Information seeking by parents of children with physical disabilities: An exploratory qualitative study

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ARTICLE INFO

ABSTRACT

Background: Evidence suggests that parents of children with disabilities feel that not all their information needs are being met, but it remains unclear how parents try to fill these information gaps.
Aims: The aim of this study is to describe how parents of children with physical disabilities search for and evaluate information.
Methods: Qualitative semi-structured interviews were conducted with 15 parents of children with a disability, aged 1.5–21 years. Data were analysed using thematic analysis.
Results: There was much variation in information needs between parents. Parents used different sources, depending on the type of information needed, the most important being healthcare professionals, peers, and websites. Peers played an important role in information provision and were the preferred source of experience-based knowledge and support. The Internet is a widely used medium to search for information and to access various sources. There was a general preference for closed Internet communities for peer contact. Information was commonly evaluated by comparing sources.
Conclusions and implications: Parents use different sources for different information needs, and evaluate information by comparing them. Healthcare professionals and parents can support each other in locating and evaluating information including experience-based knowledge. Healthcare professionals should guide parents in their search for information and experience-based knowledge from peers.

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What this paper adds

In order to help parents search for and find information, it is crucial to explicitly explore their information needs, and to guide them in getting answers. The Internet as a source of information should be acknowledged and discussed with parents. Healthcare professionals could also encourage and facilitate peer contact, e.g. by mentioning the existence of online communities or mediating personal contacts between peers, since these may provide the kind of experience-based information that is perceived as very useful by parents.

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1. Introduction

In paediatric rehabilitation, a family-centred service (FCS) is considered best practice. This approach recognises the important role of the family and parents in a child's life (MacKean, Thurston, & Scott, 2005; Rosenbaum, King, & Cadman, 1992). It focuses on the competencies of parents and on developing a partnership between parents and healthcare providers (Bamm & Rosenbaum, 2008; Kuo et al., 2012; Rosenbaum, King, Law, King, & Evans, 1998).

Although a FCS is considered best practice, there is still room for improvement (Bamm & Rosenbaum, 2008; Graham et al., 2006; MacKean et al., 2005; Siebes et al., 2007). In order to empower parents in the care process, they should have knowledge, skills, and opportunities enabling them to take a more active role in the process (Koren, DeChillo, & Friesen, 1992). Information provision is widely regarded as a crucial determinant of parents taking an active role in the care process and in decision-making (Hummelinck & Pollock, 2006; Jackson, Cheater, & Reid, 2008; Raats, van den Brink, & de Wit, 2013).

Having a child with a disability can have a great impact on the parents and the family as a whole (Rentinck, Ketelaar, Jongmans, & Gorter, 2007). Families will have many questions, and a huge need for information. This could be information about the diagnosis, prognosis, and therapeutic options, but also matters like how to make use of available services, how to find information about suitable leisure activities, how to deal with financial issues, how to manage daily care tasks in the family, and how to raise a child with a disability and his/her siblings (Bailey, Blasco, & Simeonsson, 1992; Hendriks, De Moor, Oud, & Franken, 2000; Palisano et al., 2010; Piskur, Beurskens, Jongmans, Ketelaar, & Smeets, 2015).

The literature clearly shows that these needs change over the years (Hummelinck & Pollock, 2006; Nordfeldt, Angarne-Lindberg, Nordwall, & Krevers, 2013; Pain, 1999). New needs arise in new situations associated with the child growing up and entering new life stages with the phase of the child's development, with changing family situations and/or with changing healthcare options (Nordfeldt et al., 2013; Pain, 1999; Sloper & Turner, 1992).Evidence suggests that not all of the information needs of parents of children with disabilities are being met (Huber, Dietrich, Cugini, & Burke, 2005; McDowell, Duffy, & Parkes, 2015; Palisano et al., 2010; Sloper & Turner, 1992). In previous studies, parents reported that healthcare professionals were doing a good job of providing respectful, comprehensive services in partnership with families, but the provision of specific and general information was the area most commonly mentioned as needing improvement (Cunningham & Rosenbaum, 2013; Kruijsen-Terpstra et al., 2016). A specific challenge in this respect is the fact that parents often find it difficult to pinpoint and express their information needs, as they often do not know the right questions to ask or what information is available (Alsem et al., 2013; Hummelinck & Pollock, 2006; Jackson et al., 2008).

Another important aspect of the FCS approach is that of respecting diversity. Each family will have different needs for information provision, at different levels (Longo & Woolf, 2014; Nordfeldt et al., 2013). The common goal in FCS care is to tailor the information to each particular family (Bamm & Rosenbaum, 2008; Kuo et al., 2012; MacKean et al., 2005). In order to improve the way the information needs of individual families are met, it is important to know their needs and preferences. Important in this respect is the timing of information provision (Jackson et al., 2008).

