

Experiences with general practitioners described by families of children with intellectual disabilities and challenging behaviour: a qualitative study

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ABSTRACT

Objective: To investigate parents' experiences of follow-up by general practitioners (GPs) of children with intellectual disabilities (ID) and comorbid behavioural and/or psychological problems.

Design: Qualitative study based on in-depth interviews with parents of children with ID and a broad range of accompanying health problems.

Setting: County centred study in Norway involving primary and specialist care.

Participants: Nine parents of seven children with ID, all received services from an assigned GP and a specialist hospital department. Potential participants were identified by the specialist hospital department and purposefully selected by the authors to represent both genders and a range of diagnoses, locations and assigned GPs.

Results: Three clusters of experiences emerged from the analysis: expectations, relationships and actual use. The participants had low expectations of the GPs' competence and involvement with their child, and primarily used the GP for the treatment of simple somatic problems. Only one child regularly visited their GP for general and mental health check-ups. The participants' experience of their GPs was that they did not have time and were not interested in the behavioural and mental problems of these children.

Conclusions: Families with children with ID experience a complex healthcare system in situations where they are vulnerable to lack of information, involvement and competence. GPs are part of a stable service system and are in a position to provide security, help and support to these families. Parents' experiences could be improved by regular health checks for their children and GPs being patient, taking time and showing interest in challenging behaviour.

BACKGROUND

People with intellectual disabilities (ID) are at high risk of acquiring challenging behaviour and mental health problems,^{1–3} resulting in special healthcare needs. Some

ARTICLE SUMMARY

Article focus

- The aim of this study was to investigate the experiences with general practitioners (GPs) of the parents of children with intellectual disabilities (ID) in order to identify important areas for improvement and suggest fields for further exploration.

Key messages

- This study shows that families with children with ID have low expectations of their child's assigned GP, and that their total healthcare needs are not met.
- GPs should carry out regular health checks and be prepared to take a longer time than usual for consultations.
- When children with ID have comorbid challenging behaviour and/or mental health problems, GPs seem to avoid discussing these issues during consultations.

Strengths and limitations of this study

- Participants were of both genders and had a range of diagnoses, experienced diverse challenges and lived in different locations (rural or city).
- Our findings are in line with a relatively small number of similar studies in this field.
- Sufficient data were collected quickly, so only a small group of participants were interviewed.

research indicates that the health needs of people with ID are not properly met by either community or specialist healthcare systems.^{4 5} General practitioners (GPs) play a central role in general healthcare services, as they are the first point of contact when new health problems occur, are closely connected to community services, and are the gatekeepers to specialist services and carry out much of the follow-up work. In addition, GPs are the major prescribers of psychotropic medication to people with ID, mostly to treat 'unrest'.⁶

Several papers have addressed the difficulties of providing health services for people with ID, especially when there is challenging behaviour and/or mental health problems.^{7–12} The term challenging behaviour refers to any behaviour that puts the person displaying the behaviour and others at risk. This type of behaviour can interfere with home life and family members, and can affect the person's ability to safely interact with community members and facilities.¹³ Mental health problems can be difficult to identify and diagnose in children with ID, as indicated by the vast range of prevalence rates varying from 14% to 60%.² The term mental health problems as used in this article includes all symptoms of comorbid psychiatric disorder such as depression and anxiety.

Unmet physical healthcare needs are also reported among people with ID.^{14–16} A study demonstrated higher disease detection after a health assessment programme was initiated,¹⁷ and another study demonstrated benefits in health outcomes after a health screening programme.¹⁸ People with ID with concurrent mental health problems are a particularly vulnerable group. It may be appropriate to include those with challenging behaviour because it is suggested that there is considerable overlap between mental health problems and challenging behaviour.^{19 20} This group is vulnerable because of the link between mental health problems and medical illness. Psychotropic medication can have physical side effects, physical problems can be expressed in challenging behaviour or mental health problems, and social factors such as an unhealthy lifestyle and poor living environment can contribute to physical problems.²¹ Even though caring for patients with ID and difficult behaviour is a challenge involving several health service providers, GPs often have a long-term perspective and geographical closeness that puts them in a special position. GPs' responsibility for this vulnerable and 'hard to hear' group are not clear, but should involve regular health checks and collaboration with other health services.

