

An In-depth Look at an Informal Carer's Information Needs: A Case Study of a Carer of a Diabetic Child

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Abstract

This paper proposes and reports on an empirical test of a taxonomy of information needs of informal carers. Prior research in this field is limited and has concentrated on the carer's information needs that are most directly related to the patient's needs, whereas information needs related to other aspects of being a carer have hardly been addressed. Four main categories of information needs of informal carers are proposed: (i) information needs related to the persons needing care, (ii) information needs related to the informal carers themselves, (iii) information needs related to the interaction between the persons needing care and informal carers; and (iv) information related to the interaction between informal carers and other parties in the context of care. A qualitative case study approach is taken to data from a carer of a child with Type 1 diabetes. Analysis of this case shows information needs in all four categories, although not evenly distributed across them. The paper discusses the adequacy of the four proposed categories to describe the information needs of carers, draws implications for consumer-centred health information systems and outlines directions for further research.

Keywords: Information Needs, Informal Carers, Diabetes, Children, Case Study, Consumer Health Information

1. Introduction

Much health-related information including web-based is currently provided as an integrated part of consumer-centred healthcare systems. These systems aim to help patients manage their health [1] and to enhance the abilities of other people (e.g. family members) to care for them informally. These systems tend to concentrate on medical information

without including other types of information related to health such as practical and emotional aspects of caring or other aspects of information such as its provision related to various phases of illness or over time. Moreover, these systems tend to overlook the information needs of one main group of consumers, namely informal carers [2-4]. Informal carers need support and information just as much as those persons whom they care for

[5-6]. Thus, if sponsors, technical developers and content providers of consumer health information systems want these to be relevant and effective they should include the information needs of the informal carer in designing any information system that targets the patient or person needing care.

Researchers and practitioners are increasingly paying more attention to informal carers e.g. [7-9]. However,

little research has investigated their information needs comprehensively or the kinds of information needs that arise over time and during different situations in the lived experience of being an informal carer. Moreover, this research has concentrated on those information needs of the carer that are most directly related to their patient's needs. Information needs related to other aspects of being a carer have hardly been addressed in the literature. Furthermore, a recent study conducted by James et al. [10] suggests that information provision to informal carers is largely lacking. Consequently, the aim of this paper is firstly to propose a taxonomy of information needs of informal carers that can assist in understanding their information needs comprehensively, and secondly to test the taxonomy empirically using data from a case study of a carer of a child with Type 1 diabetes. In this study, information needs were defined as any form of information that is essential to carers as a result of their role as carers. This information may take the form of advice, opinion, channel of communication and physical entity.

2. Literature Review and Taxonomy Development

2.1. Informal Carers

Researchers generally use the term "informal carer" to refer to "*someone who actively participates in sharing the patient's illness experience on a practical and / or emotional level*" [11, p. 17]. Informal carers include persons who provide unpaid healthcare services on a practical and /or emotional level for other people (e.g. parents, children, relatives, friends) who are unable to care for themselves for different reasons; i.e. frail elderly, significant disability, or chronic diseases. However, informal carers have different identities depending on whether they are:

- Co-members of the official healthcare team; if so, then the information for them become a prerequisite

for delivering the healthcare services effectively [6], or

- Co-consumers with the persons whom they care for; if so, then they have the right to receive their information needs like the persons whom they care for [6], or
- Intermediators or patient advocates for the persons whom they care for; if so, then they need the information to help them to manage their health care and daily life [6], or
- Individuals in the community; if so, then they need the information to follow the health promotion and protection guidelines and to be ready to do their role as they may become carers at anytime.

