specialist. *"I have always been very observant on whom I'm asking what question, because they [specialists] do not talk to each other"* (I:1, Mother, <1).

Six parents described the initial meeting with healthcare professionals as a securing process, and an act towards gaining knowledge about their reason for concern. Despite of this otherwise positive experience all parents also linked meetings with some healthcare professionals to feelings of uncertainty of the trustworthiness and quality of the healthcare professionals' competencies: *"Because I don't know what my vision therapist doesn't know, so everything I know, is something that I have from her"* (I:1, Mother, <1).

This uncertainty had that effect on some parents that they turned away from some healthcare professionals and as an example chose to attend highly specialized training elsewhere *"we have deselected their therapists"* (I:3, Father, 1).

All parents described situations where they had felt that the healthcare professional had helped them in an extraordinary way, meaning more than one could anticipate or expect. These situations are some that the parents emphasized as special and extra helpful. As a mother explained: *"You can always call her [the doctor], and she has been super flexible (…). It meant the world, that you had someone who was super flexible, it's a massive, massive advantage"* (I:6, Mother, <1). And as another mother described: *"It was so kind of her to stay late for work that Monday. We drove directly from Skejby to her [in Glostrup] and sat and talked with her for 1.5-hour Monday evening (…). I just think that it was very exemplary what she [doctor] did, she invited us that Monday, and she was very open* (I:1, Mother, <1). Another family had a similar story to tell: *"Yes, she [doctor] is the hope. Like I think in this whole case, like if I feel an angel, like she listened to us very carefully, and she looked at him [child] very carefully. And then she gave us a hope, like we will try, maybe he will get a light and a difference between day and night"* (I:5, Father, <1).

On the other hand seven parents also described opposite experiences: *"What a mother can do, because I have one son in the whole world, but they have a lot of patients, so they don't treat my son as their son, they just treated him as a patient"* (I:4, Mother, <1). Situations where parents feel as merely a patient is defined by the act of the healthcare professionals. When healthcare professionals happen to say the wrong name of the child, does not make an extra effort for instance bypasses a rule for the best of the family's, this is interpreted poorly. *"Then they [healthcare professionals] will read the file, and that's fine, but then you know right at first in the file, one has written the wrong name, then they keep calling him by the wrong name. You know, that's just some things where you …"* (I:1, Mother, <1).

Discussion

We performed a qualitative study of the experiences and support needs of parents caring for an infant with visual impairment or blindness around the time of diagnosis.

We found that it was an overwhelming experience for the parents to learn their infant was blind or severely visually impaired and that this immediately led to concerns for the child's possibility to obtain a worthy life in combination with a worry for additional comorbidities. Parents were concerned that the impairment would affect the lives of other family members. Consistent with prior studies, we found, that learning the diagnosis initiated a response similar to the reactions of a traumatic crisis, e.g. feeling of loss of control, loss of a worthy life for the child and a loss of the family to be (5,12,13). This reaction is quite identical throughout the parent's descriptions of their experiences and stories, despite the variation in the diagnosis given.

The parents themselves apply different strategies on how to manage, accept and cope with learning the diagnosis. Parents refer to their own effort in improving the situation for their child, that they feel there are competent people around them and how they accommodate the special needs of their child into the daily living of the family. However, despite of the parents' own efforts, parents themselves expressed a need for some form of reassurance that everything would end up fine. Nygård and Clancy (14) found that if a sense of hope in an otherwise hopeless situation could be established, parents of children with special healthcare needs, could mobilize a feeling of being able to overcome adversity. To define hope as a concept lies beyond the reach of this study but inspired by the work of Duggleby and colleagues (15), hope can be considered as a profound feeling and faith of something better to come within a framework of uncertainty.

Ophthalmologists, optometrists, nurses and vision therapists are well positioned to outline the concrete meaning and expected influence of the diagnosis, and thereby give rise to hope of a worthy life for both child and family. An exploration of the parents' experience of the time of diagnosis offers healthcare professionals insights into factors that potentially could support and help mobilize the parents own competencies in managing their new situation, allowing them to preserve resources to reorientate in their new life situation. This knowledge calls for healthcare professionals to be proactive in their interactions with these families by actively outlining individual needs for mobilizing hope and thereby reducing the feeling of hopelessness.

We identified various supportive functions as important at the time of diagnosis.
First and foremost, the support and help from the parent's close network stood out as highly important and it made a positive influence on how parents considered their situation. On one hand, we saw how a perceived good and competent network enhanced the feeling of being secure. On the other hand, we could detect a vulnerability in families who only had sparce or no network to mobilize in times of trouble. This enhanced the strain on the parents. Irrespective of the strength of the network most parents expressed that talking to a psychologist could have been a relief and support around the time of diagnosis. However only one out of eight parents had talked to a psychologist.

Parents wanted to connect with other parents who have a child with the same diagnosis. For the parents in this study the diagnosis was the thing they felt they could share, not the visual impairment or blindness, but the concrete diagnosis and its specific expression and implications on their child and everyday life. Concerning parents of children with rare diseases, Baumbusch and colleagues (16) found that they could regard other parents as peers irrespective of the cause of the rare disease, despite differences in diagnosis and prognosis. *The National Association of Parents of Blind and Visual Impaired* is a Danish network for parents of children with blindness or visual impairment. Despite of the origin of this network none of the parents were members, and most of the parents did not know it existed. It was a surprising finding that parents sought relations to others affected by the same diagnosis rather than others affected by the same degree of visual impairment.

We found that families had to spend time and emotional resources to obtain perceived rights for support and help for instance compensation for loss of earnings. Similar findings within a broad range of disabilities have been identified prior to this study (17,18). Our parents reported inconsistencies in granting support, potentially suggesting that deprived families are at a higher risk of not receiving justified support and help. However, this should be studied further to illuminate potential inequalities.

Supportive functions, both the formal and informal, and their protective capacity is highlighted in the study. This emphasizes the importance of identifying vulnerable families without strong informal support and be aware of their increased need for formal support. An important learning from the study is the need for referral to a psychologist. Likewise, the study points out a need to explore the possibilities for establishing relevant, meaningful, and attractive peer networks. The protective capacity of both formal and informal support is highlighted in the study. This finding emphasizes the importance of directing focus on families who could be considered as more vulnerable or deprived and be attentive of their potential increased need for support and help in the clinical setting. The study points out a need to explore the possibilities for establishing relevant, meaningful, and attractive peer networks, direct attention to the practice concerning granting and explore potential obstacles in the referral practice to the formal support in form of a psychologist.

