

How Do Parents of Children with Physical Disabilities Search for Information? a Qualitative Study



Brain Center
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Information provision insufficient

Evidence suggests that parents of children with disabilities feel that not all information needs are currently being met, but it is not yet clear how parents try to fill these information gaps.

How do parents fill the information gap?

We examined the way parents search and value information from different sources.

Qualitative interviews

- Twelve qualitative semi-structured interviews were held to explore the strategies of participating parents concerning information needs.
- A thematic analysis approach was performed to analyse the interviews.

“just when I thought I had everything under control, new questions rise”

“professionals at the rehabilitation centre have so much knowledge about practical things”

“only peers really know what you are going through and can assist you with practical tips”

“I appreciate hearing other people’s experiences, but I do not wish to hear their whole life story”

“to tell me not to search for information online, that’s not really of this day and age, of course I still searched the internet”

“I searched different websites, and if the information matches, it’s probably true”

Findings

- Needs for information are triggered and ongoing
- Parents prefer different sources for different information needs.
- There are two distinct entities of experience-based knowledge: practical information and support.
- Experience-based knowledge is highly valued by parents.
- The internet plays a big and twofold part in information provision: a medium to search information on different websites and a medium to contact peers; ‘Google’ versus ‘Facebook’.
- Closed internet communities are preferred.
- In general, internet use is not generally discussed with healthcare professionals, especially physicians.
- Most parents combine multiple sources to value information.
- Parents rate information from certified institutions as important and more reliable.

Conclusion

Parents search at different sources for different information needs. Information is valued through comparison of resources.

“if a website of a hospital displays the information, it must be true”

Facebook-groups: *“really nice to get into contact with other parents”* and *“the seclusion is essential for our group”*

Model of information seeking

	Objective information		Experience-based information	
	Medical	Rehabilitation-related	Practical	Support
Healthcare professionals				
Rehabilitation professionals	✓	✓	✓	
Other healthcare professionals	✓			
Institutions	✓	✓		
Other parents in similar situations			✓	✓
✓ Frequently used source for type of information				

Clinical message

- Mind the importance of additional information resources
- Guide parents in their search for information
- Acknowledge the existence of internet and use it for the benefit of parents