

# A TAXONOMY OF INFORMATION NEEDS OF INFORMAL CARERS

## *An Empirical Investigation*

Basil Alzougool, Shanton Chang

*Department of Information Systems, Faculty of Science, The University of Melbourne, Australia*

Kathleen Gray

*Biomedical Multimedia Unit- Faculty of Medicine, Dentistry and Health Sciences, The University of Melbourne, Australia*

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

**Abstract:** Researchers and practitioners are increasingly aware of the importance of the information needs of informal carers. However, little research has investigated their information needs comprehensively within the lived experience of being an informal carer. This paper presents a taxonomy of information needs of informal carers that assists in understanding their information needs more fully. This taxonomy divides information needs of informal carers into four major conceptual categories: (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 needs related to the interaction between informal carers and other parties. The usefulness of this taxonomy is demonstrated empirically using the results of eight case studies of carers of children with Type 1 diabetes. Evidence is provided to show how this taxonomy gives a multi-dimensional account of the information needs of informal carers. These results are important for those who work with such carers and for those who are concerned with addressing the information needs of informal carers in other healthcare contexts.

## 1 INFORMATION NEEDS OF INFORMAL CARERS

Researchers and practitioners are increasingly aware of the importance of the information needs of informal carers. However, little research has explored their information needs comprehensively within the lived experience of being an informal carer. Moreover, 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. Drawing upon existing research on the information needs of informal carers, the authors have previously developed a taxonomy of information needs of informal carers (Alzougool et al., 2007 & 2008) with the aim of giving a richer, more multi-faceted account of the information needs of this group. The aim of the present paper is to illustrate the usefulness of this taxonomy with empirical data gathered from eight cases of informal carers of children with Type 1 diabetes.

These cases were selected as an example of a group of healthcare information consumers whose information needs are important because of the large and growing impact of this health condition on the healthcare system. Empirical evidence is provided to show how this taxonomy assists in describing many more aspects of the information needs of informal carers than are commonly recognised.

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" (Beaver & Witham 2007, p. 17). The core tasks of informal carers are varied depending on the care situation (Zapart et al., 2007; Pickard & Glendinning, 2002). Most tasks are done at home. While caring for someone can be a positive experience, many carers are harmed physically, mentally, emotionally and socially by their caring roles (Access Economics, 2005). 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 (International Diabetes Federation, 2007). Although research has highlighted the importance of information for informal carers (e.g. Zapart et al., 2007) to do their tasks more effectively, informal carers continue to report a number of unmet needs including information needs (Pickard & Glendinning, 2002). Research has also shown that information provision for informal carers is still inadequate in many respects (Hummelinck & Pollock, 2006; Kendall et al., 2004). Topics of information that informal carers need vary widely according to: the various tasks that they do, the characteristics of informal carers, the illness's duration and stage and caring processes (Krishnasamy et al., 2007; Janda et al., 2006). Moreover, the relationship between informal carers and persons needing care is a main barrier that inhibits informal carers from accessing information that fulfils their information needs (Kendall et al., 2004). Many informal carers hardly express their information needs and some may not even know how to articulate those needs (Hummelinck & 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 & Witham, 2007). Therefore, informal carers not only need information to support the persons needing care, but also they need information to support themselves.

Most studies specifically 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 & Marrero, 2006; Lowes et al., 2004). However, there is little research that focuses on the information needs of this group (e.g. Collier et al., 2001).

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, we propose a taxonomy of information needs of informal carers which 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.

## 2 A TAXONOMY OF THE INFORMATION NEEDS OF INFORMAL CARERS

In this section we present the taxonomy of the information needs of informal carers adopted from our previous studies (Alzougool et al., 2007 & 2008). The primary purpose of the taxonomy is to provide a framework that assists in understanding and including

the diversity of information needs that ensue from informal carers' interactions and activities and is empirically testable. The taxonomy also provides a way to investigate the information needs based on these activities and interactions. This taxonomy divides information needs of informal carers into four major conceptual categories:

- 1) **Information Needs related to the Persons Needing Care.** This information arises from the condition of the patient or the person needing care and may be similar to some of the information needs of patients themselves especially the medical information. Most research has explored these information needs (e.g. Hepworth, 2004).
- 2) **Information Needs related to the Informal Carers Themselves.** Informal carers need information that draws their caring journey in order to adjust with it and predict their actions and activities. Since caring affects informal carers emotionally and physically (Zapart et al., 2007) they also need information to help them to be carers without overwhelming their personal lives. Moreover, informal carers need to maintain a personal identity beyond their role as a carer (NSW Department of Ageing, Disability and Home Care, 2006). Furthermore, they need to know their rights and obligations in terms of the confidentiality and privacy restrictions on the information related to the patient or the person needing care
- 3) **Information Needs related to the Interaction between Informal Carers and Persons Needing Care.** Interaction between the informal carers and the patient or the person needing care is central to their role and relationship. This interaction increases in certain situations, for example if the person needing care is a child with chronic disease. 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, Teachers, etc).** Informal carers may be required to interact with many parties regarding the person needing care. These interactions too may increase in certain situations, such as when the person needing care is a child. Informal carers need to know what services are provided, by and for whom. They also need to have the necessary skills to communicate with service providers (Health Canada, 2005).

In general, individuals' 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). To fully understand the information needs of informal carers we must explore their activities and interactions using all four categories in our taxonomy.

### 3 METHOD

To test the usefulness of this taxonomy of the information needs of informal carers, a study of eight informal carers of children with diabetes was undertaken, using a qualitative case study approach (Yin, 2002). This study used a convenience sample, identifying experienced informal carers of diabetic children who were willing and able to give to a researcher a full description of experiences that could be analysed to build a comprehensive picture of their information needs. Potential participants were recruited through not-for-profit, non-clinical organizations. Criteria for inclusion as a case study included any person over the age of 18 years old who provided a diabetic child with unpaid day to day caring services on a practical and /or emotional level. The eight case studies reflect a range of caring experiences. For example, six of these informal carers were mothers and two were fathers of a diabetic child. Four have African ethnic background, three Anglo-Saxons and one Arabian. The average age of these carers were approximately 40 years old, and their average caring experiences were approximately 6 years. Half of these carers had a secondary school certificate or less. Six of these carers were living in urban areas and two in rural areas. The average age of diabetic children at time of interview was approximately 11 years old.

Semi-structured interviews based on the taxonomy described in this paper were conducted between December 2007 and June 2008 with each of the carers in their own homes. The interviews lasted for approximately 40 to 150 minutes and explored a range of topics including: information background, everyday experiences and tasks with the persons needing care in regards to their illness, treatment, managing illness, and other aspects of everyday life, and their experiences in regards to their own personal lives, interaction between them and persons needing care and other parties (e.g. physicians, nurses, diabetes educators).

The interview transcripts were analysed by a researcher using two strategies (Berg, 2004): firstly, inductive content analysis was used, reading and rereading the transcripts, coding, preliminary categorisation, and further classification of data into

categories and sub-categories, working backwards and forwards between the data and the coding scheme; and secondly deductive content analysis was used to sort the categories that were identified into the four major conceptual components of the taxonomy. A second researcher was asked to evaluate the findings for accuracy and completeness.

### 4 FINDINGS

This section presents each of the components of the taxonomy with one or more representative excerpts from the raw data to show that each one was supported by data from the case studies. Each component also includes a number of categories and sub-categories of information needs that fall within it as well as the number of times each sub-category emerged from the data:

- 1) **Information Needs Related to the Persons Needing Care:** The first component of the taxonomy involves a number of categories and sub-categories of information needs required by the carers. Table 1 presents definitions for each of these categories of information needs, frequencies of sub-categories and example excerpts from transcripts to illustrate the nature of information needs of informal carers related to the person needing care. As shown in Table 1, approximately 75% of sub-categories of these information needs have been identified in at least of six out of eight cases in the study. Other sub-categories have been manifested in two to four of the cases.
- 2) **Information Needs Related to the Carers Themselves:** This component involves three categories and twelve sub-categories of information needs required by the carers. Table 2 presents definitions for each of these categories of information needs, frequencies of sub-categories and example excerpts from transcripts. As shown in Table 2, nine sub-categories of these information needs have been identified in at least of seven out of eight cases in the study. The other sub-categories have occurred five or six times.
- 3) **Information Needs Related to the Interaction between the Carer and the Person Needing Care:** The third component involves a number of categories and sub-categories of information needs required by the carers. Table 3 presents definitions for each of these categories of information needs, frequencies of sub-categories and example excerpts from transcripts. As shown in Table 3, ten sub-categories of these information needs have been highlighted by at least seven out of eight cases in the study. The other three sub-categories have appeared four to six times among the cases.

Table 1: Categories and sub-categories of information needs related to the person needing care, frequencies and representative quotes from case studies.