Globally, the total number of informal carers is unknown but there are numbers available from countries which have started to acknowledge the value of informal carers. For example, in 2005, there were 2.6 million informal carers in Australia [12]. In the United Kingdom, according to the 2001 census there were around 6 million informal carers [13]. The core tasks of informal carers are varied depending on the care situation. For example, some informal carers assist with tasks of daily living and medications management; some carers supervise or help persons needing care with their finances and transport; other carers provide emotional support [14]. However, informal carers perform different tasks ranging from simple and easy-to-do to more complex tasks. These tasks may include but are not limited to: personal care, household, transport, nursing care, technical, liaising with doctors or other health professionals, planning and management of finances, and providing emotional support to the person needing care [5, 15]. Most of these tasks are done at home. While caring for someone can be a positive experience, many carers are being harmed physically, mentally, emotionally and socially by their caring roles [12]. Caring for children is more difficult and challenging. Although research has highlighted the importance of information for informal car-

ers e.g. [5] in order to do these tasks more effectively, informal carers continue to report a number of unmet needs including information needs [15]. In terms of diabetes, over 95% of care is done at home by people living with diabetes and/or their informal carers. Managing diabetes, especially in children, is difficult and challenging [16].

2.2. Information Needs of Informal Carers

Research has shown that information is crucial to informal carers e.g. [11, 17] to help them to carry out their roles more effectively. Information also helps informal carers to manage healthcare services more effectively and to engage in the decision-making process that concerns the persons whom they care for. Moreover, it helps them to maintain their well-being and that of the persons needing care. Furthermore, it helps them to give informed consent and to explain the illness to others [18-20].

Research has also shown that topics of information that informal carers need vary widely according to: the various tasks that they do, the characteristics of informal carers, illness's time and phases and caring processes [7-8]. Moreover, research has also established a number of socio-economic benefits from satisfying the information needs of informal carers e.g. [21-22]. Nevertheless, information provision for informal carers is still inadequate in many respects such as information related to practical and emotional aspects of caring and information during various phases and over time [21,23]. Furthermore, informal carers are known to face a number of barriers to access information that fulfils their information needs such as: healthcare policies and procedures, the relationship between informal carers and persons needing care [6, 23]. Many informal carers hardly express their information needs and some may not even know how to articulate those needs [21]. In addition, informal carers may have some information needs similar to those of the persons whom they care

for; nonetheless, they also have specific types of information needs in order to be able to handle the caring process more effectively [11]. Therefore, informal carers not only need information to support the persons needing care, but also they need information to support themselves. In other words, information can facilitate multifaceted care service and keeps it feasible as well as assisting the commitment of informal carers toward caring without overwhelming their own lives.

On the other hand, most studies of informal carers of children with diabetes have investigated the impact of diabetes on the family, their worries, their coping strategies to reduce their worries and to manage the diabetes of their children at home e.g. [22, 24]. However, little research investigates the information needs of informal carers of children with diabetes e.g. [25].

In light of the above, although the literature covers many different aspects of information needs of informal carers, little research has attempted to give an integrated account of these needs. Therefore, the scope of this paper is to propose a taxonomy of information needs of informal carers that provides a comprehensive understanding of these needs and test it empirically.

2.3. A taxonomy of Information Needs of Informal Carers

This taxonomy of information needs of informal carers incorporates the possible interactions and activities between the informal carer and the person needing care, as well as between the informal carer and other parties involved in service provision, and it has four main components:

(a) Information needs related to the persons needing care: Informal carers need information related to the patients or persons needing care in order to understand their context and status. This information may be similar to some of the information needs of patients themselves and arise from the condition of the patient or the care

recipient. Most research has explored these information needs e.g. [26]. These information needs may include information about illness and treatment for example.

(b) Information needs related to the informal carers themselves: Informal carers need information related to their caring role in order to do the caring process effectively. Literature has demonstrated that mapping the caring journey is very important for informal carers but that such a map is hardly developed and informal carers are not satisfied with it [27]. As caring affects informal carers emotionally and influences their personal lives and wellbeing [5], these information needs can also be extended to include these aspects. Informal carers also need to keep their personal identity besides that of carers [28]. Acknowledging the needs of informal carers including their own information needs is an important step in supporting carers [5]. These information needs may include information on how to do the care services effectively and information on how to reduce their stress.