The Regular General Practitioner scheme was implemented in Norway in 2001. Every citizen can choose their assigned GP, and it is possible to switch to another GP or even a GP in another municipality. In Norway less than 0.5% of the population do not have an assigned GP.²² A system with a personal GP for everyone can provide personal services because the GP and their co-workers know the patient, their history and their family. People-centred primary care that puts people first can reduce return visits for unresolved health problems, improve the job satisfaction of healthcare staff, and give the patient a feeling of being listened to.²³

It is a general goal in primary care, and especially important for children with ID, to reduce health disparities in the population. Despite this, there is little knowledge of or research into families' experiences with primary healthcare services. A study investigating the primary healthcare received by the families of children

with ID demonstrated dissatisfaction with several aspects of healthcare services, including lack of discussion about the impact of the child's condition on the family and inability to answer questions about the child's condition.²⁴ Surveys are important in that they provide a representative and group-based estimate of participants' satisfaction. By providing more in-depth descriptions of the type of challenges experienced, qualitative study can help the development of hypotheses. The aim of this study is thus to investigate parents' experiences with GPs in order to identify important areas for improvement and suggest fields for further exploration.

METHODS

A qualitative method

We chose a qualitative approach in order to obtain more detailed descriptions of the challenges experienced by parents of children with ID. In-depth interviews are well suited for inquiring about people's opinions and experiences, or for facilitating a deeper understanding of opinions and attitudes to certain issues as seen from the participants' viewpoint.²⁵ We preferred open interviews so we could focus on participants' stories and their perspectives on the health services, in particular their GPs.

Participants

Data were drawn from seven interviews with a total of nine parents of young people (age 10–16) with ID and reported challenging behaviour and/or mental health problems (see [table 1](#)). The sample reflected both genders and different experiences, locations (city and rural), level of ID, ages and health service utilisation.

Each family had a different GP. The participants were recruited following a staff meeting with Hedmark Habilitation services for children at Innlandet Hospital Trust, and included patients currently engaged with the habilitation service. This service supervises approximately 450 people with ID and their caregivers. The staff identified 14 potential participants with reported challenging behaviour and/or mental health problems, and the researchers purposefully selected participants with regard to location, diagnoses, age and gender. It was estimated that a sample size of 5–10 participants would be required to achieve data saturation and identify all themes. After seven interviews the researchers found that no new themes were emerging, and so we terminated the recruiting of new participants.

Setting

Five interviews were conducted with the mother, while two interviews were conducted with both the father and the mother of the child. Participants could choose to be interviewed at home or in a meeting room at the work place of the interviewers. Five interviews were conducted in the participant's home. The participants could stop the interview whenever they wanted with no further explanation, but no one did. All participants were interviewed once and sessions lasted for 60–90 min, with

Table 1 Participant (young people with intellectual disabilities) identifier, challenging behaviour, mental health problem and service providers in addition to general practitioners (GPs) and habilitation services

Name	Challenging behaviour	Mental health problem	Present service providers in addition to GPs and habilitation services
A	Tantrums, ritualistic or repeated actions, screaming	Anxiety, panic attacks, obsessive compulsive disorder	Paediatric hospital clinic, orthopaedic hospital clinic, national epilepsy centre, educational and psychological services, auxiliary housing, health visitor, physiotherapist
B	Occasional crying	None	Auxiliary housing, educational and psychological services, support worker, community activity services, health visitor
C	Aggression, tantrums	Depression	Educational and psychological services, support worker, health visitor, community care services
D	School refusal	Depression	Child and youth psychiatric hospital services, health visitor, educational and psychological services
E	Aggression, suspicion, material damage	Paranoia, mania	Paediatric hospital clinic, community coordination services, auxiliary housing, support worker, educational and psychological services, child welfare
F	Delay in falling asleep, refusal behaviour	Anxiety	Paediatric hospital clinic, child and youth psychiatric hospital services, community coordination services, educational and psychological services, support worker, auxiliary housing, physiotherapist, ergonomist
G	Aggression, controlling others	None	Educational and psychological services, physiotherapist, community care services, health visitor, speech therapist