Internet search in general is becoming a natural part of daily life, (Eurostat, 2013) and parents frequently search for health-related information (Dominguez & Sapina, 2015; Khoo, Bolt, Babl, Jury, & Goldman, 2008; Plantin & Daneback, 2009). Although many parents do search online, (Anker et al., 2011; Bianco et al., 2013; Dominguez & Sapina, 2015; Glynn, O'Duffy, O'Dwyer, Colreavy, & Rowley, 2013; Huber et al., 2005; Khoo et al., 2008; Pehora et al., 2015) the literature suggests that online health information is not routinely discussed between doctors and parents (Bianco et al., 2013; Dominguez & Sapina, 2015), and it is difficult for parents to evaluate the health information they find on the Internet (Pehora et al., 2015).

The Internet is regarded as complementary rather than substitutive to formal healthcare (Bianco et al., 2013; Suziedelyte, 2012). Online information, together with information from healthcare providers, can empower patients or parents to make decisions (Bartlett & Coulson, 2011; Jackson et al., 2008; McMullan, 2006). The paediatric rehabilitation literature shows the need for information, but it is not clear how these parents of children with disabilities try to fill the information gaps. This knowledge is of great importance for improving the provision of information, so as to create conditions for an equal partnership between parents and healthcare professionals.

The aims of the present study were to explore experiences of Dutch parents of children with disabilities as regards their information needs, and to describe the process of seeking and evaluating information and the different sources of information.

2. Methods

2.1. Design and study sample

In this study we used qualitative research methods, based on the thematic analysis approach (Braun & Clarke, 2006). Parents were asked to participate in semi-structured interviews.

Beforehand, we expected that 10–20 interviews would be necessary to reach data saturation. Parents were recruited using multiple strategies, approaching them via paediatric rehabilitation healthcare professionals from different rehabilitation centres in the Netherlands (e.g. therapeutic toddler groups), and inviting them to participate via the websites and Twitter accounts of De Hoogstraat Rehabilitation and BOSK, the national organisation for persons with disabilities and their parents. Eventually, the request for participants also reached private Facebook groups, e.g. "Ouders van kinderen met CP" (parents of children with CP), in the Netherlands.

Inclusion criteria were being a parent of a child between the ages of 1.5 and 21 years with a physical disability, regardless of the severity or nature of the disability. Parents had to agree to an interview of approximately one hour by giving informed consent. Parents were excluded if they were unable to communicate in Dutch.

The study design was approved by the Scientific and Ethics Committee of the Centre of Excellence for Rehabilitation Medicine De Hoogstraat Rehabilitation Utrecht, The Netherlands.

2.2. Data collection

Data were collected between January and May 2015. One or two interviewers conducted each of the face-to-face interviews. The interviews were held at a location of the parents' choice, e.g. at the families' homes, at the rehabilitation centre, at a nearby hospital or at the school the child was attending.

The interviewers were guided by a topic list. The main topics for the interview were "information needs", "searching for and finding information and sources of information" and "evaluation and interpretation of information". In order to create an open atmosphere, the interview started with an open question in which parents were asked to describe a recent situation in which they had a question and describe the strategy they used to get their question answered. This was followed by more in-depth open questions.

Each interview was recorded and the interviewer took notes. Each interview lasted 50–65 min.

2.3. Data management and analysis

The interviews were audiotaped and transcribed verbatim. The data were imported into the NVIVO 10 software program to facilitate the data analysis. In view of the exploratory aim of the study, we used a thematic analysis approach. The data were coded and analysed independently by two researchers (MA and FA), using open coding, followed by axial coding using a constant comparative approach. Discrepancies were discussed between MA and FA. Themes were identified based on the relationship between codes and the frequency with which they were mentioned. New codes and themes were identified throughout the period of data analysis, and data were continuously re-examined. Themes were discussed by three researchers (MA, FA and MK). After 13 interviews, no further new themes or strategies emerged, so data saturation had been achieved. The last two interviews were used to confirm and verify the themes found in the first 13 interviews.

3. Results

3.1. Participants

A total of 15 interviews were held. Thirteen mothers and two couples participated, ranging in age from 26 to 58 years. Most parents preferred the interview to be held at their home. Child characteristics show there was a great diversity of diagnoses and abilities. The children were aged 3–20 years. Rare disorders included genetic syndromes and metabolic and mitochondrial diseases. Seven children were below the age of 4 years and thus not expected to be independent in personal care. Nevertheless they needed more assistance than their healthy peers. Characteristics can be found in Table 1.

Within the 3 topics that were explored in the interviews, axial coding identified several themes (Table 2). In addition, a bigger, overarching theme was identified: the process of empowerment.

3.2. Process of empowerment

Parents described how, in the course of the process of finding information, they became increasingly able to find information themselves, to address questions to the right person and to take a more directing role during consultations with professionals. At first, parents had difficulties formulating needs and finding information. *"Because it's about nutrition, it's about brains, it's about muscles, it's about mitochondria, it's about, well, in those early months it's a mish-mash of everything"* – (#8) As the children grew older, the parents found it easier to assume control: *"Now I have more time to take the initiative, like applying for medical transportation", "[Your life] is being taken over, [.] but now we are taking control again." – (#13).*

"Apparently you have to go through those experiences, to be able to stand up to a doctor and say no" – (#6) and *"from experience we knew which diagnostic tests we wanted. Now we were the ones to decide what happened to our son, not the doctor." – (#8).* The process seemed to be influenced by many factors, e.g. time after diagnosis, sense of self-control on the part of the parents and getting used to the role of being a parent of a child with a disability. Moreover, the pace and course of this process depended on individual factors. The process of developing the motivation and ability to be involved or participate in decision-making is called empowerment. Empowerment for parents thus constitutes a process in which information plays a major role, next to factors such as time and experience. The following paragraphs describe this process further as an overarching theme across all topics.

