

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

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## **Objective:**

This paper proposes and reports on an empirical test a taxonomy of information needs of informal carers that assists in understanding their information needs comprehensively.

## **Background:**

Little research has been done into 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 carer's 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. Drawing upon previous research on the information needs of informal carers, this paper suggests four main categories of information needs of informal carers: (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.

## **Methods:**

This paper adopts a qualitative case study approach and utilises data from a carer of a child with Type I diabetes. The qualitative approach combined data from a seven-day activity diary and a semi-structured interview.

## **Results:**

Analysis of the case study shows information needs in all four categories, although not evenly distributed across them.

## **Discussion:**

The paper discusses the adequacy of the four proposed categories to describe the information needs in this case study, and outlines directions for further research.

## **Keywords:**

Information Needs, Informal Carers, Diabetes, Children, Case Study

## **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 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, information during various phases and over time. Moreover, these systems tend to overlook the information needs of one main group of consumers, namely informal carers (Sternberg 2002). Informal carers need support and information just as much as those persons whom they care for (Zapart et al. 2007; Morris and Thomas 2002). Thus, if developers and providers want these systems to be successful and relevant they should include the information needs of this important group in designing any information system that targets the patients or persons needing care.

Researchers and practitioners are increasingly paying more attention to informal carers. 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 carer's 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. Consequently, the aim of this paper is to propose and test empirically a taxonomy of information needs of informal carers that assists in understanding their information needs comprehensively. 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 essential information may take the form of: advice, opinion, channel of communication and physical entity. This study is the first phase of a larger study investigating information needs, behaviours and sources of informal carers.

### ***Informal carers:***

Informal carers are 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 or significant disability, or chronic diseases. The core tasks of informal carers are varied depending on the care situation. 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 (Zapart et al. 2007, Pickard and Glendinning 2002). 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 (Access Economics report 2005). Caring for children is more difficult and challenging. Although research has highlighted the importance of information for informal carers (e.g. Zapart et al. 2007) in order to do these tasks more effectively, informal carers continue to report a number of unmet needs including information needs (Pickard and Glendinning 2002).

### ***Information needs of informal carers:***

Research has 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 (Krishnasamy, Wells and Wilkie 2007; Janda, Eakin et al. 2006). Research has also established a number of socio-economic benefits from satisfying the information needs of informal carers (e.g. Hummelinck and Pollock 2006; Lowes, Lyne and Gregory 2004). Nevertheless, information provision for informal carers is still inadequate in many respects (Hummelinck and Pollock 2006; Kendall, Thompson and Couldridge 2004). Moreover, 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 (Kendall, Thompson and Couldridge 2004; Morris and Thomas 2002). Many informal carers hardly express their information needs and some may not even know how to articulate those needs (Hummelinck and Pollock 2006). Furthermore, 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 (Beaver and Witham 2007). Therefore, informal carers not only need information to support the persons needing care, but also they need information to support themselves.

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. Carroll and Marrero 2006; Lowes, Lyne and Gregory 2004). However, little research investigates the information needs of informal carers of children with diabetes (e.g. Collier, Pattison et al. 2001).

In light of the above, 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.

## ***A taxonomy of information needs of informal carers:***

This taxonomy of information needs of informal carers has four main categories:

- 1) 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. Hepworth 2004). These information needs may include information about illness and treatment for example.
- 2) 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 map is hardly developed and informal carers are not satisfied with it (Health Canada 2005). As caring affects informal carers emotionally and influences their personal lives and wellbeing (Zapart et al. 2007); these information needs can also be extended to include these aspects. Informal carers also need to keep their personal identity besides that of carers (NSW Department of Ageing, Disability and Home Care 2006). Acknowledging the needs of informal carers including their own information needs is an important step in supporting carers (Zapart et al. 2007). These information needs may include information on how to do the care services effectively and information on how to reduce their stress.
- 3) 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 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 (NSW Department of Ageing, Disability and Home Care 2006). Acknowledging informal carers' relationship with the patient or the person needing care is another basic step in supporting the carers (Zapart et al. 2007). This interaction inevitably has some positive and some negative aspects. Informal carers experience a number of emotional reactions to their caring role (Zapart et al. 2007). 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.
- 4) 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 (NSW Department of Ageing, Disability and Home Care 2006). Many informal carers do not know what are services provided, by who and for whom. They may lack the skills to communicate with service providers and may not ask for them (Health Canada 2005). 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 how to interact with these parties and their legal rights to information about the person needing care.