The number of appointments at hospitals and home was demanding for many families and put a strain on the family. Caring for a sick child is associated with extra activities beyond those involved in caring for a healthy child – extra activities that can represent a potential source of stress and burden (1,2,14,19,20). Additionally, we found that parents felt they held a large share of the responsibility for coordinating appointments and bringing messages from one sector to another. Relieving the burden and stress linked to both attending appointments and upholding a coherent patient trajectory from the parents' shoulders, may give them more time and energy to concentrate on becoming a family. The coordination between appointments must be explored, to identify factors influencing negatively on workflows and direct critical attention and reflection to the needed number of appointments, which appointments can be handled at the same day and at the same location. Moreover, it seems that parents may benefit from a written overview of what they can expect, which healthcare professionals and healthcare sectors will be involved in the process and what they can expect from each and where they can get help.

Finally, we found that the interaction with healthcare professionals is a complicated act. Parents assess the quality of the interaction with healthcare professionals and evaluate their competencies (14,21). Meeting competent healthcare professionals gives rise to hope and make the parents feel secure. Whereas a devaluating of competencies makes parents withdraw from the interaction, and if possible, seek out alternatives. The assessment of the quality of the interaction is closely connected to the feeling of being viewed as a family or being left with the feeling of their child is regarded as "just a patient". Parents want their child to be seen and treated as more than "just patients".
Healthcare professionals holds the responsibility for creating a constructive and professional collaboration with the families with consideration for their individual concerns and needs. Information and individual communication are factors that help reduce anxiety and enables a good starting point for constructive collaboration (17,22).

Our study was based on qualitative interviews with parents of children under the age of two diagnosed with visual impairment or blindness. Our study provided rich data material through the nature of qualitative research and its inherent potential of capturing in-depth data material. However, this study also has some limitations. Due to our study sample of eight parents, the results are not generalizable to all parents of children with visual impairment or blindness around the time of diagnosis. We sought to minimize recall bias, by interviewing parents within 6 months of the diagnosis but it remains a risk, as parents relied on their retrospective experiences.

Conclusion

Based on the interviews with parents of infants with newly diagnosed visual impairment or blindness it seems the single most important lesson for healthcare professionals is to bring hope at a time when all hope may seem to be lost. Second, attention should be focused to families with none or sparce supportive networks as, hence they are more likely to experience heightened stress and burdens. A call for emotional support in the form of a psychologist must be investigated as well as peer networks. Third, coordinating appointments between hospital departments and at home therapies as well as reducing the number of appointments to allow parents time to establish a family relation with their child. Parents respond well to competent healthcare professionals who keeps them informed and who sees the child as an individual rather than as a diagnosis.

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Notes on contributors

Nina Milde (corresponding author)
Nina Milde is a registered nurse, Master of Arts in psychology and health promotion and Clinical Teacher at the Department of Ophthalmology at Copenhagen University Hospital - Rigshospitalet – Glostrup. Her research interest include rehabilitation, health promotion, inequalities in health, nursing, ophthalmology, and family life.

Line Kessel
Line Kessel, MD, PhD and Clinical Research Associate Professor of Ophthalmology at the Department of Ophthalmology, at Copenhagen University Hospital - Rigshospitalet – Glostrup. Her research interest are gene therapy, pediatric cataract and glaucoma, childhood myopia and hereditary eye diseases. Line has a profound career within research and has published more than 100 peer-reviewed articles.

Kamilla Rothe Nissen
Kamilla Rothe Nissen, MD, PhD and Head of The Danish Registry for the Blind and Partially Sighted Children at the Department of Ophthalmology at Copenhagen University Hospital – Rigshospitalet – Glostrup. Her research interests are focused on pediatric ophthalmology.

Annette Rasmussen
Annette Rasmussen, RN, MSc, PhD and Clinical Specialist in Nursing at the Department of Ophthalmology at Copenhagen University Hospital – Rigshospitalet – Glostrup. Her research interests are concerned about nursing, rehabilitation, PROM and ophthalmology. Annette has published nine peer-reviewed articles.

NM contributed to the main design of the study and development of the research questions, the main structure and write-up of the paper, and final amendments to the manuscript. NM and AR analyzed the data, with LK and KN supervision. All authors discussed and interpreted the data once analyzed and helped structure the manuscript. LK was responsible for overseeing the full development of the study design, data collection, the analysis and development of the final manuscript. All authors contributed to proof-reading and amendments of the final manuscript.

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Disclosure statement

No potential conflict of interest was reported by the authors.

Patient consent for publication

Consent obtained directly from patients.

Ethics approval

Ethical approval of the project was not required according to Danish regulations. The study followed the tenets of the Helsinki Declaration.

Data availability statement

Data are available on reasonable request. Background material relevant to the study are included in the article or uploaded as online supplemental information.

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Online supplementary file 1 - Interview guide

Theme 1 - The first phase

At first, I would like to hear you, if you want to tell a little about that period where you began to suspect that there was something wrong with your child's vision?

- What happened? How did you notice it?
- Who did you address with your concern?
- What was the timespan from your first concern until you talked to someone about it?
- Or was it someone else that noticed it? (health nurse, GP)
- How did they take you in?
- What was your thoughts?
- Who did you share your thoughts with?
- What made you wonder?
- How did you experience this period?

The need for help and support for parents and their everyday life

- What did you think about/what were your concerns, before you knew the explanation of your child visual challenges/disabilities?
- What need for help did you have at that time?
- Who could you share your concerns with?
- What could they help you with?
- What couldn't they help you with?
- If you look back at that time, how would a normal day look like?

Opportunities to support the child

- Did you feel that you had the right opportunities to support your child in this period? (why/why not?)
- What need for help and support did you have in this period? (knowledge, rights etc.)

If we look at the rest of the family, what were their thoughts or concerns?

- Your partner, the child (depending on age), siblings?
- Did you have similar or different needs?

Theme 2: Meeting the hospital

Let's move on to the time for the investigation of the specific reasons to the visual challenges – what was that like?

- What was your experience of this period?
- Which professionals did you communicate with?
- What worked?
- What could have been better?
- What could you have wished for?
- How did you experience the cooperation between departments?
- Did you experience any waiting time for examinations or conversations with specialists?
- What was your role in this period?
- Did you have to wait for development of symptoms before it was possible to determine a diagnosis?
- Did your child's diagnosis make any difference?
- Did the professionals explain the meaning of the diagnosis?

Opportunities to support the child

- Did you feel that you had the right opportunities to support your child at this time? (why/why not?)
- What need for help and support did you have in this period? (knowledge, rights etc.)

If we look at the rest of the family, what were their thoughts or concerns?

- Your partner, the child (depending on age), siblings?
- Did you have similar or different needs?

At this time where you offered any support, help or counselling – or did you look for it yourself?