(c) Information needs related to the interaction between informal carers and persons needing care: In order to care for the patient or the person needing care, interaction between the two of them is unavoidable. Such interaction has to be recognised because it affects the carer's decisions regarding the patient or person needing care [28]. Acknowledging informal carers' relationship with the patient or the person needing care is another basic step in supporting the carers [5]. This interaction inevitably has some positive and some negative aspects, such as confidence, satisfaction, irritation, aggression, and violence [29]. Informal carers also experience emotional reactions to their caring role [5]. Informal carers need information about how to interact with the patient or the person needing care and information about how to encourage the positive aspects of this interaction and reduce and manage the negative aspects of it.

(d) Information needs related to the interaction between informal

carers and other parties (professionals, nurses, social workers, other carers, teachers, etc): Informal carers engage in an interaction with many parties regarding the patient or person needing care. These interactions particularly increase if the informal carers care for a child. These interactions are also complex, especially those that involve official home and community care systems [28]. Many informal carers do not know what services are provided, by who and for whom. They may lack the skills to communicate with service providers and may not ask for them [27]. Acknowledging informal carers' identity by service providers is another issue, in addition to the confidentiality and privacy restrictions on the information related to the patient or the person needing care. These information needs may include information on how to interact with these parties and their legal rights to information about the person needing care.

3. Methods

In general, people's information needs do not exist in isolation; they exist when people perform a role/task, experience a problem or difficulty or are under some pressure/stress. Understanding these dimensions is crucial to identify the information needs associated with them [30]. Therefore, in this study the information needs of the informal carers were explored in relation to their role and tasks as carers only, as well as the problems, difficulties, and stress associated with these roles and tasks. This has been achieved by talking to an informal carer about these issues and day-to-day life in the real world of this carer.

This study was conducted in December 2007, and adopted a qualitative case study approach [31]. This qualitative approach enabled us to explore and gain an in-depth understanding of the information needs of a mother of a diabetic child. Ethical approval was provided by the University of Melbourne-Human Research Ethics Committee. Participation was

voluntary and the confidentiality of the information was assured.

3.1. Recruitment

The participant was recruited through one of not-for-profit, non-clinical organizations (Type 1 diabetes network). The participant was firstly contacted by telephone to discuss her interest, ascertain her eligibility and explain the study to her. Criteria for inclusion as a case study included any person over the age of 18 years old who provided a diabetic child under the age of 15 years old with unpaid day to day caring services on a practical and /or emotional level. After agreeing to participate she was sent a letter with more information about the study and telephoned to ascertain a convenient time and date for the interview and completing the diary. Written consent was obtained from the participant prior to filling out the activity diary and commencement of the interview.

3.2. Data Collection

Data were collected via an activity diary and a semi-structured interview, applying the principles of multiple methods to assist in triangulation and validation of research findings [32]. These two methods have also been used to gain deeper insights than might result from simply asking the carer to itemise her information needs. The activity diary was developed by the authors and was used to capture the smaller events and day-to-day tasks and activities that elicit the information needs; previous research has confirmed the effectiveness of this method for gathering data at this level of detail with a small sample e.g. [33]. The participant was also asked to record what information is essential to resolve these issues. The participant completed one written sheet each day (7 tasks) for a period of one week. The activity diary was used to create additional questions during the interview and to support the findings of the interview. Following the activity diary, the interview

was arranged and conducted for approximately 150 minutes in the participant's home. With the participant's permission, the interview was tape-recorded and explored a range of topics including: information background, everyday experiences and tasks as a carer in regards to the illness, treatment, managing illness, and other aspects of everyday life, and experiences in regards to personal life, interaction between participant and person needing care and other parties (physicians, nurses, diabetes educators, dietitians, social workers, school teachers) to derive implications of the information needs. Such open and unbiased questions allowed the participant to tell the actual information needs without any restrictions.