a mean of 70 min. Interviews were carried out from August to October 2010 and were recorded on audio files. The interviews were conducted by two of the authors (TF and KK) and consisted of largely open-ended questions based on an interview guide consisting of main questions and a checklist.

The main questions asked in the interviews were:

1. Can you tell us about your child?
2. Can you tell us about you, your child and your family's relationship with your GP?

The checklist was used to gather information that was otherwise missing, or to deepen incomplete information. Typical follow-up questions were related to type of challenging behaviour, service offers from primary healthcare services and secondary healthcare specialities, mental health problems, health check routines and frequency of contact with the GP.

Analysis

Throughout the meeting, the interviewers noted the participant's frequently used words and phrases, statements that needed to be followed up and state of engagement, laughter, pauses and tones, all of which were used to analyse data. The interviews were transcribed for further analysis which was carried out using systematic text condensation.^{25–27} The first author read the transcript multiple times to get a comprehensive sense of the interview, identified meaningful units and transformed these into themes and subthemes capturing 'essential expressions'. This was then discussed among all the authors who independently commented and confirmed the appropriateness of coding, and provided additional and alternative ideas.

The initial findings were presented for discussion at research meetings and feedback was used to revise the

final themes. For example, in these meetings, other researchers and GPs pointed out the relevance of points for this study, asked for additional information and gave alternative interpretations of the material. Finally, the first author constructed a model to visualise themes and subthemes (figure 1), and meaningful units were discriminated and categorised.

The regional committee for medical research approved the study. Every participant signed an informed consent form.

RESULTS

During the interview, parents described past events, contact with health services, daily living and the family situation. The parents interviewed were eager and enthusiastic about telling their story. The interviews revealed both challenging behaviour and mental health problems (eg, depression, anxiety, tantrums, aggression and delay in falling asleep). Despite contact with several primary and specialist health services, the families still had unmet health needs. Typically, the primary health services accessed in addition to the assigned GP were educational and psychological services, child welfare services, individual coordinators and auxiliary housing services. In addition to habilitation services, other involved specialist services typically were psychiatric services for children and adolescents and paediatric hospital services (for more details see table 1).

Three main categories with 13 subordinate themes emerged from the descriptions of the parents of the relationship they and their child had with their GP. The model (see figure 1) shows how the themes influence each other.