Table 1
Interview characteristics.

Number of interviews: N = 15	N=	
Participants		
Mothers	13	
Couple (Father and mother together)	2	
Parents' age, mean (range)	38.5	(26–58 years)
Location of the interviews		
At home	9	60%
At rehabilitation centre	2	13.3%
At school	2	13.3%
At nearby hospital	1	6.7%
Other	1	6.7%
Recruited through		
Therapeutic toddler group	3	20%
Private Facebook community	1	6.7%
Open Facebook community	5	33.3%
Newsletter of school	3	20%
Doctor's appointment	2	13.3%
Mailing list	1	6.7%
Children's age		
1–3 years	7	46.7%
4–12 years	6	40%
13–21 years	2	13.3%
Children's diagnosis		
Cerebral palsy, GMFCS[a] 2–5	6	40%
Rare syndromes	5	33.3%
Other[b]	4	26.7%
Children's walking		
Independent without aid	5	33.3%
Independent with aid	3	20%
Dependent	7	46.7%
Children's personal care		
Needs some help[c]	5	33.3%
Needs much help	6	40%
Total dependence	4	26.7%

[a] Gross Motor Function Classification System.
[b] e.g. metabolic disorders, developmental disorder of unknown origin.
[c] More help than expected for the child's age.

Table 2
Topics and Themes.

Topic	Theme	Key finding
Information Needs	- Trigger for needs - Changing needs	- Questions change over time and vary greatly between parents
Information Seeking	- Types of information - Information from healthcare professionals versus experience-based information - Online sources and communities	- Difference between 'professional' information and experience-based information - Source depends on type of question
Interpreting Information	- Preferred sources - Comparing sources	- Information from different sources compared for trustworthiness

3.3. Information needs

Many participating parents had difficulty finding the information they needed. Parents of children with rare conditions in particular had a hard time finding information about their child's condition *(#9, #11)*. There was much individual variation in the parents' information needs: *"When my child was just one year old, I already wanted to know about special needs schools"* – *(#2)* and *"not too much [information], otherwise you might worry too much"* – *(#1)*.

These information needs were often triggered by a particular experience, situation, or other factors. A question could arise at home: *"searching for a walking aid, because our daughter wants to walk"* – *(#2)* or *"the buggy doesn't suffice, how will we solve this problem"* – *(#1)*, or an idea could be put forward by other parents in a similar situation *"I should remember this for when she is the appropriate age"* – *(#10)* or after a meeting with a healthcare professional *"the idea was brought to our attention during an outpatient consultation"* – *(#12)*. These triggers functioned as a starting point for parents to formulate their specific needs, after which they could start searching for answers.

Information needs also changed over time in relation to the age of the child, the time since diagnosis and practical transitions. *"Of course each parent goes through a different process. We knew immediately when our child was born that she had a disability, while some people only find out their child is different from other children when she's 9 years old. – (#2) 'When they're still small, you get more assistance, but as they grow up, the relation with the hospital changes. There are fewer problems, and you get a different sort of question' – (#13).*

"You just focus on the problems. [. . .] I've just come across reimbursements for transport costs, when you have to visit the hospital a lot, you might get some money back. And as soon as that has stabilised, you start to search for the next thing you can work on." – *(#10)*.

3.4. Information seeking

The parents mentioned different search strategies and preferences: *"well, we searched everything [on the Internet]"* – *(#6)* and *"I prefer talking to other parents in person"* – *(#7)*. When parents were triggered to actively search for information, most of them appeared to search in different ways simultaneously, and to search for answers mostly from more than one source, *"ask a question at the rehabilitation centre and at the same time at the special needs contact of the community"* – *(#9)* or *"the same question on WhatsApp, Facebook and at the school"* – *(#10)*. Asking questions enabled most parents to fill their information and knowledge gaps. Still, some parents waited for healthcare professionals to address a subject, which may be related to their unawareness of the available information *"I said: what do I know, I need your expertise to tell me what I need to know"* – *(#1)* or to the fact that they did not know where to look for information *"There just wasn't any information about SDR [Selective Dorsal Rhizotomy] on the Internet"* – *(#5)* or because they trusted healthcare professionals to give them the information at the right time.

Parents used different sources of information. The four main ones the parents in our study used were healthcare professionals in general, professionals affiliated to the rehabilitation centre, institutions (e.g. government, hospitals) and peer contact. The most frequently mentioned sources were peers and doctors.

3.4.1. Types of information

Types of information included "professional" information and experience-based knowledge. Professional information included medical information about a child's disability, e.g. diagnosis, prognosis, and medical therapy options, and rehabilitation-related information, e.g. available services, different types of aids and the specific requirements of their child. Professional information could be generally applicable, especially if found online, but could also specifically relate to the situation of their own child. Experience-based knowledge included questions about the home situation or day-to-day care.