3.3. Data Analysis of Information Needs

After the semi structured interview was transcribed in full, it was merged and coded with the activity diary. Data relevant to information needs were organised according to themes grouped into four main categories of the taxonomy, with categories developed from the data in order to identify primary patterns. In other words, the data analysis followed two strategies: i) inductive content analysis [34]. This strategy involved reading and rereading the transcripts, coding, preliminary categorisation, and further classified data into categories. The accuracy of these categories was verified by working backwards and forwards between the data and the coding scheme. Following this strategy, ii) the deductive content analysis [34] was used to sort the categories identified within the four main categories of the taxonomy. The findings have been verified and confirmed by the carer and one expert academic, both of whom have been asked to evaluate the accuracy and completeness of the findings.

3.4. Case Study Summary

The participant in this case study was a 52 year old woman with three

children; her younger son was diagnosed with diabetes in 2005 when he was twelve years old. She needed information immediately upon diagnosis in order to reassure her son. Although she sought clarification from their GP as to the appropriateness of the diagnosis and what to expect at the hospital, she did not obtain that information from the GP. She had very little information about diabetes in general (e.g. she knew that it had to be treated with insulin but was not aware of the extent of monitoring). She felt that with information she would be able to look after him at home. She did not need specific types of information upon diagnosis (e.g. how to get a health card and how to treat hypoglycaemia) because her child did not start to take insulin until six months after his diagnosis. As time went on she tried to get those types of information, as well as information to reduce her anxiety and stress. Following the diagnosis she read as much as possible about Type 1 diabetes and ways of diagnosis, because she wished to ground her belief that the very latest technology was being employed in her son's treatment. Immediately after diagnosis her relationship with her son changed slightly. She started to look out for him more than one would normally do for a twelve year old. She in turn realised that she needed information regarding the most effective ways of dealing with an independent diabetic child and about his feelings at this stage. She learned and planned in the future to learn more skills (e.g. use of Microsoft Excel to type up information about sugar levels and calculate insulin amounts) in order to care for her son effectively. She constantly checked her information with the endocrinologist before giving her son any other medications or vitamins. She had a wide variety of information needs that could be satisfied only by consulting a network of many professionals and organisations (hospitals, doctors, nurses, dietitians, support groups, etc). She expected, unrealistically, that doctors would know all of these network parties.

4. Results (Data Support for the Components of the Taxonomy)

This section presents each of the categories and components of the taxonomy with one or more representative quotes from the raw data to show that each one was supported by data from the case study. These quotes are sufficient to show the nature of the components of the taxonomy, and the categories as well as the types of data that were collected.

4.1. Information Needs Related to the Persons Needing Care

The first component of the taxonomy involves a number of categories of information needs required by the carer. The carer needed information relating to the condition itself, treatment, ongoing management of the condition, impact of the condition on personal and social life of the person needing care, nutrition and diet and exercise requirements for the person needing care, personal care of the per-

son needing care, specialised health services for other health problems affecting the condition, routine activities outside the home, and information about administrative and financial procedures related to the person needing care. Table 1 presents definitions for each of these categories of information needs and example quotes from the carer's interview transcript and activity diary illustrate these categories of information needs related to the person needing care.

Table 1: Information needs related to the person needing care and representative quotes from the case study