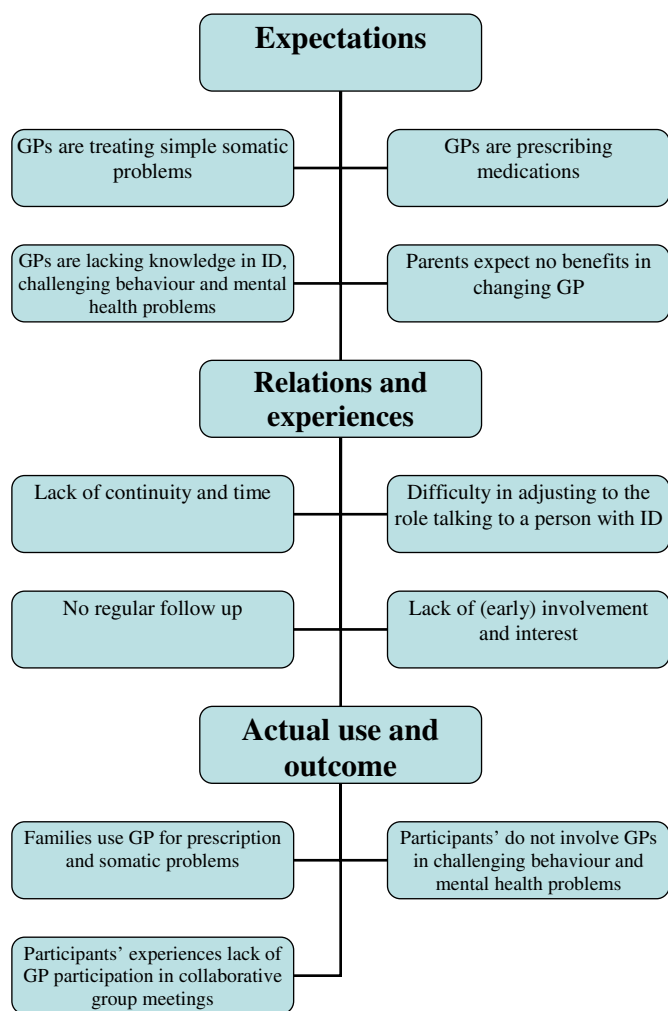


Figure 1 Model with themes and subthemes. GP, general practitioner; ID, intellectual disability.

Expectations

The first main category encompasses the expectations parents had of their child's GP. The parents also described how they had selected their present GP, and also described changes in GP attendance and continuity.

A common understanding was that the GP only prescribes medication and treats simple somatic problems. The parents did not expect the GP to treat anything other than somatic health problems, and a participant illustrated it like this:

Actually he has mental problems... in general he is in good health.

No one had searched for a GP with special competence with children with ID. All but one had experienced involuntary change of their GP, caused by GPs changing their work place or continuing education. The parents did not expect the GPs to be specialists in ID, challenging behaviour or mental health problems, but relied instead on hospital services. Even though it is easy to change GP, none of the participants interviewed had changed their child's GP. A mother said:

I don't know if it helps to change to another GP, and that's why I haven't done anything about it.

This participant used the same GP as her child, and was satisfied with the GP for herself but not for her child.

Relationships and experiences

The second main category includes contact and communication between the GP and the family, through descriptions of meetings and contacts with the GP. The frequency of children visiting their GP varied from never to monthly. One participant saw no reason to take their child to the GP, and explained that the GP had never asked about it. Another participant went to the doctor for simple treatment they could have done at home. An explanation for frequent appointments was to strengthen the relationship between the child and the GP, and to reduce the child's anxiety when visiting doctors. Regular health checks, primary care-based health reviews or more frequent appointments initiated by the GP were not mentioned.

Participants' descriptions of involuntary changes in GPs also highlight the resulting challenges regarding the GP–patient relationship, the GP's knowledge of the child's medical and family history and the participant's trust in the GP. The participants also described some previous GPs who were enthusiastic and interested in psychiatric problems, but this was seen as unusual. Participants describing such a GP missed these qualities. A participant said this about her child's first GP:

I trusted him more, and could talk with him about everything.

The interviews show the need for GP relationships that allow the discussion of issues that are not strictly medical or somatic; the participant mentioned above experienced a GP who was really interested in her and her child, and a relationship that could meet her and her child's total health needs.

Participants also described the role their GP took when talking to their child with ID. The GPs focused on and looked at their child during the consultation, but asked the parent for more detailed descriptions. Some had children with little or no vocal verbal skills, but nevertheless the GP was oriented towards the child. Although this was a positive experience, the participants also reported that there was not time enough to properly discuss a complex situation. One participant had solved this by always asking for extra time when they called for an appointment, and they described good experiences with their GP:

Actually it's the GP we are most satisfied with, except that he takes little initiative on his own.

This participant described a GP who listened to them and acted on their proposals, but seldom or never suggested anything beyond that initiated by the parents.

Another cluster of experiences dealt with the regularity or existence of follow-up consultations. There was only one description of regular follow-up, in this case annual consultation. Another participant who had never taken her child to their GP, said:

We are satisfied for our own sake, but for my child it has never really been an option to visit the GP.