Categories	Sub-Categories	Frqcy (n = 8)	Example Quotes from Case Studies
<b>(1) Information about the condition itself:</b> This refers to information about causes of the condition, its symptoms, its types, and its possible complications as well as if there are any precautions to prevent the condition and how it is diagnosed.	Causes of the conditions	8	“At that time...we’ve never known about type 1 and type 2, but people in the hospital explained to us about type 1 and type 2” [Case 2].
	Different types of the conditions	6	
	Symptoms of the condition	6	
	Precaution to prevent the condition	3	
	Possible complications of the condition	3	
	Diagnosis process of the condition	2	
<b>(2) Information about treatment of the condition:</b> This refers to information about treatment options and their functionality and suitability of particular treatments to the person needing care, advantages and disadvantages of these options and technologies used in treatment and management of the condition and latest research findings about new treatments, cure and trials.	Treatment options and their functionality	8	“We’ve (he and his wife) asked them to explain to us the positives and the negatives (of the pump) and different other options” [Case 1].
	Suitability of the treatment to the person	7	
	Advantages and disadvantages of the treatment	4	
	Technology used in the treatment and management of the condition	4	
	Latest news about the treatment possibilities and research, cure, and trials	4	
<b>(3) Information about ongoing management and control of the condition:</b> This includes information that is related to guidelines, procedures, times and places of managing and controlling the condition, symptoms of controlling and non-controlling of the condition, and things that carers should do to control and manage the condition including guidelines that help carers to take decisions to facilitate this process.	Guidelines and procedures to manage and control the condition during the day and night	8	“No one told me how to manage it, doctor told me quickly but I’ve forgotten, after that I’ve found other parents and books (to learn from them) [Case 4].
	Times and places of controlling of the condition	8	
	Symptoms of controlling and non-controlling of the condition	8	
	Guidelines for taking decisions during the condition management and control	8	
	Things to be done to manage the condition	8	
<b>(4) Impact of the condition on personal and social life of the person needing care:</b> This refers to information about effects of the condition on the abilities, development, feelings, behaviour, attitude, professional and family life of the person needing care and their activities with friends.	Effects of the condition on the abilities and development of person needing care	8	“How your child feels...A psychologist’s view on signs of distress in my son...difficulties within marriage related to my son’s diabetes management” [Case 8].
	Effects of the condition on the his/her feelings	8	
	Effects of the condition on the behaviour and attitude of the person needing care	6	
	Effects of the condition on the professional and family life of the person needing care	6	
<b>(5) Nutrition and diet requirements:</b> This includes information about choices, types, times, amounts of food that are suitable for the person needing care including recipes, shopping guidelines and places that sell this food as well as effects of food, eating and non-eating on the condition of person needing care.	Choices and types of food that are suitable for the person needing care	8	“You spend your time wondering is that a serve or is it not a serve...I don’t really know...so it’s not until you go eat it or you use it” [Case 5].
	Times and amounts of the food	8	
	Effects of food, eating and non-eating on the condition of person needing care	8	
	Preparation and recipes of food	8	
	Shopping guidelines of food and places that sell it	3	
<b>(6) Exercise requirements:</b> This refers to information about choices, types, times and periods of exercises that are suitable for the person needing care including things to do, avoid and have during the exercises as well as effects of exercise and non-exercise on the person needing care.	Choices and types of exercises that are suitable for the person needing care	8	“I...need more ...information related to just how much her body needs this (exercise) continually” [Case 6].
	Times and periods of the exercises	8	
	Effects of exercises and non-exercises on the person	8	
	Things to do, avoid and have during the exercises	7	
<b>(7) Routine activities outside the home (school, work, camping, travel):</b> This refers to information about things that persons needing care have to take, do, avoid, have and will do while they are outside the home, and the services available that are of interest to the person needing care as well as the effects of the condition on activities outside home and vice versa.	Things that persons needing care have to take with them while they are outside the home	8	“The written materials that we still have at home that are explaining every thing that child may be need, at home, outside, at school, every where” [Case 7].
	Things that persons needing care should do, avoid or have while they are outside home.	8	
	Effects of the condition on activities outside the home	7	
	Things that they will do while they are outside home	4	
	what services available outside the home	2	



Table 2: Categories and sub-categories of information needs related to carers themselves, frequencies and representative quotes from case studies.