Category	Quotes from Case Study
(1) Information about the condition itself: Information that carers might need that is related to the diagnosis and disease and its possible complications.	<i>"In the general community that there is no enough information about type 1 diabetes in particular...The way it was diagnosed here in Australia, the latest thing that is happen overseas as well...More knowledge about possible complications from diabetes"</i> [Interview].
(2) Information about treatment of the condition: Information on the treatments available, related advantages, disadvantages and side effects.	<i>"A lot of it (information) is about...how to treat hypo"</i> [Interview]. <i>"Information regarding likelihood of insulin effectiveness in hot weather and effective pump pouches... Side effects of insulin other than hypos"</i> [Activity Diary].
(3) Information about ongoing management of the condition: Information that is related to procedures and times of blood test, monitoring sugar levels and managing illness.	<i>"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"</i> [Interview].
(4) Impact of the condition on personal, social life of the person needing care: Information about feelings of the person needing care, controlling and dealing with his/her depression, effects of the condition on the abilities and sexual development, and life attitudes, and guidelines for going out and participating in scientific research affecting the person needing care.	<i>"what I did is gaining information from that (website) as to how young people feel, and that gives me a little bit of inside view ... When they tell you that you check you blood sugar ... or whatever they tell you...But what about the emotional impact ...The information on what exactly is necessary for young man going out"</i> [Interview]. <i>"Concern about my son's ability to cope with all the diabetes "stuff" and adolescence, a psychologist's view on signs of distress in my son"</i> [Activity Dairy].
(5) Nutrition and diet requirements: information on choices of food and desserts and recipes and how food, eating and not eating impacting the condition of the person needing care.	<i>"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?"</i> [Activity Diary]. <i>"How eating late at night or not eating enough late at night can have any impact"</i> [Interview].
(6) Exercise requirements: information that is related to the ways of doing exercise and its benefits, times and periods, and impact of exercise on the condition. Also things to do, or avoid or have during exercise.	<i>"Reading again about exercise, people focus on type 2, but it is very important for type 1 as well...Information about how tiredness can have any impact... if your child is...walking home... (He) will need the bracelets, will need the lollies, will need to get in the habit of doing a test before they take off for a walk"</i> [Interview].

<p>(7) Personal care of the person needing care: Information that carers might need that is related to the ways and times of doing personal care of the person needing care.</p>	<p><i>“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].</i></p>
<p>(8) Specialised health services for other health problems affecting the condition: Information on caring for other illnesses that might happen in conjunction with the condition and the specialised health services available for these illnesses.</p>	<p><i>“About the dentist I think that it is needed to be specific dental services just for people with diabetes, people do not think about it...A catalogue of where to go to podiatry or whatever) [Interview].</i></p>
<p>(9) Routine activities outside the home (school/work/camping): Information that is related to the condition impact on activities and achievements, and things that person needing care need during performing these activities.</p>	<p><i>“Information from other parents regarding their child/adolescent being late or missing school as a result of diabetes care and/or difficulties” [Activity Diary]. “The knowledge that he should perhaps do blood test before he leaves school to give him an indicator” [Interview].</i></p>
<p>(10) Information about administrative and financial procedures related to the person needing care: Information that is related to procedures, availability and details of organisations that provide these services.</p>	<p><i>“A lot of it...(Information) is about getting a healthcare care card.” [Interview].</i></p>

4.2. Information needs related to the carers themselves

This component involves four categories of information needs. The carer needed information relating to

the caring process, coping with the condition and caring, new skills that carer has to learn in order to be able to care, and information about administrative and financial procedures related to the carer. Table 2 presents definitions for each of these categories

of information needs and example quotes from the carer’s interview transcript and activity diary illustrate these categories of information needs related to the carers themselves.

Table 2: Information needs related to the carers themselves and representative quotes from the case study

Category	Quotes from Case Study
<p>(1) Information about caring process: information that provides a future map (scenarios) of the caring journey, and its complications, and its impact on the caring and carer with real examples from the life of other carers.</p>	<p><i>“People have no idea of the care involved...About the physical care of my son...The knowledge that the formal carers have an understanding of the scenario that happens at home, and how it can affect the carer” [Interview]. “How other carers cope (with tiredness and frustration at getting up so many times during the night)” [Activity Diary].</i></p>
<p>(2) Coping with the caring process: Information about feelings of the carers and ways of dealing with these feelings, ways of relaxation and being patience, coping strategies with the caring situation and journey, how carers should look after themselves and not feeling guilty or bad and verbal support.</p>	<p><i>“About how you feel...dealing with the emotions and reactions around diabetes in the teenagers, this the information that I want, there probably should be specialised information for a carer...how to let go a little bit and not think that the world can fall apart for that coke...Probably looking after myself more” [Interview]. “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) [Activity Diary].</i></p>
<p>(3) Information about new skills that carers may have in order to care effectively and organise the work related to caring process (e.g. typing, computer programs).</p>	<p><i>“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].</i></p>