This participant had a child with several challenges, and had been followed up by both habilitation services and paediatrics, but contact with paediatrics had ended a few months previously. Nevertheless, the GP was responsible for prescribing psychotropic medication to treat panic disorder and anxiety and had called a paediatric physician for advice. The paediatric physician had then called a specialist department for ID and psychiatric comorbidity, and the decision had been that the child should to be given psychotropic medication, although none of the doctors actually had seen the child. Another participant had also been prescribed medication by phone, and their parent said:

His GP has prescribed sleeping medicine once, and I recall that's the only time his GP had to deal with him. And then he didn't need to show up.

The parents reported that medication was given for acute or more permanent problems, and that GPs did not consider it necessary to see the child or conduct a personal examination. In such cases, the GP has to rely exclusively on their own interpretations of what the parents or others say, in combination with information from a patient journal and possible earlier examinations. In addition, none of the parents were instructed on how to evaluate the possible effects of the medication.

Actual use and outcome

The third and last main category covers descriptions of how the participants use their GP.

The participants noted that their GP focused on somatic problems during consultations and showed a lack of involvement. Each child received services from several primary and specialist health services, and the parents were unsure where to seek help for their child's specific challenges.

A cluster of descriptions demonstrate that GPs end up being doctors for simple somatic problems and prescriptions, and are not involved in the behavioural issues or mental health problems of the children. A participant said this when asked why they do not use their GP for challenging behaviour or mental health problems:

I think... first of all my GP is sceptical about it, and I think it's too special for them.

Parents' expectations are that GPs cannot deal with challenging behaviour and mental health problems, and

explain that they did not involve their GP in the total situation regarding their child.

A subtheme is GP participation and involvement in collaborative groups and group meetings. When several health services are involved, collaborative group meetings are conducted to coordinate services to better meet the needs of the patient. Participants reported a lack of GP participation in collaborative group meetings. Two scenarios were revealed in the interviews: (i) GPs were invited to collaborative group meetings, but did not attend; and (ii) GPs were not expected to contribute in a collaborative group meeting, and were therefore not invited. A participant said this at the end of the interview when we asked if they would involve their GP in collaborative group meetings:

Yes, it is actually a new dimension we haven't thought of before.

This illustrates the need for information on the possibilities and benefits families with an ID child might achieve by involving their GP in collaborative group meetings. It also illustrates the bi-directionality of an interview setting, showing that participants and interviewers share information and influence each other.

DISCUSSION

The main findings from this study are that parents have low expectations of their GP, accept a low frequency of contact and feel that the GP is focused on somatic and medical issues. The families use their child's GP for prescriptions and simple somatic problems, but do not involve them in dealing with challenging behaviour or mental health issues. In addition, the parents described a lack of GP participation in collaborative group meetings. However, none of the parents wanted to change their child's assigned GP.

GPs represent a stable service, and can provide these families with a consistent collaborative partner in close contact with other healthcare services. However, the results of this study suggest that GPs do not act as coordinators for this patient group: the participants noted low or no attendance from GPs in collaborative group meetings, and ended up being the ultimate coordinators themselves. The fact that none of the participants had current GPs who participated or were involved in group meetings, strengthens the impression that GPs deal with simple problems only. This can result in lack of involvement and underuse of the GPs competence and knowledge of the health services, in turn leading to low expectations from parents and reduced health services from their GP.

General practice based health assessment programmes for people with ID have demonstrated benefits related to the identification of health needs, meeting health needs and reducing health inequalities.^{17 18} Regular GP health checks might afford the GP the means for a successful consultation: a good relationship with the child. There are several areas of concern in relation to children with

ID. Nutrition, constipation, epilepsy, thyroid disease, medication, physical activity, challenging behaviour and mental health problems require attention and need to be checked on regular basis. Frequent follow-up ensures that the patient actually meets the GP and can engender a feeling of security between the GP, the child with ID and their family. This may contribute to the parents' feeling of security and may prevent health problems in both the child and these families. The families need to be able to trust their GP so they can contact them whenever necessary. The parents interviewed did not expect their GP to be involved in their child's total health needs as long as issues like challenging behaviour and mental health problems were avoided in GP consultations.