- Which kind of support, help or counselling where you offered? (GP, synskonsulent, health nurse etc.)
- Did you accept the help or support? (why/why not?)
- How did you experience the help that you received?
- Have you sought for help yourself? If yes, how did you experience the help that you received?

If we look at the rest of the family, have they been offered any kind of help or support? If yes, what were their experiences? (partner, siblings, grandparents)

Were their any help or support you could have wished for in this period – that you didn't received?

What help or support did you find most valued in this period?

Theme 3: From hospital to municipality

Let us talk a little about the time from your child was registered in the Danish Registry for the Blind and Partially Sighted Children (diagnosis) till you had your first contact with the synskonsulent.

- When you think back, how did you experience this period?
- What do you think worked well/not well?
- When you think back at this period, what surprised you the most?
- If you had some questions, who could you ask?

Opportunities to support the child

- Did you feel that you had the right opportunities to support your child in this period? (why/why not?)
- What need for help and support did you have in this period? (knowledge, rights etc.)

Need for help and support

- What were your concerns in this period?
- What need for help and support did you have?
- Who did you turn to for help and support?
- What could they help you with?
- What couldn't they help you with?

At this period where you offered any support, help or counselling – or did you look for it yourself?

- Which kind of support, help or counselling where you offered? (GP, health nurse etc.)
- Did you accept the help or support? (why/why not?)
- How did you experience the help that you received?
- Have you sought for help yourself? If yes, how did you experience the help that you received?

If we look at the rest of the family, have they been offered any kind of help or support? If yes, what were their experiences? (partner, siblings, grandparents)

Were there any help or support you could have wished for in this period – that you didn't received?

What help or support did you find most valued in this period?

Theme 4: The everyday life and the future

Until now we have been talking a lot about the past experiences. Now we move on to talk about your everyday life and your thoughts about the future

- What do you think takes a lot effort or time in your everyday life?
- What need for support or help do you have now?

- Do you have someone you can turn to for help and support?
- What can they help you with?
- What are they not able to help you with?
- How would you describe your role as a parent in this process?
- What have worked well?
- What could have been better?
- Would you say that your role as a parent in this process have changed over time?

Opportunities to support the child

- Did you feel that you have the right opportunities to support your child in this period? (why/why not?)
- What need for help and support do you have now? (knowledge, rights etc.)

When you think back at this period of your life as a hole, do you then think that your child's visual impairment has had consequences for your;

- Relationship
- Friendships
- Work situation
- Economy

What is other people's reaction when you tell them about your child's disabilities?

Do you feel that the help you receive are of the quality and standard that you expect? (yes – no, please elaborate/tell more)

Theme 5: Closure

Now we just have some final questions.

- From your point of view what would you have wished that could have been different?
- If you were to give an advice for any future families, what would that be?
- If you were to give an advice to the hospital, municipality etc. concerning help and support for families in similar situations, what would that be?
- From your actual position, what have then been the biggest surprise?
- Do you have any comments or questions to us?

Thank you for your help and time!

Rigshospitalet

HovedOrtoCentret

Dato: 12. juli 2021

Online supplementary file 2

Informed consent to participation in a development project

Cross-sectoral support to the parents of a child with visual challenges – A development project in the Ophthalmological Department

Declaration from the informant:

I have been given both written and oral information about the project to feel that I know enough about the purpose, method, advantages and disadvantages concerning my participation in the project to accept participation.

I know that my participation in the project is voluntary, and that I, at any time can pull back my consent without losing current or future rights to treatment.

I agree to participate in this development project and have been given a copy of this consent formula and a copy of the written information about the project.

Name of informant:

Date: Signature:

Do you wish to receive information about the project findings?

Yes: No:

Declaration from the one who has given the information:

I declare that the informant has been given both written and oral information about the project.

After my best belief there have been given enough information to take a fully informed choice about participation.

Name of the person who have given the information:

Date: Signature:

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	4
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	11
Occupation	3	What was their occupation at the time of the study?	11
Gender	4	Was the researcher male or female?	11
Experience and training	5	What experience or training did the researcher have?	11
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	3
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	3
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	4
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	3
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	3
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	3
Sample size	12	How many participants were in the study?	4
Non-participation	13	How many people refused to participate or dropped out? Reasons?	4
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	4
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	4
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	4
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	4
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	4
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	4
Field notes	20	Were field notes made during and/or after the inter view or focus group?	N/A
Duration	21	What was the duration of the inter views or focus group?	4
Data saturation	22	Was data saturation discussed?	4
Transcripts returned	23	Were transcripts returned to participants for comment and/or	N/A

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	4
Description of the coding tree	25	Did authors provide a description of the coding tree?	4
Derivation of themes	26	Were themes identified in advance or derived from the data?	4
Software	27	What software, if applicable, was used to manage the data?	N/A
Participant checking	28	Did participants provide feedback on the findings?	N/A
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	4
Data and findings consistent	30	Was there consistency between the data presented and the findings?	4-8
Clarity of major themes	31	Were major themes clearly presented in the findings?	4-8
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	8-11

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

BMJ Open

Support needs around the time of diagnosis of parents caring for an infant with visual impairment or blindness in Denmark: a qualitative study

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Enseignement Superieur (ABES) .

Title

Support needs around the time of diagnosis of parents caring for an infant with visual impairment or blindness in Denmark: a qualitative study

Nina Milde (https://orcid.org/0000-0002-5726-4571) (nina.milde@regionh.dk)(linkedin.com/in/nina-milde-08a04a129),[1] Annette Rasmussen,[1] Kamilla Rothe Nissen,[1,2] and Line Kessel (https://orcid.org/0000-0002-9375-1510)[1,3]

[1] Department of Ophthalmology, Copenhagen University Hospital - Rigshospitalet – Glostrup. Copenhagen, Denmark
[2] Department of Ophthalmology, Copenhagen University Hospital - Rigshospitalet – KennedyCenter, Copenhagen, Denmark
[3] Department of Clinical Medicine, University of Copenhagen, Copenhagen, Denmark

Corresponding author

Nina Milde
Valdemar Hansens Vej 1-23, Pavillonen, 1. sal
2600 Glostrup
E-mail: nina.milde@regionh.dk
Telephone: +0045 9117 2427
Fax: +0045 3863 4699

Abstract

OBJECTIVE

The whole family is affected when an infant is diagnosed with visual impairment or blindness. We aimed to describe the support needs of parents around the time of diagnosis.

DESIGN

We used a descriptive qualitative method based on the theory of critical psychology and conducted five semi-structured interviews with a total of eight parents of children under the age of two who had been diagnosed with blindness or visual impairment before the age of one. Thematic analysis was used to extract primary themes.

SETTING

The study was initiated by a tertiary hospital center specialized in the ophthalmic management of children and adults with visual impairment.