Categories	Sub-Categories	Freqcy (n = 8)	Example Quotes from Case Studies
<b>(1) Information about caring process:</b> This refers to information that provides a step by step guide, times and places of the caring process and things that carers have to engage in, in order to care effectively and possible scenarios that can happen and how to deal with, supported with real examples from other carers.	A step by step guide for performing the caring process	8	“The dietician and educator have taught us how to...handle him, how to prepare the needle, when to give him it...all you need to care about him” [Case 1].
	Times and places of caring process	8	
	Things that carers should do to care	8	
	Map of the caring journey with real examples from other carers	7	
<b>(2) Coping with the condition and caring process:</b> This includes information about feelings and feelings management, and strategies that help carers to cope with the condition and look after themselves including verbal support from any person who comes into contact with carers, especially family, healthcare professionals and other carers.	Feelings and feelings management of the carer	8	“It’s not like ok “do you find it overwhelming? Get a diary that will make it easier” or, “there is no information for you ...sometimes how to cope” [Case 5].
	Coping strategies with the condition and caring journey	8	
	Verbal support to the carer	6	
	Strategies for carers to look after themselves	5	
<b>(3) Information about new skills:</b> This refers to information that provides carers with kinds of skills, applicable place and timeliness of skills, as well as lengths of time the skills might be needed in order to carry out the caring process effectively including the purposes and reasons for learning these skills. This information also includes carers’ rights and how to negotiate with third parties.	Kinds of skills that carers have to learn to care	8	“I didn’t know before how to inject the insulin...I couldn’t do her finger test... (It took her) about three...months to learn ... now I know how to do it” [Case 3]. “I am not a nurse...so I need (to learn to be like a nurse)” [Case 7].
	Purposes and reasons for learning these skills	7	
	Carers’ rights and how they interact with other parties regarding the person needing care	7	
	Time, period, cost and place of skills training	6	

4) **Information Needs Related to the Interaction between the Carer and other Parties:** This component involves two categories and six sub-categories of information needs required by the carers. Table 4 presents definitions for each of these categories of information needs, frequencies of sub-categories and example excerpts from transcripts. As shown in Table 4, four sub-categories of these information needs have been identified in all cases in the study. The other two sub-categories have been manifested in four to five of the cases.

## 5 DISCUSSION

This empirical investigation 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. By asking the carers about their every day tasks and activities and interactions (with the person needing care and other parties), it was possible to identify what their information needs were. The taxonomy was useful in revealing their information needs related to their diabetic children, themselves, interaction between them and their children, and interaction between them and other parties in regards to their children.

More than half (as measured by number of categories) of the information needs of these informal carers were not directly related to the condition of the person needing care, rather they were indirect than this. Therefore, 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,

these findings suggest that the other three components of the taxonomy maybe just as important as the first component. This in turn may have an impact on the way we provide information to informal carers and take into consideration their wider information needs. 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 emphasises the importance of ongoing support for carers through the provision of information beyond the initial diagnosis.

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 condition of the person needing care (e.g. Beaver & Witham, 2007), treatment and medications (e.g. Hummelinck & Pollock, 2006), physical, psychological and social aspects of the caring services (e.g. Richardson et al., 2007), coping strategies (e.g. Kendall et al., 2004), side effects and diet (e.g. Hepworth, 2004), and illness’s management plan (e.g. Hummelinck & 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 related to the persons needing care. The other three components of the

Table 3: Categories and sub-categories of information needs related to the interaction between the carer and the person needing care, frequencies and representative quotes the case studies.