3.4.2. Professional medical information

Many parents were in need of medical information prior to or after a doctor's visit. While most parents preferred to get medical information from a doctor, some parents felt that not all of their information needs were met during a consultation with the doctor or that additional questions arose afterwards. Institutions were also a valuable source for many parents. Medical information was also found on websites of hospitals and rehabilitation centres, or specific websites (e.g. kinderneurologie.eu). In some hospitals, especially in specialised outpatient departments, a nurse practitioner or social worker was available for specific medical or other questions. Parents described them as approachable and accessible *"She is someone we're allowed to call at 7a.m. with questions, and she knows a lot"* – *(#13)*.

Parents reported that answers to specific rehabilitation questions were best provided by healthcare professionals affiliated to a rehabilitation centre or the rehabilitation departments of hospitals. Rehabilitation-related information included information about aids and adaptations, specific physical therapies, and interventions to improve daily functioning. Since most children entered the rehabilitation process at around two years of age, several parents indicated that they were relieved to have finally found a reliable source of medical and rehabilitation information. *"I was really happy to find the information I had longed for so long. At the Rehabilitation centre, the therapists have so much knowledge. The way it's provided could be better, but we got more information here than anywhere else"* – *(#6)*, *"I would never have been able to state all the requirements for his wheelchair application the way the occupational therapist did"* – *(#1)* and *"if someone could have told me sooner a rehabilitation centre can help with walking aids, that would have saved me lots of time and frustration"* – *(#2)*. After the introduction to the rehabilitation department, most parents were more easily able to find information directly from therapists *"the therapeutic toddler groups facilitate intensive contact with therapists, so every week you have a few opportunities to ask questions about anything"* – *(#7)* and from institutions *"when you need to apply for aids, occupational therapists can point you in the right direction, so next time you know what to do"* – *(#1)*.

3.4.3. Experience-based knowledge

The term experience-based knowledge refers to information obtained through personal experience and is divided into two categories: practical experience-based knowledge and support. Practical experience-based knowledge included practical advice and suggestions for strategies, e.g. "we are considering a therapeutic option or aid, what is your experience", "where can we find a suitable hairdresser", "what should we bring to scheduled hospitalisation". Support comprises emotional and personal support, e.g. finding recognition and acknowledgement and sharing feelings about difficulties and joys. The experience-based knowledge is gathered through experiences with individual children, either by parents or by professionals. These experiences can also be passed on by others, e.g. healthcare professionals explaining how other parents handled a situation.

Experience-based knowledge was highly valued by the parents. This kind of information was mainly provided by other parents and rehabilitation professionals. *"professionals at the rehabilitation centre have so much knowledge about practical things"* – (#6), *"other parents already went through this process with their child, because their child is somewhat older, and I think it's good to hear their considerations"* – (#12), *"only peers really know what you are going through and can assist you with practical tips"* – (#4).

Some parents preferred personal contact with peers *"I prefer personal contact, so I know them and their child"* – (#7) while others made contact through Internet fora or Facebook groups, *"otherwise contact with parents all over the world would hardly be possible"* – (#4) or both. Many parents helped others in return, *"I really valued the information from other parents, so yes, you want to pass it on. I think it's nice I can help others as well"* – (#5) and *"I participated in television programs to share our experiences and spread the information"* – (#3).

An important difference in contacts with peers was mentioned: the difference between practical knowledge and emotional support. *"I appreciate hearing other people's experiences, but I do not wish to hear their whole life story"* – (#12), or *"it's all about sharing objective knowledge and not talking about feelings all the time, because that's not really my cup of tea, especially not online"* – (#5) or *"it's just really nice to know others had the same issues after the surgery and to learn from their experiences"* – (#11).

3.4.4. Online sources and communities

The Internet played a major part in information provision. All participating parents used the Internet, though to different degrees. The use of the Internet as a source of information can be divided into searching for information on different websites and making contact with other parents. The Internet was used as a medium to find different sources. Websites were usually found through Google, while Facebook was mentioned most when it came to contacting peers.

Although all parents used the Internet to search for information, only a few talked about it with their doctors or asked for advice about reliable websites. Two parents actually reported that doctors had advised them not to search the Internet for information, *"telling me not to search for information online, that's an outdated view; of course I still searched the Internet"* – (#4) and *"just that one website I was supposed to look at, the doctors said, and although sometimes I am very curious, so far I've abided with that"* – (#7).

Most parents preferred a closed Internet community without professionals or people who do not belong to the target population, *"not all my Facebook contacts need to know what I write in the community"* – (#5), *"if it weren't a closed community, I don't think I would tell my story"* – (#11), *"I wouldn't post a comment if it wasn't a closed Facebook community"* – (#4) and *"the fact that it's closed is essential for our group"* – (#6). Other respondents did not mind so much, but they mainly referred to open communities for practical information only.

3.5. Interpreting information

Parents chose specific sources for different kinds of information and in general rated their value accordingly. Medical information was considered most valuable when it came from healthcare professionals, while practical experience-based knowledge was preferably obtained from other parents or rehabilitation professionals.