<p>(4) Information about administrative and financial procedures related to the carers: Information that is related to procedures, carers' right, availability and details of organisations that provide these services</p>	<p><i>"A lot of it is about claiming... that we would not actually need at that time"</i> [Interview]. <i>"How others have coped in this situation (appeal to have carer payment backdated)"</i> [Activity Diary].</p>
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4.3. Information needs related to the interaction between the carer and the person needing care

The third component involves a number of categories of information needs. The carer needed information relating to information transfer to the

person needing care, ways of interaction with the person needing care, ways of controlling and dealing with the feelings associated with the interaction with the person needing care, impact of the condition on the whole and wider family and changing the routine life of the person needing care, the carer and the family.

Table 3 presents definitions for each of these categories of information needs and example quotes from the carer's interview transcript and activity diary illustrate these categories of information needs related to the interaction between the carer and the person needing care.

Table 3: Information needs related to the interaction between the carer and the person needing care and representative quotes from the case study

Category	Quotes from Case Study
<p>(1) Ways of transferring knowledge and information to the person needing care without frustrating him/her and worrying about it. Carers might need to know amounts, types and times of information.</p>	<p><i>"The information to impart that knowledge to him in such a way but it is not overbearing, and it is not treating him like a little child"</i> [Interview]. <i>"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?"</i> [Activity Diary].</p>
<p>(2) Ways of interactions with the person needing care: information on the ways of building trust and friendship and maintaining self-esteem of the person needing care, also the ways of dealing and parenting an adolescent with an illness or condition.</p>	<p><i>"I do not want to hassle him all the time... I try to think of ways maybe slipping him 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"</i> [Interview]. <i>"What to expect during the teen years"</i> [Activity Diary].</p>
<p>(3) Ways of controlling and dealing with the feelings associated with the interaction with the person needing care: Information on the kinds of feelings that might arise from the interaction and the ways of controlling and dealing with each one.</p>	<p><i>"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"</i> [Interview].</p>
<p>(4) Impact of the condition on the whole and wider family: information that is related to ways of achieving commitment of the family toward caring, types and ways of transferring information to the family, as well as consequences of the condition on the family.</p>	<p><i>"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 wider family and to the community"</i> [Interview]. <i>"How diabetes management affects family relationships...how to respond when acquaintances enquire after my son"</i> [Activity Diary].</p>
<p>(5) Ways and strategies of changing the routine life of the person needing care, the carer and the family. Information that is related to the kinds of routine that should be changed and how to do that smoothly and its benefits.</p>	<p><i>"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"</i> [Interview].</p>

4.4. Information needs related to the interaction between the carer and other parties (professionals,

nurses, social workers, other carers, teachers,etc.)

This component involves three categories of information needs. The carer needed information relating to

other parties who may interact with the carer and the person needing care, transferring information about the person needing care to those parties, and impact of the condition on friendships and activities with friends. Table 4 presents definitions for each

of these categories of information needs and example quotes from the carer’s interview transcript and activity diary illustrate these categories within this component.