Categories	Sub-Categories	Frqcy (n = 8)	Example Quotes from Case Studies
<b>(1) Transferring information to the person needing care:</b> This refers to information about types, times and amounts of information that carers have to give to the person needing care, which is supported by strategies on how to transfer these types of information to the person needing care.	Types of information (what and how to) that carers should give to the person needing care	8	“The information to impart that knowledge to him in such a way, but it is not overbearing, and it isn’t treating him like a little child” [Case 8].
	Times and amounts of information that should be given to the person needing care	8	
	Strategies to transfer the information to the person needing care	8	
<b>(2) Strategies of interactions with the person needing care:</b> This includes information that provides carers with strategies that help them to convince persons needing care to apply caring process, to deal with and parenting persons needing care during different stages, to build trust, to maintain self-esteem, and address questions of persons needing care related to their conditions.	Strategies to convince the person needing care to apply caring process	8	“I have trouble with him not rotating his needles, his injections, he constantly wants to have them in his thighs, so I...sought information from doctors about that...it’s a battle it’s a fight...even with the food it’s a fight to get him to eat” [Case 5].
	Strategies to deal with and parenting the different stages of the person needing care	8	
	Strategies to build trust and maintain self-esteem to the person needing care	7	
	Strategies to address questions of the persons needing care related to their conditions	5	
<b>(3) Impact of the condition on the whole and wider family:</b> This refers to information about consequences of the condition on the family and information that carers have to give to family including strategies to achieve commitment of the family toward caring for the person needing care and strategies to deal with and parenting other siblings.	Consequences of the condition on the family	8	“I felt it was very important, very early on, to make the girls aware of what was going on...we went through everything that I’d been taught in hospital” [Case 6].
	Information that should be given to the family	8	
	Strategies to achieve family commitment toward caring of the person needing care	6	
	Strategies to deal and parenting other siblings of the person needing care	4	
<b>(4) Changing the routine life of the person needing care, the carer and the family:</b> This refers to information that provides carers with kinds of routine life that may be changed and strategies to do that. It also includes the benefits of changing the routine life and consequences of not changing it.	Kinds of routine life that should be changed and the strategies to do that	8	“We have to wake up in certain times...we must look after him during the day... even the doctor said to me...your life will not be the same ... that is really what happened” [Case 2].
	Benefits of changing the routine life and consequences of not changing it	7	

Table 4: Categories and sub-categories of information needs related to the interaction between the carer and other parties, frequencies and representative quotes from case study.

Categories	Sub-Categories	Frqcy (n = 8)	Example Quotes from Case Studies
<b>(1) Other parties that may interact with carer and the person needing care:</b> This refers to information that provides carers with identity and services provided by these parties, and their duties and responsibilities toward the carers and persons needing care including carers’ expectations when they interact with them.	Duties and responsibilities of other parties toward the person needing care	8	“I had an awful time with the school...they didn’t get the importance of it...they didn’t understand that he has to eat every 2.5 hrs...I’ve fought them...lots of letters to Department of Education” [Case 5].
	Carers’ expectations from other parties when they interact with them	8	
	Services provided by other parties	5	
	Who are other parties that may interact with the person needing care	4	
<b>(2) Transferring information about the person needing care to other parties:</b> This includes transferring any relevant information about the person needing care to third parties, including their specific needs and care process supported by strategies on how to transfer this information to these parties.	Types and times of information that carers should give to other parties regarding the person needing care.	8	“The information is... to check whether school nurse or teachers...would know what to do if he had a hypo...to insist upon things where they stored” [Case 8].
	Strategies to transfer the information to other parties regarding the person needing care.	8	

taxonomy have not been specifically explained and adopted in the literature to date. These findings have 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.

For example, these findings may help community organisations 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. These findings may also help systems designers to take account of these information needs when they design systems that target patients or consumers in general.

## 6 CONCLUSIONS

This paper has reported findings from empirical testing of a taxonomy of information needs of informal carers.

The method and analytical framework were shown to be useful to systematise the detail and pattern of information needs in eight case studies. The carers were keen to talk about their lives and experiences and they were able to cope very well during the interviews. In this respect, the interview protocol was acceptable to the carers and shows its applicability in uncovering their lived experiences in different contexts. By using the four-part taxonomy, it was possible to capture most of the interview data regarding informal carers' information needs associated with their daily tasks and activities and interactions. Analysis of the case studies shows information needs in all four components, although not evenly distributed across them. This research project is continuing to test the usefulness of this taxonomy with more case studies of informal carers of children with diabetes. Future research is also needed to test the usefulness of this taxonomy with other groups of informal carers.