An important aspect is that most parents used multiple sources. This included comparing different websites to evaluate the content *"I searched different websites, and if the information matches, it's probably true"* – (#6), but also comparing information from different healthcare professionals: *"with the information I got from the physiotherapist, I went back to the rehabilitation centre"* – (#1) or information from two different kinds of sources: *"the idea I got from Facebook, and then I went to the occupational therapist"* – (#4), *"I saw something on Facebook about reimbursement for diapers. Later I searched the insurance website to see if I could benefit from such an arrangement"* – (#10).

In evaluating Internet sources it was also important for many parents that a website was linked to an official institution, for instance the government, rehabilitation centres or hospitals, *"if the website of a hospital displays the information, it must be true"* – (#11), *"I only click on a website with a formal URL, a website linked to a known authority [when searching with Google]"* – (#7) or *"I only trust the official site of the government, as far as reimbursements go"* – (#6). Some parents also mentioned that they used their gut feelings to assess the value of Internet content. *"well, my gut tells me whether I can trust the information or not"* – (#2).

4. Discussion

This qualitative study investigated information needs, the process of searching for information and the way this information is evaluated among parents of children with disabilities. Although differences between participants were found, there were also many similarities. In general, when parents were triggered to actively search for information, most of them appeared to search in different ways simultaneously, and to seek answers mostly from more than one source. Parents evaluated the different sources by comparing the information they provided. Information was obtained through personal contacts or online. Parents highly valued "experience-based knowledge", information based on individual experiences of peers or professionals.

The process of searching for, obtaining and sharing information supports parents in getting things done and taking a more active role in decision-making, which is part of the process of empowerment (Fumagalli, Radaelli, Lettieri, Bertele, & Masella, 2015). Getting information and going through experiences equipped parents with the skills and motivation to take matters into their own hands.

It is the task of healthcare professionals to ensure that parents feel sufficiently informed to participate in decision-making. Knowledge about the strategies parents use and the importance of other sources could assist these professionals in providing information. Recognising the role played by the Internet and other parents in this process is vital to understanding the parents' information-seeking process.

4.1. Comparing findings with previous literature

As was expected on the basis of earlier research, parents in our study had many information needs (Alsem et al., 2013; Huber et al., 2005; McDowell et al., 2015; Palisano et al., 2010; Sloper & Turner, 1992). These needs were not all being met, and all parents in our study described how new needs kept arising with changing situations, successive stages of disease trajectories and increasing age, which is in accordance with what has been reported in the literature (Hummelinck & Pollock, 2006; Nordfeldt et al., 2013; Pain, 1999; Sloper & Turner, 1992). In this process of changing needs, parents also change their information seeking strategies (De Rouck & Leys, 2013). Thus, information seeking and finding is a dynamic process, differing between parents and varying over time (Plantin & Daneback, 2009).

Parents of young children consume vast amounts of information, with experience-based information playing an important role (Plantin & Daneback, 2009). We found that parents preferred different sources for different types of information, which they reached in different ways, e.g. in person or through the medium of the Internet (Jackson et al., 2008). Previous studies have reported that parents of children with various conditions mainly obtain medical information from doctors, and experience-based information and support from peers through social networks (Gabbert, Metze, Buehrer, & Garten, 2013; Jackson et al., 2008). Furthermore, parents compared information from different sources to establish reliability (Jackson et al., 2008)."This is in line with our findings in this population.

The parents in our study made it clear that they were not just passive consumers of online health content; they were active producers as well. Online communities were increasingly being used as venues for the exchange of information and advice. This was also found earlier with different parent groups (Fox, 2011; Gage & Panagakis, 2012; Hether, Murphy, & Valente, 2014; Plantin & Daneback, 2009). The importance of online communities, especially closed fora, was striking. Being able to talk to other parents in a similar situation is valuable for most parents with a child with a disability (Hendriks et al., 2000; Pain, 1999). Fora such as Facebook thus provide opportunities for exchanging information. Not only searching, but also sharing information is regarded by parents as important and a way to help others. Since this is mostly personal information, parents prefer closed groups for this.

Information coming from institutions was mentioned as a reliable and valuable source by many parents in our study. Other research has shown that websites of government-certified (Grewal & Alagaratnam, 2013) and academic institutions (Kulasegarah, Harney, Walsh, & Walsh, 2012) are trusted more than other sites. It is important to realise that Internet users rarely browse past the first few hits (Eysenbach & Kohler, 2002) and judge information primarily on the basis of design features, (Sillence, Briggs, Harris, & Fishwick, 2007) and that prominent search engine ranking does not guarantee reliability of information (Tavare, Alsafi, & Hamady, 2012). Guidance should be provided on how to find reliable information. Most parents in our study compared the information found on the Internet with information from other sources, in order to appraise its reliability. In general, however, the parents used no systematic method to appraise reliability.