PARTICIPANTS

Eight parents representing five families caring for a child under the age of two with visual impairment or blindness participated in the study. The parents were recruited from the Department of Ophthalmology at Rigshospitalet, Denmark in relation to appointments in the clinic or by phone or e-mail.

RESULTS

We identified three themes 1) Recognition and reactions during the time of diagnosis, 2) Family, network, and struggles and 3) Interaction with healthcare professionals.

CONCLUSION

The single most important lesson for healthcare professionals is to bring hope at a time when all hope may seem to be lost. Secondly, a need to direct attention to families with none or sparce supportive networks. Thirdly, coordinating appointments between hospital departments and at home therapies and reducing the number of appointments to allow parents time to establish a family relation with their child. Parents respond well to competent healthcare professionals who keeps them informed and who sees the child as an individual rather than as a diagnosis.

Strengths and limitations of this study

- We used qualitative interviews which allowed us to gain in-depth insight
- We conducted a thematic analysis to condensate the essential findings
- The result of this study offers transferability to other settings, however limitations concerning generalizability must be considered due to the sample size of the study

Introduction

All members of the family are affected when an infant is diagnosed with visual impairment or blindness, and the responsibility for the course of the disease and the subsequent rehabilitation process becomes a substantial part of the family’s everyday life (1,2). In general, parents of children with a profound impairment or disability face significant challenges around the time of diagnosis (3,4). The diagnosis is a milestone, which in many aspects outline the prognosis of the disease. Transitioning to being a parent of an infant with a visual impairment or blindness can cause significant stress as parents negotiate the many challenges associated with caring for their child, and the implications of the impairment or disability for their child and family (5). It is therefore essential that the parents receive support and help around the time of diagnosis.

In Denmark, children <18 years of age are registered in The Danish Registry for the Blind and Partially Sighted Children when the child is diagnosed with a visual impairment defined as visual acuity 0.3 (≤6/18) or significant visual field defect. In addition, children with a hereditary and progressive retinal eye disease are included in the registry irrespective of their visual function at the time of diagnosis. The most important function of the registry is to ensure that the children receive the help needed to be able to manage at home, in school, or at an institution. After registration in the database, every child will be assigned a *vision rehabilitation therapist,* who may help with guidance and counselling in the home, daycare, or school. Optical rehabilitation such as spectacles, contact lenses, magnifying glasses and binoculars will be economical supported.

In Denmark the provision of diagnostic and highly specialized treatment lies within the secondary health care sector, primarily hospitals, whereas the responsibility for other healthcare services, including rehabilitation, lies in the primary health care sector - the municipalities (6). Therefore, patients and parents must navigate between different healthcare sectors in their patient trajectory to get the help they need, which may create unnecessary burdens and delays. This may be of particular concern around the time of diagnosis, which is given at the hospital and the following formal support and help provided by the municipalities, because of a possible delay due to the shift in sectors.

This qualitative study sets out to describe the support needs of parents caring for an infant with visual impairment or blindness around the time of diagnosis, with the purpose of elucidating potential uncovered need for support and help.

Materials and Methods

We used a descriptive qualitative method based on the theory of critical psychology to explore the experiences and needs of families to an infant with newly diagnosed severe visual impairment or blindness. Critical psychology draws on an explicit focus on the subject (e.g. the family’s) lived experiences but within the social context of their origin (7,8). Critical psychology originates from a historical dialectical materialism where subject and context cannot be seen as separated but are constantly interwind and mutually dependent. This is to be understood as a constant double relationship where the subject creates its own living conditions but at the same time also are subordinated to living conditions that originates from the social context (7,8).

The parents were recruited from the Department of Ophthalmology at Rigshospitalet, Denmark in relation to appointments in the clinic or by phone or e-mail. The main criteria for participation were 1) to be a parent of a visually impaired or blind child diagnosed in infancy (0–1 year of age), 2) learning of the diagnosis within the past 5-6 months and 3) the child should be in The Registry for the Blind and Partially Sighted Children.

This timespan was partly chosen because most are diagnosed in the early years, and partly due to the authors experience of this timespan being particularly vulnerable.

We excluded families of children with severe systemic comorbidities that could interfere with the child's development at the time of the interview to keep a strong focus on the impact of visual impairment or blindness.

Parents were informed on the study and given an information leaflet. If they agreed to participate, contact information was exchanged, and a meeting was arranged. All invited parents agreed to participate, and there were no dropouts during the study. Parents were interviewed one time only.

The study was performed using a semi-structured interview guide (online supplementary file 1). The interview guide was intensively discussed and revised in collaboration between all authors of the study. The interview guide included the following five themes: (1) The initial concern about a potential visual disorder in the infant. (2) Establishing contact with the hospital; Focus on the process of investigating the reason for concern leading to the receiving of the diagnosis. (3) Establishing contact with the vision rehabilitation therapist in the municipality. (4) The experience of everyday life and expectations to the future. (5) Closing of the interview; room for final comments.

The themes followed a chronological logic. The methodological and theoretical approach also materialized in the development of the semi-structured interview guide where we were interested in the family but also had a focus on the surrounding environment, network, siblings, etc.

The same two researchers were present at all interviews. These could be performed in the homes of the families or at the hospital according to parents' preferences. Interviews were audio recorded and transcribed at a later timepoint. Interviewer 1 (NM) was responsible for conducting and transcribing the interviews. Interviewer 2 (AR) ensured that all aspects of the interview guide were covered by the interviewer and that potential uncertainties or vague/misleading answers were resolved during the interview.

The analytic methodology used for the interview data was a thematic analysis, which embraces a dynamic process in the analysis of moving back and forth throughout the different phases of the analysis (9). The thematic analysis allowed us to sort data attained from the interviews in manageable units (9). Data was organized by two of the authors using a category scheme. The category scheme was arranged in compliance with our interview guide. Having read and re-read the scheme and all the data in its entirety we started to identify patterns, themes, and relationships within our data.

The data sample was characterized by in-depth material, since data collection continued until redundancy and saturation was achieved (9). Informants were assigned a code to provide anonymity and confidentiality. When referred to in the text, informants are identified by a code: I:1 [informant number], Mother or Father, 1 [age at interview].

Before the beginning of each interview, the informants received written and oral information about the study and that study participation was voluntary and that consent could be withdrawn at any time point. Informants signed an informed consent form (online supplementary file 2).

Ethical approval of the project was not required according to Danish regulations (10). The study followed the tenets of the Helsinki Declaration (11).

Patient and Public Involvement

None.