## REFERENCES

- Access Economics, 2005. The economic value of informal care. Report for Carers Australia. Available from: <http://www.carersaustralia.com.au/images/stories/Access%20Economics%20study%20full.pdf>
- Alzougool, B., Chang, S., & Gray, K., 2007, 'Modeling the information needs of informal carers', in M. Toleman, A. Cater-Steel, & D. Roberts (Eds.), *ACIS 2007: Proceedings of the 18th Australasian Conference on Information Systems* (pp. 345-355). Toowoomba, 5-7 December 2007, University of Southern Queensland, Australia. Available from: <http://www.acis2007.usq.edu.au/assets/papers/62.pdf>
- Alzougool, B., Gray, K., & Chang, S., 2008, 'Toward a Taxonomy of Information Needs of Informal Carers: A Case Study of a Carer of a Child with Diabetes', in H. Grain (Eds.), *HIC 2008: Proceedings of Australia's Health Informatics Conference*. Melbourne, 31 August-2 September 2008, Health Informatics Society of Australia (HISA), Australia. Available from: <http://www.hisa.org.au/system/files/u2233/07-Chapter02.pdf>.
- Beaver, K., & Witham, G., 2007. Information needs of the informal carers of women treated for breast cancer? *European Journal of Oncology Nursing*, 11(1), 16-25.
- Berg, B. L., 2004. *Qualitative research methods for social sciences*, Pearson; Allyn and Bacon. Boston, Mass, 5<sup>th</sup> edition.
- Carroll, A. E., & Marrero, D. G., 2006. How do parents perceive their adolescent's diabetes: a qualitative study. *Diabetic Medicine*, 23(11), 1222-1224.
- Collier, J., Pattison, H., Watson, A., & Sheard, C., 2001. Parental information needs in chronic renal failure and diabetes mellitus. *European Journal of Pediatrics*, 160, 31-36.
- Health Canada, 2005. The information needs of informal caregivers involved in providing support to a critically ill loved one. *A synthesis report*, prepared by Janet Dunbrack. Available from: [http://www.hc-sc.gc.ca/hcs-sss/alt\\_formats/hpb-dgps/pdf/pubs/2005-info-caregiver-aidant/2005-info-caregiver-aidant-eng.pdf](http://www.hc-sc.gc.ca/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2005-info-caregiver-aidant/2005-info-caregiver-aidant-eng.pdf)
- Hepworth, M., 2004. A framework for understanding user requirements for an information service: Defining the needs of informal carers. *Journal of the American Society for Information Science and Technology*, 55(8), 695-708.
- Hummelink, A., & Pollock, K., 2006. Parents' information needs about the treatment of their chronically ill child: A qualitative study. *Patient Education and Counselling*, 62(2), 228-234.
- International Diabetes Federation, 2007. *Diabetes Atlas*, 3<sup>rd</sup> edition. Available from: <http://www.eatlas.idf.org/>
- Janda, M., Eakin, E. G., Bailey, L., Walker, D., & Troy, K., 2006. Supportive care needs of people with brain tumours and their carers. *Supportive Care in Cancer*, 14(11), 1094-1103.
- Kendall, S., Thompson, D., & Couldridge, L., 2004. The information needs of carers of adults diagnosed with epilepsy. *Seizure*, 13(7), 499-508.
- Krishnasamy, M., Wells, M., & Wilkie, E., 2007. Patients and carer experiences of care provision after a diagnosis of lung cancer in Scotland. *Supportive Care in Cancer*, 15(3), 327-332.
- Lowes, L., Lyne, P., & Gregory, J. W., 2004. Childhood diabetes: parents' experience of home management and the first year following diagnosis. *Diabetic Medicine*, 21(6), 531-538.
- Nicholas, D., 1996. Assessing information needs: tools and techniques. *ASLIB know how series*, edited by Sylvia P. Webb. ASLIB, London.
- NSW Department of Ageing, Disability and Home Care, 2006. Diverse Strategies for Diverse Carers: The Cultural Context of Family Carers in NSW. *A report*, prepared by Beatriz Cardona, Sharon Chalmers, Brett Neilson (Centre for Cultural Research, University of Western Sydney). Available from: [www.uws.edu.au/download.php?file\\_id=18052&filename=FINAL\\_REPORT\\_JULY.pdf&mimetype=application/pdf](http://www.uws.edu.au/download.php?file_id=18052&filename=FINAL_REPORT_JULY.pdf&mimetype=application/pdf).
- Pickard, S., & Glendinning, C., 2002. Comparing and contrasting the role of family carers and nurses in the domestic health care of frail older people. *Health and Social Care in the Community*, 10(3), 144-150.
- Richardson, A., Plant, H., Moore, S., Medina, J., Cornwall, A., and Ream, E., 2007. Developing supportive care for family members of people with lung cancer: a feasibility study. *Supportive Care in Cancer*, 5(11), 1259-1269.
- Yin, R.K., 2002. *Case Study Research: Design and Methods*, Sage Publications. Newbury Park, 3<sup>rd</sup> edition.
- Zapart, S., Kenny, P., Hall, J., Servis, B., & Wiley, Sh., 2007. Home-based palliative care in Sydney, Australia: the carer's perspective on the provision of informal care. *Health and Social Care in the Community*, 15(2), 97-107.