In clinical practice, the challenge will be to tailor the information provision and guidance to each individual family in the context of a FCS (Bamm & Rosenbaum, 2008; Kuo et al., 2012; Kuo, Frick, & Minkovitz, 2011; Longo & Woolf, 2014). Professionals need to realise that parents have individual information needs, and that they use different sources of information to support them in making decisions (Jackson et al., 2008). The individual nature of information needs makes timing of information provision by professionals crucial in the process of empowerment.

4.2. Strengths and limitations

Although some of the findings in our study had been described before by studies in other populations, the role of information in the process of empowerment of these parents, and the important role of experience-based information, had not been described before.

One strength of the qualitative semi-structured interviews we used was the possibility of discovering new information in this specific population. Open questions concerning information needs gave us the opportunity to examine the experiences of parents and learn from them. The methodology enabled the parents to mention information that was important to them, rather than comprehensively covering all the information they had received. The data were therefore possibly biased, but reflect the parents' agenda and needs.

Limitations of the study include the selection process. The participating parents were recruited through multiple strategies and in different regions of the Netherlands, but mainly via online channels. The parents in this study all used the Internet as a source of information, and might thus form a biased sample. In the general population, the use of the Internet differs between parents, and social class, income, and education play a role in the degree of Internet use (Plantin & Daneback, 2009). The role of the Internet might thus have been overestimated in our study. Moreover, there could be differences in information-seeking behaviour between parents of different educational levels and/or other family characteristics. In this study we did not differentiate between these characteristics.

The children in our sample had a variety of diagnoses and ranged in age from 3 to 20 years. However, parents of children with rare conditions were relatively over-represented. Also, most of the parents had children with congenital disabilities; parents of children with acquired disabilities (e.g. trauma) may have different search strategies.

Finally, the 15 parents participating in the interviews included 13 mothers and two couples of mother and father, which may make generalisation across families difficult, although most mothers expressed greater information needs than their spouses and therefore spoke for the whole family. This was also found in earlier studies among mothers and fathers of young children (Plantin & Daneback, 2009).

5. Conclusion

Parents of children with disabilities had varied and continuously changing information needs and questions. There is an important difference between 'medical' or 'professional' information and 'experience-based' information. Parents use different sources for different types of information. Medical information was mostly sought from healthcare professionals and on the internet. 'Experience-based' information is mainly exchanged with peers, in person as well as through the internet. Information was commonly assessed by comparing multiple sources, e.g. different websites and experiences of peers and healthcare professionals.

Contributors

All authors played a role in conception and design of the study, revising the article and final approval of the manuscript. MA and FA played a major role in data acquisition and analysis of data and drafting the manuscript. MK, MV, JM and MJ helped analyse and interpret the data.

Declarations

The authors confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

Conflicts of interest

None.

Acknowledgements

References

Alsem, M., Siebes, R., Gorter, J., Jongmans, M., Nijhuis, B., & Ketelaar, M. (2013). Assessment of family needs in children with physical disabilities: development of a family needs inventory. *Child: Care, Health and Development*, *40*, 498–506. http://dx.doi.org/10.1111/cch.12093

Anker, A. E., Reinhart, A. M., & Feeley, T. H. (2011). Health information seeking: a review of measures and methods. *Patient Education and Counseling*, *82*(3), 346–354. http://dx.doi.org/10.1016/j.pec.2010.12.008

Bailey, D. B., Jr., Blasco, P. M., & Simeonsson, R. J. (1992). Needs expressed by mothers and fathers of young children with disabilities. *American Journal of Mental Retardation: AJMR*, *97*(1), 1–10.

Bamm, E. L., & Rosenbaum, P. (2008). Family-centered theory: Origins, development, barriers, and supports to implementation in rehabilitation medicine. *Archives of Physical Medicine and Rehabilitation*, 89(8), 1618–1624. http://dx.doi.org/10.1016/j.apmr.2007.12.034

Bartlett, Y. K., & Coulson, N. S. (2011). An investigation into the empowerment effects of using online support groups and how this affects health professional/patient communication. *Patient Education and Counseling*, 83(1), 113–119. http://dx.doi.org/10.1016/j.pec.2010.05.029

Bianco, A., Zucco, R., Nobile, C. G., Pileggi, C., & Pavia, M. (2013). Parents seeking health-related information on the internet: Cross-sectional study. *Journal of Medical Internet Research*, 15(9), e204. http://dx.doi.org/10.2196/jmir.2752

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. http://dx.doi.org/10.1191/1478088706qp063oa

Cunningham, B. J., & Rosenbaum, P. L. (2013). Measure of processes of care: A review of 20 years of research. *Developmental Medicine and Child Neurology*, http://dx.doi.org/10.1111/dmcn.12347

De Rouck, S., & Leys, M. (2013). Illness trajectory and internet as a health information and communication channel used by parents of infants admitted to a neonatal intensive care unit. *Journal of Advanced Nursing*, 69(7), 1489–1499. http://dx.doi.org/10.1111/jan.12007

Dominguez, M., & Sapina, L. (2015). Pediatric cancer and the internet: Exploring the gap in doctor-parents communication. *Journal of Cancer Education: The Official Journal of the American Association for Cancer Education*, 30(1), 145–151. http://dx.doi.org/10.1007/s13187-014-0700-4