## ***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 (Nicholas 1996). 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 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 (Yin 2002). This qualitative approach enabled us to explore and gain an in-depth understanding of the information needs of a mother of a diabetic child. The qualitative case study combined two methods. Using multiple methods assists in triangulation and validation of research findings (Gorman and Clayton, 2005). Ethical approval was provided by the University of Melbourne-Human Research Ethics Committee. Participation was voluntary and the confidentiality of the information was assured. Participant was recruited through one of not-for-profit; non-clinical organizations (Type I diabetes network). The participant was firstly contacted by telephone to discuss her interest, ascertain her eligibility and explain the study to her. After agreeing to participate she was sent a letter with more information about the study and telephoned to ascertain 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.

Data were collected via an activity diary and a semi-structured interview. These two methods have 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. Agosto and Hughes-Hassell 2006). 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, dietician, 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.

### **Case study summary:**

The participant in this case study was a 52 years old woman with three children; her younger son has been diagnosed with diabetes on 2005 when he was twelve years old. She needed information immediately upon diagnosis in order to reassure her son. Although she sought clarifications from their GP as to 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 hypo) because her child started to take insulin 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 diabetes type I 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 fourteen 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 by cooperation of a network of many professionals and organisations (Hospitals, doctors, nurses, dieticians, support groups...etc). She expected that doctors would know all of these network parties.

## Data analysis of information needs:

After transcribing the semi structured interview 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 (Berg 2004). 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 (Berg 2004) 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.

## 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. However, these quotes should be sufficient to show the nature of the components of the taxonomy, and the categories as well as the types of data that were collected.

**Information needs related to the persons needing care:** Table 1 presents example quotes from transcript illustrate the categories of information needs related to the person needing care:

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

<b>Information about the condition itself:</b> 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 Australasia, the latest thing that is happen overseas as well...More knowledge about possible complications from diabetes" [Interview].</i>
<b>Information about treatment of the condition:</b> Information on the treatments available, related advantages, disadvantages and side effects.	<i>"Information regarding likelihood of insulin effectiveness in hot weather and effective pump pouches... Side effects of insulin other than hypos" [Activity Diary].</i>
<b>Information about Management of the condition:</b> 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" [Interview].</i>
<b>Impact of the condition on personal, social life of the person needing care:</b> 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" [Interview].</i> <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" [Activity Dairy].</i>
<b>Nutrition and diet requirements:</b> 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?" [Activity Diary].</i> <i>"How eating late at night or not eating enough late at night can have any impact" [Interview].</i>



<b>Exercise requirements:</b> 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" [Interview].</i>
<b>Personal care of the person needing care:</b> Information that carers might need that is related to the ways and times of doing personal care of the person needing care.	<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>
<b>Specialised health services for other health problems affecting the condition:</b> Information on caring for other illnesses that might happen in conjunction with the condition and the specialised health services available for these illnesses.	<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>
<b>Routine activities outside the home (school/work/camping):</b> Information that is related to the condition impact on activities and achievements, and things that person needing care need during performing these activities.	<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>
<b>Information about administrative and financial procedures related to the person needing care:</b> Information that is related to procedures, availability and details of organisations that provide these services.	<i>"A lot of it (information) is...about getting a health care card" [Interview].</i>

**Information needs related to the carers themselves:** Table 2 presents example quotes from transcript illustrate the categories of information needs related to the carers themselves:

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

Category	Quotes from Case Study
<b>Information about Caring Process:</b> information that provides a future map (scenarios) of the caring journey, ant its complications, and its impact on the caring and carer with real examples from the life of other carers.	<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>
<b>Coping with the caring process:</b> 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.	<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>
<b>Information about new skills</b> that carers may have in order to care effectively and organise the work related to caring process (e.g. typing, computer programs).	<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>
<b>Information about administrative and financial procedures related to the carers:</b> Information that is related to procedures, carers' right, availability and details of organisations that provide these services.	<i>"A lot of it is about claiming... that we would not actually need at that time" [Interview]. "How others have coped in this situation (appeal to have carer payment backdated)" [Activity Diary].</i>

Information needs related to the interaction between the carer and the person needing care: Table 3 presents example quotes from transcript illustrate the 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 case study*

Category	Quotes from Case Study
<b>Ways of transferring knowledge and information</b> to the person needing care without frustrating him/her and worrying about it. Carers might need to know amounts, types and times of information.	"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" <b>[Interview]</b> . "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?" <b>[Activity Diary]</b> .
<b>Ways of interactions with the person needing care:</b> 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.	"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" <b>[Interview]</b> . "What to expect during the teen years" <b>[Activity Diary]</b> .
<b>Ways of controlling and dealing with the feelings associated with the interaction with the person needing care:</b> Information on the kinds of feelings that might arise from the interaction and the ways of controlling dealing with each one.	"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" <b>[Interview]</b> .
<b>Impact of the condition on the whole and wider family:</b> 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.	"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" <b>[Interview]</b> . "How diabetes management affects family relationships...how to respond when acquaintances enquire after my son" <b>[Activity Diary]</b> .
Category	Quotes from Case Study
<b>Ways and strategies of changing the routine life of the person needing care, the carer and the family.</b> Information that is related to the kinds of routine that should be changed and how to do that smoothly and its benefits.	"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" <b>[Interview]</b> .

**Information needs related to the interaction between the carer and the other parties (professionals, nurses, social workers, other carers, teachers, etc):** Table 4 presents example quotes from transcript illustrate the categories that are fallen within this main category:

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

Category	Quotes from Case Study
<b>Ways to impart information about the person needing care to other parties</b> (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.	<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" [Interview].</i> <i>"How to respond when friends enquire after my son" [Activity Diary].</i>
<b>Information about other parties dealing with carer and the person needing care:</b> 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.	<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 acknowledgement 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" [Interview].</i>
<b>Impact of the condition on friendships and activities with friends:</b> 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.	<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" [Interview].</i>

## Discussion:

The taxonomy provided a comprehensive and useful way of understanding (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. Consistently with previous studied, information needs related to the person needing care form most of the information needs of the carers. The other three components of the taxonomy account for approximately half of the information needs related the person needing care. However, it is reasonable to suggest that the taxonomy 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 than previous researchers have found.

This study 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 (Beaver and Witham 2007; Bulsara and Fynn 2006; Hepworth 2004), treatment and medications (Hummelinck and Pollock 2006), physical, psychological and social aspects of the caring services (Richardson, Plant et al. In Press; Lin and Tsao 2004), information about coping strategies (Kendall, Thompson and Couldridge 2004; Hepworth 2004), side effects, diet, administrative and financial issues, organizations and systems (Hepworth 2004), and illness's management plan (Hummelinck and Pollock 2006). 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 available literature.



## Conclusion:

This paper was concerned with proposing and testing empirically a taxonomy of information needs of informal carers that assists 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 informal carers' information needs associated with their daily tasks, activities and interactions. Analysis of the case study has shown information needs in all four main categories, although not evenly distributed across them. 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. This is an ongoing study and is currently testing the usefulness of this taxonomy with more carers of children with diabetes. Future research is also needed to test the usefulness of this taxonomy with other groups or informal carers.

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