Results

We interviewed eight parents (five families) of children under the age of two diagnosed with a visual impairment or blindness before the age of one. All five children were blind or severely visually impaired from birth. All children had congenital eye conditions characterized by panocular malformations but were otherwise healthy. Four out of five interviews were conducted in the homes of the families, one was conducted in the hospital in connection with the family coming in for a routine examination. The interviews were completed between May 2021 and January 2022 (this period lasted longer than expected due to the covid-19 pandemic). The interviews lasted approximately 1-1.5 hours, resulting in approximately a total of 80 pages of transcribed text. An overview of the interviews is presented in Table 1.

Table 1.

Overview of interviews

Interview	Parents present at the interview	Number of children in family	Family structure
Interview no. 1	Mother and Father	2	Cohabiting
Interview no. 2	Father	2	Cohabiting
Interview no. 3	Mother and Father	3	Cohabiting
Interview no. 4	Mother	1	Single parent
Interview no. 5	Mother and Father	3	Cohabiting

At the time of interview four out of five children were under the age of one year. These children were taken care of at home by a parent on parental leave. One child, age 1.5 years, attended daycare with normal sighted peers. For the families with more than one child, the child with the impairment, was the youngest sibling. The thematic analysis identified a total of three themes.

Recognition and reactions during the time of diagnosis

The concern about a potential visual impairment presented itself in different ways for the parents and with a variety in timespan with a median of one to two weeks after the birth. In some cases, the parents were the first to notice something different about the eye or the periocular area. In other cases, it was a community nurse that raised concern, e.g., due to lack of eye-contact, involuntary eye-movements, or abnormal physical appearance of the eyes or periocular area.

Whether it was the parents or the community nurse who first articulated concern this immediately entailed a both shocking and overwhelming experience: *"We had an appointment right away, and my world totally collapsed. I am a single mother, but I have tried, it has been a very long process"* (I:6 [informant number], Mother, <1 [age at interview]).

Moreover, learning the infant had a visual impairment brought out reminiscence of losing the possibility of maintaining a worthy life. As a mother of a blind infant explained *"Well I just think that we were pretty sure of that our life would end (...). That is, we are going to have a child who can't do anything at all, because of his blindness. Well, none of us have any experience with blind people at all, and to us, it was just like saying, nothing matters anymore, and then just let him be"* (I:1, Mother, <1).

This quote sums up a thought raised by all the parents, how the impairment would impact the life of their child, which possibilities they would have for maintaining a worthy life, e.g. would the child be able to obtain an education and be independent as adolescent or adult. All parents expressed concerns about how the impairment would impact the family for example the possibility for parents to maintain their job, having to move etc. elevating potential stressors: *"Will one of us never return to our job, can we afford to stay in our house, are we going to rethink moving one more time (...). When so many things happen at one time, things we don't have to worry about right now, then I just think things stumbles a little bit"* (I:2, Father, <1).

Likewise one mother expressed concern on how to manage the upbringing of the child, hence children also learn by engaging with peers and observing how others behaves: *"(...) That you must explain your child, that it's okay to take ones coat off when it's warm outside, but it's not okay to take one's trousers off. You don't have to explain such things to a child that can see, because they have already observed that no other people walk around without trousers. Well, I just think that the 'social' aspect of upbringing a visually impaired child is a big responsibility"* (I:1, Mother, <1).

Additionally, the diagnosis initiated a process where the families had to accept the loss of a healthy child, and to rethink and reorganize their expectations of the family to be by seeing the family in a new, unknown, and different light: *"So, one might say, that he has overcome a lot of things, and I hope that things are moving in the right direction. I'm doing what I can to help him in the best possible direction"* (I:6, Mother, <1).

Common for all the parents was that once the possibility of an impairment was raised everything happened quickly which on one hand made the situation even more overwhelming and extreme, but on the other hand also made the parents feel safe, as expressed in the following quote: *"You can say that the process is extremely overwhelming, and because everything happens so quickly, just makes it even more devastating. But it was also a good thing that things moved quickly. (...) One can't just sit and wait around when you have been told that you child is blind or have cancer, then you just have to get going, right"* (I:1+2, Mother & Father, <1).

Six out of eight parents described being given the diagnosis also emphasized a general concern of what might else be wrong with their child, leaving them in a heightened preparedness for handling a sudden emergency: *"I saw that my baby is not fine, so that is like hard, and it is very difficult to accept that. And still, it's fear all the time, will he have other problems"* (I:4, Mother, <1). For all parents this concern had an interconnectedness to the concrete diagnosis of their child which had embedded a risk of associated comorbidities that could present at a later stage: *"Then you also realize that glaucoma also is a concept that you have to relate to, and obviously that is something that we are really afraid of her [daughter] getting"* (I:3, Father, 1).

When asked what support and help would have been most helpful at the time of diagnosis, parents indicated that they wanted reassurance of everything ending well: *"If I were to say it face-to-face, then I would say, that even though things right now seem completely hopeless, then everything is going to work out. Well, it will get better, and try to stay calm. It's some really skilled people that are working with your child right now, and they know what they are doing, and they are doing everything possible to help"* (I:3, Father, 1).

Family, network, and struggles

Support from family and friends was perceived as crucial for relief and relaxation in everyday life. Support from family and friends was provided in many ways, ranging from conversations to practical assistance e.g. babysitting older siblings in relation to visits to the hospital. *"But we have a close relationship to both sets of grandparents, so I just think that he [big brother], the days where we had to go to the hospital, he was at his grandparents, and that was something he thought of as quite awesome"* (I:1, Mother, <1). Not all parents had close relatives living nearby and they reported a lack of support and help from relatives, also leaving them with having to manage on their own, and not having anyone to share their burdens and griefs with: *"He was crying all the time, like first 3-4 months, like no, he would not allow me to take a little break. He was not sleeping, and dad working at days, and girls also disturb so much, and nobody in this country, like you know, when you are tired you can see all the windows look like everybody is happy, but you are not"* (I:4, Mother, <1).

Likewise, four parents also reported that even though they had someone to share their burdens with, they also felt responsible for not hurting the other person with their grief as in to protect the ones nearest even though the parents were hurting themselves. *"Well I have had some friends, that I have talked to, and then off course my mother who are so connected to us, but it can also be very hard at times when it's one that you are very close to, because she has also been very sad and sad on my behalf. (...) But the thing with all the time protecting one another, and with my mother in this situation, where I haven't turned so much to her"* (I:6, Mother, <1). The same form of protection of ones nearest in times of grief are also experienced between spouses: *"Like my father was dead, my mother was dead (...), and I'm alone. I don't have any brother or friend closely where I share. I can't share with my wife, I know she is the mother, she has more, if I share something, then we fall down"* (I:5, Father, <1).