Eurostat. (2013). *Eurostat database*. (Accessed 2 February 2016). http://ec.europa.eu/eurostat/statistics-explained/index.php/Archive:Internet_use_statistics_-_individuals

Eysenbach, G., & Kohler, C. (2002). How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. *BMJ (Clinical Research Edition)*, 324(7337), 573–577. http://dx.doi.org/10.1136/bmj.324.7337.573

Fox, S. (2011). *Peer-to-peer healthcare many people —especially those living with chronic or rare diseases —use online connections to supplement professional medical advice*. (Accessed November 2015). www.pewinternet.org/files/old-media/files/reports/2011/Pew_P2PHealthcare_2011.pdf

Fumagalli, L. P., Radaelli, G., Lettieri, E., Bertele, P., & Masella, C. (2015). Patient empowerment and its neighbours: clarifying the boundaries and their mutual relationships. *Health Policy*, 119(3), 384–394. http://dx.doi.org/10.1016/j.healthpol.2014.10.017

Gabbert, T. I., Metze, B., Buehrer, C., & Garten, L. (2013). Use of social networking sites by parents of very low birth weight infants: Experiences and the potential of a dedicated site. *European Journal of Pediatrics*, 172(12), 1671–1677. http://dx.doi.org/10.1007/s00431-013-2067-7.ER

Gage, E. A., & Panagakis, C. (2012). The devil you know: Parents seeking information online for paediatric cancer. *Sociology of Health & Illness*, 34(3), 444–458. http://dx.doi.org/10.1111/j.1467-9566.2011.01386.x

Glynn, R. W., O'Duffy, F., O'Dwyer, T. P., Colreavy, M. P., & Rowley, H. M. (2013). Patterns of internet and smartphone use by parents of children attending a pediatric otolaryngology service. *International Journal of Pediatric Otorhinolaryngology*, 77(5), 699–702. http://dx.doi.org/10.1016/j.ijporl.2013.01.021

Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., et al. (2006). Lost in knowledge translation: Time for a map? *The Journal of Continuing Education in the Health Professions*, 26(1), 13–24. http://dx.doi.org/10.1002/chp.47

Grewal, P., & Alagaratnam, S. (2013). The quality and readability of colorectal cancer information on the internet. *International Journal of Surgery (London, England)*, 11(5), 410–413. http://dx.doi.org/10.1016/j.ijsu.2013.03.006

Hendriks, A. H., De Moor, J. M., Oud, J. H., & Franken, W. M. (2000). Service needs of parents with motor or multiply disabled children in dutch therapeutic toddler classes. *Clinical Rehabilitation*, 14(5), 506–517. http://dx.doi.org/10.1191/0269215500cr353oa

Hether, H. J., Murphy, S. T., & Valente, T. W. (2014). It's better to give than to receive: The role of social support, trust, and participation on health-related social networking sites. *Journal of Health Communication*, 19(12), 1424–1439. http://dx.doi.org/10.1080/10810730.2014.894596

Huber, J. T., Dietrich, J. D., Cugini, E., & Burke, S. (2005). F2F connection: A community health information needs assessment of texas families who have children with chronic illnesses and/or disabilities and their care providers. *Journal of the Medical Library Association*, 93(2), 278–281.

Hummelinck, A., & Pollock, K. (2006). Parents' information needs about the treatment of their chronically ill child: A qualitative study. *Patient Education and Counseling*, 62(2), 228–234. http://dx.doi.org/10.1016/j.pec.2005.07.006

Jackson, C., Cheater, F. M., & Reid, I. (2008). A systematic review of decision support needs of parents making child health decisions. *Health Expectations*, 11(3), 232–251. http://dx.doi.org/10.1111/j.1369-7625.2008.00496.x

Khoo, K., Bolt, P., Babl, F. E., Jury, S., & Goldman, R. D. (2008). Health information seeking by parents in the internet age. *Journal of Paediatrics and Child Health*, 447–448, 419–423. http://dx.doi.org/10.1111/j.1440-1754.2008.01322.x

Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology*, 37(4), 305. http://dx.doi.org/10.1037/h0079106

Kruijsen-Terpstra, A. J., Verschuren, O., Ketelaar, M., Riedijk, L., Gorter, J. W., Jongmans, M. J., et al. (2016). Parents' experiences and needs regarding physical and occupational therapy for their young children with cerebral palsy. *Research in Developmental Disabilities*, 53–54, 314–322. S0891-4222(16)30033-6 [pii].