One participant always asked for extra time for a GP appointment, and they were generally satisfied with their GP, even though they told him what to do because of his lack of initiative. There is little knowledge of or research on families' satisfaction with primary healthcare services, but some surveys have shown similar results to our qualitative study.^{24 28} An important issue for further research is to address medical school curricula regarding ID, challenging behaviour and mental health problems. The parents interviewed seemed to turn to sources other than GPs for information, but were at the same time unsure where to seek help. It is also important to examine how responsibility is shared between the habilitation services, GPs and other health services. It may be that lack of GP involvement is due to a fear of upsetting specialists. All service providers have a responsibility and can play an important role in recognising ill health.

Focus also needs to be directed at GPs who prescribed medication without a personal examination. Information from people who know the child is important, but can not fully replace the GP's own observations. Interpretation of verbal information is important, especially when patients have problems or lack adequate communication skills. As they provide a mainstream service, GPs need a broad competence, but it can be difficult to acquire knowledge about minority groups such as people with ID, especially when they have behavioural and psychopathological challenges. The major classification systems, DSM-IV-TR and ICD-10, are difficult to apply and diagnosis requires specialist multi-professional involvement.^{10 29} In particular, specialist advice will differ regarding challenging behaviour and mental health problems among people with ID, and there are no national guidelines. This may explain why GPs do not raise psychopathological or behavioural issues, or avoid involvement when these topics are mentioned.

Limitations and relevance

Everyone in the research group read transcriptions of the interviews, and when seven interviews had been completed, agreed that the data were sufficient. Data saturation may have been due to the fact that the

participants represented a relatively homogenous group. They were all from the same county, were in a narrow age range (10–16 years), received health services from habilitation services for children, and were recruited because they had challenging behaviour and/or mental health problems. This obviously affects external validity and limits the generalisation of our results. Nevertheless, the participants were of different genders, had different diagnoses and challenges and lived in different locations (rural or city), and the results are consistent with international research that describes the difficulties experienced by families, and problems with general healthcare for people with ID.^{24 28 30 31} Our findings, therefore, may be transferable and important for further research in the field.

CONCLUSION

This study shows that GPs are underused by families with children with ID. In addition, several healthcare providers are involved with each child, but the child's total healthcare needs are not met. Attention needs to be focused on GP involvement in issues such as preventive screening services for somatic health, participation in collaborative meetings and involvement in challenging behaviour and mental health problems.

In general, the families investigated in this study have low expectations of their GPs, and seldom involve them in major issues such as challenging behaviour and mental health problems. When GPs are involved, it seems to be on a temporary basis, although the problems continue for the families and their child. The minor involvement of GPs may be due to the fact that paediatric department habilitation services are involved and thus the GPs assume that healthcare needs are being met. GPs have a close connection with community services and are the gate-keepers of specialist health services, but this potential was not fully exploited by the participants we interviewed. Regular health checks and participation in collaborative meetings could allow the GP provide more support for families needing complex health services for their child.

Further research is needed to investigate factors that could influence GP follow-up of children with ID, and this paper highlights some issues that need to be addressed. There has been little study of how GPs interact with children with ID and their caregivers, and this report has pinpointed some important issues in this field. In summary, the recommendations of the families involved are: (i) there should be regular GP health checks, (ii) GPs should be flexible regarding the length of the consultation, and (iii) GPs should be interested in the problems of daily living including the situation of the parents.

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Competing interests None.

Ethics approval The Norwegian regional committee for medical research approved this study.

Contributors TF contributed to acquisition of data, transcription, analysing data, drafting and critical revision of the article and approval of the final version. ORH, LJD and LL contributed to the design of the study, analysing data, critical revision of the article and approval of the final version. KK participated in the interviews, analysing data, critical revision of the article and approval of the final version.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement No additional data are available in order to protect the identities of the participants.