To be able to share and process the hard feelings associated with having an infant with a visual impairment or blindness, six out of eight parents expressed a general need for professional emotional support for instance sessions with a psychologist. However only one out of eight had seen a psychologist. Reasons for not seeing a psychologist included long waiting lists, difficulties getting a referral and that it was not free of charge. Most parents had considered the possibility of connecting with other parents in the same situation but had not established any contact. Only three parents had engaged (virtually) with parents of children with the same diagnosis: *"I have found a network of people who have children with the same diagnosis or have the diagnosis themselves in USA. Talking with someone who has older children, of what to expect of the future, that was what I needed the most"* (I:7, Mother, <1).

All the parents reported having experienced *struggles* after becoming parents to an infant with an impairment. The parents defined struggles as having to secure the right support and help for their child and family: *"I just think, that when you have a child that is a little bit different than the rest, then you will experience some struggles. And that just requires an enormous amount of effort, a lot I would say. And maybe especially concerning the blindness, because no one really knows what to do"* (I:1, Mother, <1). One couple experienced having their claim for compensation for loss of earnings rejected, which made them file a complaint to their municipality. In the meanwhile, a local newspaper interviewed them about their point of view of the situation resulting in a sudden change of event: *"After 2-3 days we were called in for a new meeting (...) and are told that we now are granted compensation for loss of earnings"* (I:3, Father, 1). Not all parents experience receiving/being granted those services that they apply for, as a father explained: *"I have requested the municipality almost 20 times, but they refuse me clearly, and school refuse me clearly; we don't give you, we don't give you anything"* (I:5, Father, <1).

Interaction with healthcare professionals

After been given the diagnosis, the parents experienced having to attend to a considerable number of appointments both in the hospital at different departments such as the ophthalmological, genetic etc. moreover they also had appointments in their own home with a vision rehabilitation therapist, community nurse, physiotherapist etc. The parents estimated that they would have 2 – 3 visits every week at hospital or home in the first 5 – 6 months after diagnosis. Appointments were experienced both as reassuring and calming but also as a stressor in everyday life as they had to coordinate visits at different places and timepoints: *"I just had to say 'Hey try and listen to this, we have been at the hospital several times a week, I'm not able to cope with more or having to adjust to more things. It's not because you don't want to, but you just have a lot on your hands, both having to handle the emotional challenge of having a child with an impairment, but also handling all the practical aspects of everyday life"* (I:6, Mother, <1).

In relation to these appointments the parents also describe a feeling of being responsible for coordinating the course and bringing messages from one specialist to another specialist. *"I have always been very observant on whom I'm asking what question, because they [specialists] do not talk to each other"* (I:1, Mother, <1).

Six parents described the initial meeting with healthcare professionals as a securing process, and an act towards gaining knowledge about their reason for concern. Despite of this otherwise positive experience all parents also linked meetings with some healthcare professionals to feelings of uncertainty of the trustworthiness and quality of the healthcare professionals' competencies: *"Because I don't know what my vision rehabilitation therapist doesn't know, so everything I know, is something that I have from her"* (I:1, Mother, <1). This uncertainty led some parents to turn away from some healthcare professionals and as an example chose to attend highly specialized training elsewhere *"We have deselected their therapists"* (I:3, Father, 1).

All parents described situations where they had felt that the healthcare professional had helped them in an extraordinary way, meaning more than one could anticipate or expect. These situations are some that the parents emphasized as special and extra helpful. As a mother explained: *"You can always call her [the doctor], and she has been super flexible (...). It meant the world, that you had someone who was super flexible, it's a massive, massive advantage"* (I:6, Mother, <1). And as another mother described: *"It was so kind of her to stay late for work that Monday. We drove directly from Skejby to her [in Glostrup] and sat and talked with her for 1.5-hour Monday evening (...). I just think that it was very exemplary what she [doctor] did, she invited us that Monday, and she was very open* (I:1, Mother, <1). Another family had a similar story to tell: *"Yes, she [doctor] is the hope. Like I think in this whole case, like if I feel an angel, like she listened to us very carefully, and she looked at him [child] very carefully. And then she gave us a hope, like we will try, maybe he will get a light and a difference between day and night"* (I:5, Father, <1).

On the other hand, seven parents also described opposite experiences: *"What a mother can do, because I have one son in the whole world, but they have a lot of patients, so they don't treat my son as their son, they just treated him as a patient"* (I:4, Mother, <1). Situations where parents feel as merely a patient is defined by the act of the healthcare professionals. When healthcare professionals happen to say the wrong name of the child, does not make an extra effort to bypass rigid systems for the best of the family's, this is interpreted poorly. *"Then they [healthcare professionals] will read the file, and that's fine, but then you know right at first in the file, one has written the wrong name, then they keep calling him by the wrong name. You know, that's just some things where you ..."* (I:1, Mother, <1).

Discussion

We performed a qualitative study of the experiences and support needs of parents caring for an infant with visual impairment or blindness around the time of diagnosis.

We found that it was an overwhelming experience for the parents to learn that their infant was blind or severely visually impaired and that this immediately led to concerns for the child's possibility to obtain a worthy life in combination with a worry for additional comorbidities. Parents were concerned that the impairment would affect the lives of other family members. Consistent with prior studies, we found, that learning the diagnosis initiated a response similar to the reactions of a traumatic crisis, e.g., feeling loss of control, loss of a worthy life for the child and a loss of the family to be (5,12,13). This reaction is quite identical throughout the parent's descriptions of their experiences and stories, despite the variation in the diagnosis given.

The parents themselves apply different strategies on how to manage, accept and cope with learning the diagnosis. Parents refer to their own effort in improving the situation for their child, that they feel there are competent people around them and how they accommodate the special needs of their child into the daily life of the family. However, despite the parents' own efforts, parents themselves expressed a need for some form of reassurance that everything would end up fine. Nygård and Clancy (14) found that if a sense of hope in an otherwise hopeless situation could be established, parents of children with special healthcare needs, could mobilize a feeling of being able to overcome adversity. To define hope as a concept lies beyond the reach of this study but inspired by the work of Duggleby and colleagues (15), hope can be considered as a profound feeling and faith of something better to come within a framework of uncertainty. Ophthalmologists, optometrists, nurses, and vision rehabilitation therapists are well positioned to outline the concrete meaning and expected influence of the diagnosis, and thereby give rise to hope of a worthy life for both child and family. McDowell's study on parents of children with cerebral visual impairment also shows how healthcare professionals holds a unique position to empower parents around the time of diagnosis by providing them with clear and relevant information (16). An exploration of the parents' experience of the time of diagnosis offers healthcare professionals insights into factors that potentially could support and help mobilize the parents' own competencies in managing their new situation, allowing them to preserve resources to reorientate in their new life situation. This knowledge calls for healthcare professionals to be proactive in their interactions with these families by actively outlining individual needs for mobilizing hope and thereby reducing the feeling of hopelessness.