Kulasegarah, J., Harney, M., Walsh, M., & Walsh, R. M. (2012). The quality of information on three common ENT procedures on the internet. *Irish Journal of Medical Science*, 181(2), 221–224. http://dx.doi.org/10.1007/s11845-011-0787-0

Kuo, D. Z., Frick, K. D., & Minkovitz, C. S. (2011). Association of family-centered care with improved anticipatory guidance delivery and reduced unmet needs in child health care. *Maternal and Child Health Journal*, 15(8), 1228–1237. http://dx.doi.org/10.1007/s10995-010-0702-8

Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-centered care: Current applications and future directions in pediatric health care. *Maternal and Child Health Journal*, 16(2), 297–305. http://dx.doi.org/10.1007/s10995-011-0751-7

Longo, D. R., & Woolf, S. H. (2014). Rethinking the information priorities of patients. *JAMA*, 311(18), 1857–1858. http://dx.doi.org/10.1001/jama.2014.3038

MacKean, G. L., Thurston, W. E., & Scott, C. M. (2005). Bridging the divide between families and health professionals' perspectives on family-centred care. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 8(1), 74–85. http://dx.doi.org/10.1111/j.1369-7625.2005.00319.x

McDowell, B. C., Duffy, C., & Parkes, J. (2015). Service use and family-centred care in young people with severe cerebral palsy: A population-based, cross-sectional clinical survey. *Disability and Rehabilitation*, 1–6. http://dx.doi.org/10.3109/09638288.2015.1019649

McMullan, M. (2006). Patients using the internet to obtain health information: How this affects the patient-health professional relationship. *Patient Education and Counseling, 63*(1–2), 24–28. S0738-3991(05)00315-0 [pii].

Nordfeldt, S., Angarne-Lindberg, T., Nordwall, M., & Krevers, B. (2013). Parents of adolescents with type 1 diabetes–their views on information and communication needs and internet use. A qualitative study. *PUBLIC LIBRARY OF SCIENCE*, 8(4), e62096. http://dx.doi.org/10.1371/journal.pone.0062096

Pain, H. (1999). Coping with a child with disabilities from the parents' perspective: The function of information. *Child: Care, Health and Development*, 25(4), 299–312. http://dx.doi.org/10.1046/j.1365-2214.1999.00132.x

Palisano, R. J., Almarsi, N., Chiarello, L. A., Orlin, M. N., Bagley, A., & Maggs, J. (2010). Family needs of parents of children and youth with cerebral palsy. *Child: Care, Health and Development*, 36(1), 85–92. http://dx.doi.org/10.1111/j.1365-2214.2009.01030.x

Pehora, C., Gajaria, N., Stoute, M., Fracassa, S., Serebale-O'Sullivan, R., & Matava, C. T. (2015). Are parents getting it right? A survey of parents' internet use for children's health care information. *Interactive Journal of Medical Research*, 4(2), e12. http://dx.doi.org/10.2196/ijmr.3790

Piskur, B., Beurskens, A. J., Jongmans, M. J., Ketelaar, M., & Smeets, R. J. (2015). What do parents need to enhance participation of their school-aged child with a physical disability? A cross-sectional study in the Netherlands. *Child: Care, Health and Development*, 41(1), 84–92. http://dx.doi.org/10.1111/cch.12145

Plantin, L., & Daneback, K. (2009). Parenthood, information and support on the internet. A literature review of research on parents and professionals online. *BMC Family Practice*, 10 http://dx.doi.org/10.1186/1471-2296-10-34 [34-2296-10-34]

Raats, I., van den Brink, R., & de Wit, F. (2013). Participatieladder CBO. In *Handboek patiënten-/cliëntenparticipatie* (pp. 8).

Rentinck, I. C., Ketelaar, M., Jongmans, M. J., & Gorter, J. W. (2007). Parents of children with cerebral palsy: A review of factors related to the process of adaptation. *Child: Care, Health and Development, 33*(2), 161–169 [CCH643].

Rosenbaum, P. L., King, S. M., & Cadman, D. T. (1992). Measuring processes of caregiving to physically disabled children and their families. I: Identifying relevant components of care. *Developmental Medicine and Child Neurology, 342*, 103–114. http://dx.doi.org/10.1111/j.1469-8749.1992.tb14976.x

Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-centred service: A conceptual framework and research review. *Physical & Occupational Therapy in Pediatrics, 18*(1), 1–20. http://dx.doi.org/10.1080/J006v18n01_01

Siebes, R. C., Wijnroks, L., Ketelaar, M., van Schie, P. E., Gorter, J. W., & Vermeer, A. (2007). Parent participation in paediatric rehabilitation treatment centres in the netherlands: A parents' viewpoint. *Child: Care, Health and Development, 33*(2), 196–205. http://dx.doi.org/10.1111/j.1365-2214.2006.00636.x

Sillence, E., Briggs, P., Harris, P. R., & Fishwick, L. (2007). How do patients evaluate and make use of online health information? *Social Science & Medicine (1982), 64*(9), 1853–1862. S0277-9536(07)00016-0 [pii].

Sloper, P., & Turner, S. (1992). Service needs of families of children with severe physical disability. *Child: Care, Health and Development, 18*(5), 259–282. http://dx.doi.org/10.1111/j.1365-2214.1992.tb00359.x

Suziedelyte, A. (2012). How does searching for health information on the internet affect individuals' demand for health care services? *Social Science & Medicine (1982), 75*(10), 1828–1835. http://dx.doi.org/10.1016/j.socscimed.2012.07.022

Tavare, A. N., Alsafi, A., & Hamady, M. S. (2012). Analysis of the quality of information obtained about uterine artery embolization from the internet. *Cardiovascular and Interventional Radiology, 35*(6), 1355–1362. http://dx.doi.org/10.1007/s00270-012-0345-9