Toward a Taxonomy of Information Needs of Informal Carers
A Case Study of a Carer of a Child with Diabetes

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Presentation Outline

✓ Goals
✓ Literature Background
✓ Proposed Taxonomy
✓ Research Method and Analysis
✓ Research Findings
✓ Conclusions and Future Implications
Research Goal

To propose and test empirically a taxonomy of information needs of informal carers that assists in understanding their information needs comprehensively.
Literature Background

Patient-Centered Health Information Systems

- Help patients manage their health and support other people who care for them informally (Tang, Ash et al. 2006).
- Concentrate on medical information related to the patients (Sternberg 2002).
- Rarely consider information needs of informal carers (Sternberg 2002).
- Rarely consider the perspective of patients or informal carers (Keselman, Logan et al. 2008).
- Informal carers need support and information just as much as those persons whom they care for (Zapart et al. 2007).
Information Needs of Informal Carers

- Information provision for informal carers is still inadequate in many respects (Hummelinck and Pollock 2006).
- Little research has explored their information needs comprehensively.
- Existing research has concentrated on carers’ information needs that are most directly related to their patients’ needs.
- Information needs related to other aspects of being a carer have hardly been addressed in the literature.

A richer and more multi-faceted account of the information needs of informal carers is needed.
A Taxonomy of the Information Needs of Informal Carers

- Information needs related to the persons needing care.
- Information needs related to the informal carers themselves.
- Information needs related to the interaction between informal carers and persons needing care.
- Information needs related to the interaction between informal carers and other parties (professionals, nurses, social workers, other carers, teachers, etc).
Research Method and Analysis

- Qualitative case study approach (Yin 2002).
- Convenience sample.
- Experienced informal carers.
- Potential participants are being recruited through not-for-profit, non-clinical organizations.
- Inclusion criteria:
  - Any person over the age of 18 years old.
  - Care for a diabetic child under the age of 15 years old.
  - Provide unpaid day to day caring services on a practical and/or emotional level.
- Activity diary and Semi-structured interviews.
- Inductive and deductive content analysis (Berg 2004)
- NVivo 7 for data management and analysis.
Case Study Summary

- A 52 years old mother cares for her 15 years old diabetic son.
- Her caring experience is 3 years.
- Before diagnosis she had very little information about diabetes in general.
- She needed information immediately upon diagnosis in order to reassure her son.
- She did not need specific types of information upon diagnosis (e.g. how to get a health card)
- Following the diagnosis she read as much as possible about diabetes type 1.
- She had a wide variety of information needs that could be satisfied by cooperation of a network of many professionals and organisations (Hospitals, doctors, nurses, dieticians, support groups...etc).
Research Findings

Information needs related to the persons needing care

1. The condition itself.
2. Treatment of the condition.
3. Ongoing management, monitoring and control of the condition.
4. Impact of the condition on personal and social life of the person needing care.
5. Nutrition and diet requirements.
6. Exercise requirements.
7. Personal care of the person needing care.
8. Specialised health services for other health problems affecting the condition.
9. Routine activities outside the home (school, work, camping).
10. Information about administrative and financial procedures related to the person needing care.

"My son telling me that he hurt his toe at a friend's house, checking his toe and giving advice as to care, (information needed is) how much emphasis to place on care of feet in an adolescent without worrying him unnecessarily... Cutting my son's finger and toe nails and thinking about his care, (information needed is) the best way of dealing with foot care" [Activity Diary].

"Making my son's lunch and thinking about the best diet for him, information about healthy diet especially for people with diabetes and at his age...Buying white Turkish bread for my son and then worrying that I should only get wholemeal, just how important diet is?" [Activity Diary].

"In the general community there is no enough information about type 1 diabetes in particular... The way it was diagnosed here in Australasia, the latest thing that is happening overseas as well... More knowledge about possible complications from diabetes" [Interview].

"I've questioned him (Doctor) with regard to the testing... I was not aware of the extent of monitoring... He is on insulin pump now which is only being since April 2007, so that routine has changed with regards to injection... I've still got more to learn about the pump" [Interview].

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Research Findings

Information needs related to the carers themselves

1. The Caring Process

2. Coping with the condition and caring process

3. Information about new skills

4. Information about administrative procedures related to the carers

“People have no idea of the care involved...About the physical care of my son...The knowledge that...have an understanding of the scenario that happens at home, and how it can affect the carer” [Interview].

“How other carers cope with (different scenarios)...Going out in evening and worrying about being available if my son needed...Support information for me as a carer)” [Activity Diary].

“How others have coped in this situation (appeal to have carer payment backdated)” [Activity Diary].

“Using the computer I mean I can always type but I could not use excel before, but now I do all my son’s blood levels and everything I do on excel spread sheets and so on, and doing that oh that it is not gaining information that it is well, this gaining information because I gain information on how to use excel, other people will not do that” [Interview].
Research Findings

Information needs related to the interaction between the carer and the person needing care

1. Ways of transferring knowledge and information to the person needing care
2. Ways of interactions with the person needing care
3. Ways of controlling and dealing with the feelings associated with the interaction with the person needing care
4. Impact of the condition on the whole and wider family
5. Ways and strategies of changing the routine life of the person needing care, the carer, and the family

Research Findings

“I think impact on the whole family is something that needs to be looked at...Education of the wider family that is not looked at really...Dietary information is good to impart to...” [Interview]

“It is a good idea to have the knowledge to change that pattern early, rather than let go on, and then the kid is thinking oh well it does not matter” [Interview].

“Yes (information to reduce this anxiety and stress and worries) and that was not forthcoming that information, I think now that would be really helpful, but I think it was not, in the end I did...Learning to deal with that, so perhaps information regarding that ways of dealing with it would be useful” [Interview].

Worrying that my son will access disturbing information about diabetes via the internet... (information needed is) what is suitable information for 14 years old boy with diabetes?” [Activity Diary].

“I do not want to hassle him all the time...I try to think of ways maybe slipping on the conversation...It is still important for them (carers) to be given that knowledge, because it can help them to learn new ways of parenting...information about the importance of maintaining self-esteem especially as this case” [Interview].

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Research Findings

Information needs related to the interaction between the carer and other parties

1. Information about other parties dealing with carer and the person needing care

2. Ways to impart information about the person needing care to other parties (friends, school teachers, healthcare professional)

3. Impact of the condition on friendships and activities with friends.

“About how friends can be important...The information about... how diabetes can affect ... friendships...The knowledge about how can impact on activities with friends” [Interview].

“The information is ... that you have a right to check whether the school nurse or teachers have the knowledge that your son has diabetes, whether they would know what to do if he had a hypo, yes the knowledge to be able to give them the emergency packs, and to insist upon things where they stored...the knowledge to step forth and do that, because otherwise it is so dangers situation” [Interview].
Conclusions

- The taxonomy worked well in portraying a comprehensive picture of information needs in this case study.
- The taxonomy provides a way to investigate the information needs.
- The interview protocol and activity diary were acceptable to the carer and show their applicability in uncovering the lived experience of the carer.
- The activity diary requires too much commitment of the carer’s valuable time.
Future Implications

Since this is an ongoing research, the findings will be important for various parties:

- Informal carers themselves.
- People who work directly with informal carers or persons needing care.
- Health information and education providers.
- Health information and education developers.
References


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Thank You

Questions & Suggestions