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Research check list - Fredheim et al. 2011

Domain 1: Research team and reflexivity

Personal characteristics

- | | |
|-------------------------------|--|
| 1. Interviewer/facilitator 1: | Terje Fredheim |
| 2. Credentials: | Master of Learning in Complex Systems |
| 3. Occupation: | PhD-student |
| 4. Gender: | Male |
| 5. Experience and training: | Participated in earlier qualitative and quantitative research |
| | |
| 1. Interviewer/facilitator 2: | Kari Kjønsgberg |
| 2. Credentials: | Reg. nurse, MMHC |
| 3. Occupation: | Reg. nurse specialised in mental health care. |
| 4. Gender: | Female |
| 5. Experience and training: | Participated in different earlier qualitative health research studies. |

Relationship with participants

- 6. Relationship established: There was no relationship prior to study commencement.
- 7. Participant knowledge of the interviewer: They were informed about researchers' professional background and interest in the project.
- 8. Interviewer characteristics: The interviewers' connection with specialised health care may be regarded as bias, but was considered as a minor problem.

Domain 2: Study design

Theoretical frame work

- 9. Methodological orientation and theory: The study relies on a phenomenological approach with content analysis and systematic text condensation as the main method in analysing data.

Participant selection

- 10. Sampling: Names of possible participants were given the interviewers from habilitation services on specialised health care level. The interviewers then recruited strategically from this list to represent different gender, age, diagnosis and location (rural or city).
- 11. Method of approach: Participants were contacted by telephone. Information was given and request made, and appointment made with those who were positive.
- 12. Sample size: Nine participants were interviewed, representing seven children.
- 13. Non-participation: Two persons refused/hesitated to participate. No drop-outs. The reason for non-participation was not asked for.

Setting

- 14. Setting of data collection: Five interviews were conducted in the participants' own home, two in a meeting room at the researchers' working place, by the participants' own choice.
- 15. Presence of non-participants: None.
- 16. Description of sample: Seven females and two males were interviewed (parents). They represented seven children of various gender, age, location and health service offers.

Data collection

- 17. Interview guide: A guide with themes and main questions was provided by the researchers and discussed with the supervisors. Also a checklist was used to get more information on topics that seemed important or topics not mentioned by the participant. No pilot was tested.
- 18. Repeat interviews: Repeated interviews were not used. Participants were encouraged to contact the interviewers if they wanted to add something and one of them made contact by telephone to give some more information.
- 19. Audio/visual recording: Audio recording was used to collect data.
- 20. Field notes: The two interviewers made field notes during the interviews, and immediately after each interview.
- 21. Duration: Interviews lasted 60 – 90 minutes.
- 22. Data saturation: Saturation was discussed in the research group after the seven interviews had been conducted and was then regarded as satisfactory.
- 23. Transcripts returned: Transcripts were not returned to participants for comment or corrections.

Domain 3. Analysis and findings

Data analysis

- 24. Number of data coders: All five in the research group read the complete transcript. One of the interviewers presented identified meaningful units and themes derived from the material and they were discussed in the research group.
- 25. Description of the coding tree: The coding tree is illustrated with a figure of major and minor themes.
- 26. Derivation of themes: Themes emerged from the data.
- 27. Software: No additional software was used.
- 28. Participant checking: Participants were offered feedback on the findings. Two of them expressed a request for feedback.

Reporting

- 29. Quotations presented: Participant quotations were used to illustrate findings. Quotations are not identified in this paper due to a small number of participants.
- 30. Data and findings consistent: The themes developed by the researcher(s) were logically consistent and reflective of the data.
- 31. Clarity of major themes: The major themes are described in the article, and reflect the research question.
- 32. Clarity of minor themes: Minor themes are described in the article, and reflect meaningful units. Diverse cases are described where necessary.