We identified various supportive functions as important at the time of diagnosis. First and foremost, the support and help from the parent's close network stood out as highly important and it made a positive influence on how parents considered their situation. On one hand, we saw how a perceived good and competent network enhanced the feeling of being secure. On the other hand, we could detect a vulnerability in families who only had sparce or no network to mobilize in times of trouble. This enhanced the strain on the parents. This finding emphasizes the importance of directing focus to families who could be considered as vulnerable or deprived of a social network and be attentive of their potential increased need for support and help.

Irrespective of the strength of the network most parents expressed that talking to a psychologist could have been a relief and support around the time of diagnosis. However only one out of eight parents had talked to a psychologist. The reason for this seemingly small number is however unknown but could give rise to an exploration of potential obstacles in the referral practice to the formal support in form of a psychologist.

Parents wanted to connect with other parents who have a child with the same diagnosis. For the parents in this study the diagnosis was the thing they felt they could share, not the visual impairment or blindness, but the concrete diagnosis and its specific expression and implications on their child and everyday life. Concerning parents of children with rare diseases, Baumbusch and colleagues (17) found that they could regard other parents as peers irrespective of the cause of the rare disease, despite differences in diagnosis and prognosis. *The National Association of Parents of Blind and Visual Impaired* is a Danish network for parents of children with blindness or visual impairment. Despite of the origin of this network none of the parents were members, and most of the parents did not know it existed. It was a surprising finding that parents sought relations to others affected by the same diagnosis rather than others affected by the same degree of visual impairment.

We found that families had to spend time and emotional resources to obtain perceived rights for support and help for instance compensation for loss of earnings. Similar findings within a broad range of disabilities have been identified in other studies (18,19). Our parents reported inconsistencies in granting support, potentially suggesting that deprived families are at a higher risk of not receiving justified support and help. However, this should be studied further to illuminate potential inequalities.

The number of appointments at hospitals and home was demanding for many families and put a strain on the family. Caring for a sick child is associated with extra activities beyond those involved in caring for a healthy child – extra activities that can represent a potential source of stress and burden (1,2,14,20,21). Additionally, we found that parents felt they held a large share of the responsibility for coordinating appointments and bringing messages from one sector to another. Relieving the burden and stress linked to both attending appointments and upholding a coherent patient trajectory from the parents' shoulders, may give them more time and energy to concentrate on becoming a family. The coordination between appointments must be explored to identify factors influencing negatively on workflows and direct critical attention and reflection to the number of appointments. Moreover, it seems that parents may benefit from a written overview of what they can expect, which healthcare professionals and healthcare sectors will be involved in the process and what they can expect from each and where they can get help.

Finally, we found that the interaction with healthcare professionals is a complicated act. Parents assess the quality of the interaction with healthcare professionals and evaluate their competencies (14,22). Meeting competent healthcare professionals gives rise to hope and help the parents coping the uncertainty. Whereas a devaluating of competencies makes parents withdraw from the interaction, and if possible, seek out alternatives. The assessment of the quality of the interaction is closely connected to the feeling of being viewed as a family or being left with the feeling of their child is regarded as "just a patient". Parents want their child to be seen and treated as more than "just patients".
Healthcare professionals holds the responsibility for creating a constructive and professional collaboration with the families with consideration for their individual concerns and needs. Information and individual communication are factors that help reduce anxiety and enables a good starting point for constructive collaboration (17,23).

Our study was based on qualitative interviews with parents of children diagnosed with visual impairment or blindness before the age of one. Our study provided rich data material, but the study also has some limitations. Due to our study sample of eight parents, the results are not generalizable to all parents of children with visual impairment or blindness around the time of diagnosis. We sought to minimize recall bias, by interviewing parents within 6 months of the diagnosis but it remains a risk, as parents relied on their retrospective experiences.

Conclusion

Based on the interviews with parents of infants with newly diagnosed visual impairment or blindness it seems the single most important lesson for healthcare professionals is to bring hope at a time when all hope may seem to be lost. Second, attention should be focused to families with none or sparce supportive networks as they are more likely to experience heightened stress and burdens. A call for emotional support in the form of a psychologist must be investigated as well as peer networks. Third, coordinating appointments between hospital departments and at home therapies as well as reducing the number of appointments to allow parents time to establish a family relation with their child. Parents respond well to competent healthcare professionals who keeps them informed and who sees the child as an individual rather than as a diagnosis.

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Notes on contributors

Nina Milde (corresponding author)
Nina Milde is a registered nurse, Master of Arts in psychology and health promotion and Clinical Teacher at the Department of Ophthalmology at Copenhagen University Hospital - Rigshospitalet – Glostrup. Her research interest include rehabilitation, health promotion, inequalities in health, nursing, ophthalmology, and family life.

Line Kessel
Line Kessel, MD, PhD and Clinical Research Associate Professor of Ophthalmology at the Department of Ophthalmology, at Copenhagen University Hospital - Rigshospitalet – Glostrup. Her research interest are gene therapy, pediatric cataract and glaucoma, childhood myopia and hereditary eye diseases. Line has a profound career within research and has published more than 100 peer-reviewed articles.

Kamilla Rothe Nissen
Kamilla Rothe Nissen, MD, PhD and Head of The Danish Registry for the Blind and Partially Sighted Children at the Department of Ophthalmology at Copenhagen University Hospital – Rigshospitalet – KennedyCenter. Her research interests are focused on pediatric ophthalmology.

Annette Rasmussen
Annette Rasmussen, RN, MSc, PhD and Clinical Specialist in Nursing at the Department of Ophthalmology at Copenhagen University Hospital – Rigshospitalet – Glostrup. Her research interests are concerned about nursing, rehabilitation, PROM and ophthalmology. Annette has published nine peer-reviewed articles.

Contributorship statement

NM contributed to the main design of the study and development of the research questions, the main structure and write-up of the paper, and final amendments to the manuscript. NM and AR analyzed the data, with LK and KN supervision. All authors discussed and interpreted the data once analyzed and helped structure the manuscript. LK was responsible for overseeing the full development of the study design, data collection, the analysis and development of the final manuscript. All authors contributed to proof-reading and amendments of the final manuscript.

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Data availability statement

Data are available on reasonable request. Background material relevant to the study are included in the article or uploaded as online supplemental information.

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Online supplementary file 1 - Interview guide

Theme 1 - The first phase

At first, I would like to hear you, if you want to tell a little about that period where you began to suspect that there was something wrong with your child's vision?

- What happened? How did you notice it?
- Who did you address with your concern?
- What was the timespan from your first concern until you talked to someone about it?
- Or was it someone else that noticed it? (health nurse, GP)
- How did they take you in?
- What was your thoughts?
- Who did you share your thoughts with?
- What made you wonder?
- How did you experience this period?

