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

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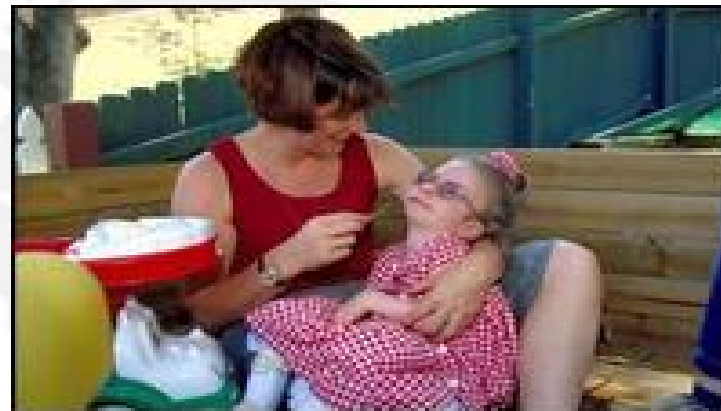The University of Melbourne
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Presentation Outline

- ✓ Goals

- ✓ Literature Background

- ✓ Proposed Taxonomy

- ✓ Research Method and Analysis

- ✓ Research Findings

- ✓ Conclusions and Future Implications

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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).

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Literature Background

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.
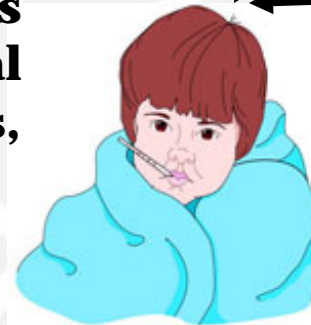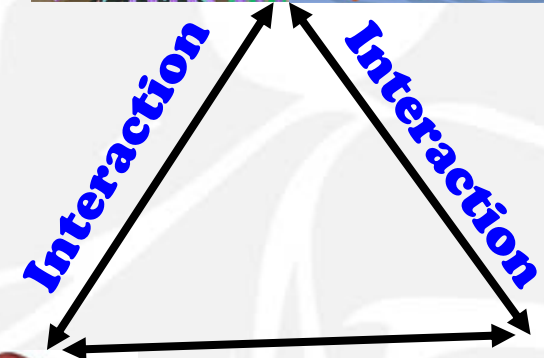
A richer and more multi-faceted account of the information needs of informal carers is needed.

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A Taxonomy of the Information Needs of Informal Carer

- 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).

Other Parties

Interaction

Interaction

Interaction

Person Needing Care   **Informal Carer**

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.

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Research Findings

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 of the condition.
4. Impact of the condition on the person.
5. Nutrition.
6. Exercise.
7. Personal care of the person needing care.
8. Specialised health services affecting the condition.
9. Routine activities outside the home (e.g. work, camping).
10. Information about administrative matters 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].**

The knowledge that he should perhaps do blood test before he leaves school to give him an indicator" **[Interview].**

"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].**

Research Findings

Information needs related to the carers themselves

1. The Caring Process

2. Coping with the condition and

3. Information about new skills

4. Information about administrative procedures related to the

"People have no idea of the care involved...About the physical care of my son...The knowledge that...have an

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

"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].**

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11

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

1. Ways ... ...tion to the person...

2. Ways ...

3. Ways ... associa... care

4. Impact of the co...dition or...

5. Ways and strategies of c... person needing care, the carer...

"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 ... ...munity" **[Interview]**

"How dia... relationships... enquire after...

"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].**

...hat my son will ...bing information ...family ...intances all the time... I try ...ping him on the ...portant for them ...that knowledge because it

"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].**

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 care to other parties (friends, healthcare professional)

3. Impact of the care 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.

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14

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.

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Thank You

Questions & Suggestions