Table 4: Information needs related to the interaction between the carer and other parties and representative quotes from the case study:

Category	Quotes from Case Study
<p>(1) Ways to impart information about the person needing care to other parties (friends, school teachers, and healthcare professional): Information on types, times and ways of transferring information to other people, and the carers’ rights when they interact with these parties.</p>	<p><i>“Difficulty in knowing how to respond when friends, acquaintances enquire after my son... How others have coped in this situation...The information is to not be afraid to speak up, that you have a right to speak up, 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...I think the parents, the carer needs the knowledge to step forth and do that, because otherwise it is so dangers situation”</i> [Interview]. <i>“How to respond when friends enquire after my son”</i> [Activity Diary].</p>
<p>(2) Information about other parties dealing with carer and the person needing care: Information that is related to what carers should expect when they interact with these parties, and what services they provide and available, as well as the duties and responsibilities of these parties, and whether they know the carers rights or not.</p>	<p><i>“What to expect when we did go to the hospital...To actually finding someone who knows about diabetes as well is a good idea, not so easy to do...A catalogue of where to go to podiatry or whatever...There is some acknowledgment of the carers by the formal carers ...and a direction that they can heading to...But there is no generalised acknowledgment of the absolute impact it has on you and your child...I think it is acceptance without having to deal with the business side of diabetes”</i> [Interview].</p>
<p>(3) Impact of the condition on friendships and activities with friends: Information on importance of friendships for the person needing care and effects of the condition on activities with friends, as well as types of information that should be transferred to friends about the person needing care during the activities.</p>	<p><i>“About how friends can be important...The information about... how diabetes can affect ... friendships...The knowledge about how can impact on activities with friends”</i> [Interview].</p>

5. Discussion

The investigation of this case study suggests that the research method and the analytical framework applied here can be used to add depth and breadth to previously reported understandings of the information needs of informal carers. The carer was keen to talk about her life and experience and she was able to cope very well during the interview - in this respect, the interview guide and activity diary were acceptable to the carer and show their applicability in uncovering her lived experience in different contexts (although keeping an activity diary has been shown to be an inappropriate research tool in that it requires too much commitment of the carer’s valuable time). As shown in the Tables (1) to (4), the taxonomy provided a comprehensive and useful way of collecting, analysing and organising

information needs of informal carers. By asking the carer about her every day tasks and activities and interactions (with the person needing care and other parties), it was possible to identify what her information needs were. The taxonomy was useful in revealing her information needs related to her diabetic child, herself, interaction between her and her son, and interaction between her and other parties in regards to her child.

The case study findings broadly validate the proposed four components of the taxonomy. Information needs related to the person needing care form approximately half of the information needs of the carer (as measured by number of categories). The other three components of the taxonomy account for the other half of the information needs related to the person needing care. Therefore, it is reasonable to suggest that these other

three components of the taxonomy may be just as important as the first component and the taxonomy as a whole revealed a more holistic view of information needs of carers than previous studies have done. In other words, the carer in this study needed more information and more types of information than previous researchers have found. This study also confirmed some types of information needs that researchers have identified. For example, previous researchers have found that informal carers need information regarding the status of the person needing care such as illness, disability, and elderly [11, 19, 26], treatment and medications [21], physical, psychological and social aspects of the caring services [18, 20], information about coping strategies [23, 26], side effects, diet, administrative and financial issues, organizations and systems [26], and illness’s

management plan [21]. Although there have been some information needs identified by previous researchers that may fall into some other components of the taxonomy, most of the available literature has focused on the first component, namely, the information needs of informal carers related to the patients or persons needing care. The other three components of the taxonomy have not been specifically explained and adopted in the literature to date.

This study has several implications for consumer-centred health information systems development. First, the four components of the taxonomy provide an insight into the delivery of information. Information providers may present the information relating to each component such as information related to the person needing care or information related to the carers themselves. This may be preferable to presenting information as a list of information types that informal carers may not readily relate to their daily experiences, components and situations of caring.