The need for help and support for parents and their everyday life

- What did you think about/what were your concerns, before you knew the explanation of your child visual challenges/disabilities?
- What need for help did you have at that time?
- Who could you share your concerns with?
- What could they help you with?
- What couldn't they help you with?
- If you look back at that time, how would a normal day look like?

Opportunities to support the child

- Did you feel that you had the right opportunities to support your child in this period? (why/why not?)
- What need for help and support did you have in this period? (knowledge, rights etc.)

If we look at the rest of the family, what were their thoughts or concerns?

- Your partner, the child (depending on age), siblings?
- Did you have similar or different needs?

Theme 2: Meeting the hospital

Let's move on to the time for the investigation of the specific reasons to the visual challenges – what was that like?

- What was your experience of this period?
- Which professionals did you communicate with?
- What worked?
- What could have been better?
- What could you have wished for?
- How did you experience the cooperation between departments?
- Did you experience any waiting time for examinations or conversations with specialists?
- What was your role in this period?
- Did you have to wait for development of symptoms before it was possible to determine a diagnosis?
- Did your child's diagnosis make any difference?
- Did the professionals explain the meaning of the diagnosis?

Opportunities to support the child

- Did you feel that you had the right opportunities to support your child at this time? (why/why not?)
- What need for help and support did you have in this period? (knowledge, rights etc.)

If we look at the rest of the family, what were their thoughts or concerns?

- Your partner, the child (depending on age), siblings?
- Did you have similar or different needs?

At this time where you offered any support, help or counselling – or did you look for it yourself?

- Which kind of support, help or counselling where you offered? (GP, synskonsulent, health nurse etc.)
- Did you accept the help or support? (why/why not?)
- How did you experience the help that you received?
- Have you sought for help yourself? If yes, how did you experience the help that you received?

If we look at the rest of the family, have they been offered any kind of help or support? If yes, what were their experiences? (partner, siblings, grandparents)

Were their any help or support you could have wished for in this period – that you didn't received?

What help or support did you find most valued in this period?

Theme 3: From hospital to municipality

Let us talk a little about the time from your child was registered in the Danish Registry for the Blind and Partially Sighted Children (diagnosis) till you had your first contact with the synskonsulent.

- When you think back, how did you experience this period?
- What do you think worked well/not well?
- When you think back at this period, what surprised you the most?
- If you had some questions, who could you ask?

Opportunities to support the child

- Did you feel that you had the right opportunities to support your child in this period? (why/why not?)
- What need for help and support did you have in this period? (knowledge, rights etc.)

Need for help and support

- What were your concerns in this period?
- What need for help and support did you have?
- Who did you turn to for help and support?
- What could they help you with?
- What couldn't they help you with?

At this period where you offered any support, help or counselling – or did you look for it yourself?

- Which kind of support, help or counselling where you offered? (GP, health nurse etc.)
- Did you accept the help or support? (why/why not?)
- How did you experience the help that you received?
- Have you sought for help yourself? If yes, how did you experience the help that you received?

If we look at the rest of the family, have they been offered any kind of help or support? If yes, what were their experiences? (partner, siblings, grandparents)

Were there any help or support you could have wished for in this period – that you didn't received?

What help or support did you find most valued in this period?

Theme 4: The everyday life and the future

Until now we have been talking a lot about the past experiences. Now we move on to talk about your everyday life and your thoughts about the future

- What do you think takes a lot effort or time in your everyday life?
- What need for support or help do you have now?

- Do you have someone you can turn to for help and support?
- What can they help you with?
- What are they not able to help you with?
- How would you describe your role as a parent in this process?
- What have worked well?
- What could have been better?
- Would you say that your role as a parent in this process have changed over time?

Opportunities to support the child

- Did you feel that you have the right opportunities to support your child in this period? (why/why not?)
- What need for help and support do you have now? (knowledge, rights etc.)

When you think back at this period of your life as a hole, do you then think that your child's visual impairment has had consequences for your;

- Relationship
- Friendships
- Work situation
- Economy

What is other people's reaction when you tell them about your child's disabilities?

Do you feel that the help you receive are of the quality and standard that you expect? (yes – no, please elaborate/tell more)

Theme 5: Closure

Now we just have some final questions.

- From your point of view what would you have wished that could have been different?
- If you were to give an advice for any future families, what would that be?
- If you were to give an advice to the hospital, municipality etc. concerning help and support for families in similar situations, what would that be?
- From your actual position, what have then been the biggest surprise?
- Do you have any comments or questions to us?

Thank you for your help and time!

Rigshospitalet

HovedOrtoCentret

Dato: 12. juli 2021

Online supplementary file 2

Informed consent to participation in a development project

Cross-sectoral support to the parents of a child with visual challenges – A development project in the Ophthalmological Department

Declaration from the informant:

I have been given both written and oral information about the project to feel that I know enough about the purpose, method, advantages and disadvantages concerning my participation in the project to accept participation.

I know that my participation in the project is voluntary, and that I, at any time can pull back my consent without losing current or future rights to treatment.

I agree to participate in this development project and have been given a copy of this consent formula and a copy of the written information about the project.

Name of informant:

Date: Signature:

Do you wish to receive information about the project findings?

Yes: No:

Declaration from the one who has given the information:

I declare that the informant has been given both written and oral information about the project.

After my best belief there have been given enough information to take a fully informed choice about participation.

Name of the person who have given the information:

Date: Signature:

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	4
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	11
Occupation	3	What was their occupation at the time of the study?	11
Gender	4	Was the researcher male or female?	11
Experience and training	5	What experience or training did the researcher have?	11
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	3
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	4
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	4
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	3
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	3
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	3
Sample size	12	How many participants were in the study?	5
Non-participation	13	How many people refused to participate or dropped out? Reasons?	4
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	5
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	4
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	4-5
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	4
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	4
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	4
Field notes	20	Were field notes made during and/or after the inter view or focus group?	N/A
Duration	21	What was the duration of the inter views or focus group?	5
Data saturation	22	Was data saturation discussed?	4
Transcripts returned	23	Were transcripts returned to participants for comment and/or	N/A

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	4
Description of the coding tree	25	Did authors provide a description of the coding tree?	4
Derivation of themes	26	Were themes identified in advance or derived from the data?	5
Software	27	What software, if applicable, was used to manage the data?	N/A
Participant checking	28	Did participants provide feedback on the findings?	N/A
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	4
Data and findings consistent	30	Was there consistency between the data presented and the findings?	5-11
Clarity of major themes	31	Were major themes clearly presented in the findings?	5-11
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	5-11

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.