Second, the categories and subcategories of information needs – under each component – would need to be taken into account when providing information to informal carers. A consumer health information system should enable and facilitate providing the types of information needs that fall under each component, in order to support the situation of the person needing care more effectively. In this regard, meeting the information needs of informal carers will require these systems to provide a wide range of timely and up-to-date information which can be absorbed by informal carers gradually. System design should focus on providing user-friendly interfaces and smart search systems that can navigate the wide range of information needs. These systems must be able to be trusted by carers to provide frequent regular updates. This means that in the education, support and networks of information for informal carers, it is necessary to provide more than basic diagnostic information about the person needing care. For example, in

terms of providing support to families where a child has been diagnosed with diabetes, it is just as essential to provide timely information on many aspects such as: child development, social life, caring progress and coping, and interactions inside and outside the home. This also emphasises the importance of ongoing support for carers through the provision of information beyond the initial diagnosis. Moreover, there is also a need for the information to be appropriate for informal carers with little medical background and to be endorsed not only by clinical experts but also by a network of people with similar experiences of being a carer and other information sources such as books, leaflets and Internet. Furthermore, findings from this case study indicate that some of these types of information are currently available while other types are yet to become available, such as information about specialised health services and impact of the condition and caring process on the whole family.

Third, from this study, meeting some of the information needs will require enabling and facilitating contact, communication and sharing information between informal carers and other carers with same experiences. Communication between informal carers and experts is also required in order to deliver some of the information needs of informal carers. Communication between informal carers and the person needing care are also important especially when the person needing care or carer goes outside the home.

Fourth, the interactions between informal carers and both persons needing care and other parties have implications for information services design. For example, a consumer health information system could take as one of its assumptions that informal carers are likely going to experience these interactions. Such system should in turn be able to draw a map of these interactions and provide solutions on how to manage these interactions. This map may help informal carers to prepare themselves for these interactions and show/teach them

how to manage and solve the issues related to these interactions. Finally, the consumer health information system would need to enable informal carers to map and navigate the stages of caring process. This map may show the needed information for each stage and sources of where and how to get this information if any. This system would also need to provide information and help on how to manage and finalise the administrative and financial procedures related to the situation of the informal carer and person needing care.

This work has the potential to increase the effectiveness of carers and service providers who deal with them, and to be relevant for those with system-level interests in meeting the information needs of informal carers in many contexts. In this regards, these findings may be important for various parties:

- **Informal carers themselves:** For example, these findings may raise the awareness of informal carers of children with diabetes regarding the information that is important and useful for them in order to be able to articulate and demand it from healthcare providers.
- **People who work directly with informal carers or persons needing care:** For example, these finding may help healthcare providers (physicians, nurses, dietitians, etc) to evaluate the information they have currently offered to the carers of their patients and try to improve it.
- **Health information and education providers:** For example, these findings may help community organisations (e.g. Diabetes Australia) that currently work and support informal carers or patients to be aware of these multi-dimensional information needs and take account of these needs in their future programs and events that target these groups of people.
- **Health information and education developers:** For example, these findings may help systems designers to take account of these information needs when they

design systems, electronic or otherwise, that target patients or consumers in general. These findings also may help those who are interested in developing training programs that aim to enhance the skills of professionals who are dealing and communicating with informal carers.

6. Conclusion

This paper was concerned with proposing and testing empirically a taxonomy of information needs of informal carers, to assist in understanding carers' information needs comprehensively. The taxonomy worked well in portraying a comprehensive picture of information needs in this case study. By using this taxonomy, it was possible to identify the informal carer's information needs associated with her daily tasks, activities and interactions. Analysis of this case study has shown information needs in all four main categories of the proposed taxonomy, although not evenly distributed across them. Emerging social web technologies may provide new opportunities for consumer health information systems to meet carers' needs with the kind of sophistication and subtlety that findings to date suggest is required. In addition, carers' expectations that clinical care providers dealing with the patient are themselves in a networked information environment may be met somewhat through the wider adoption of shared electronic health records. Further research is needed to test the usefulness of this taxonomy with more carers of children with diabetes and other groups of informal carers. This future research is also needed to study the ways in which the taxonomy and the case study findings may be used as an organising framework and evidence base, by designers and developers of consumer health information system.

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