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# Modeling the Information Needs of Informal Carers

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## Abstract

*There is not only a lack of research that conceptualises the information needs of informal carers but also a shortage in research that addresses those needs from the perspective of information systems in the health care system. This shortage of systematic and conceptualised research on information needs of informal carers often prohibits the information providers and developers from knowing what types of information informal carers need to support their roles and tasks as carers and to evaluate how well they are fulfilling the information needs of informal carers. Drawing upon the previous available research on information needs in general and information needs of informal carers in particular, this paper proposes a conceptual model of the information needs of informal carers. The conceptual model illustrates four abstraction groups of information needs of informal carers i.e. recognised demanded, unrecognised demanded, recognised undemanded, and unrecognised undemanded. The paper highlights the potential usefulness of the model.*

## Keywords

Informal Carers, Information Needs, Information Behaviour, Health Information Systems, Information Modeling

## Introduction

Healthcare developers and providers are increasingly developing and deploying many Health Information Systems (HIS) which have the potential to shift a physician-centred healthcare relationship to one of individual-centred healthcare by giving the role to the individual to manage his/her own health (Detmer 2003) and to help others to do the same. Whereas there seems to be significant growth in the development of HIS, these systems have yet to reach their potential (Riet et al. 2001); one of the reasons is that designers have not actually investigated the real needs of the end-users and they have assumed what these needs are without consulting the end-users (Sternberg 2002). Therefore, it may be important to analyse these information needs as experienced by the end-users themselves. This can assist in conceptualising how the end-users understand and express their experiences of information needs. Then, developers can take these real needs of end-users into consideration when designing the information systems that target those end-users.

One important group that have often been ignored by HIS developers over the years is informal carers. Informal carers have an important role in helping and assisting the persons needing care on a daily basis and they need support and information in the same way as those persons whom they care for. In fact, primary and community healthcare are a cornerstone of the healthcare system. As a result, informal carers start and continue to provide most of the care services for persons needing care (Odhiambo, Harrison & Hepworth 2003). For example, they provide care services for their relatives and friends who are unable to care for themselves for different reasons such as old age, disability, or disease.

Therefore, information needs of informal carers become important (Morris & Thomas 2002) given the fact that information helps them to carry out their roles more effectively as carers. Thus, if developers and providers want HIS to be successful they should include the information needs of this important group in designing any information system that targets the patients or persons needing care. Understanding the information needs of the informal carers may help make the systems more relevant for them.

Research on information needs of informal carers is generally descriptive. Very little research has focused on the information needs as a separate aspect of information behaviour; most of it has studied the information needs as

something obvious and in conjunction with other aspects of information behaviour (seeking, searching and resources). Most research also tends to be limited because it still describes the information need itself rather than looking at the whole picture of the information needs process and understanding it by creating models and frameworks that provide explanation and understanding of the information needs of informal carers. Marcella, Baxter and Moore (2002) have highlighted the shortage of such models and frameworks in general, yet very few researchers have tried to conceptualise the study of information needs of informal carers (e.g. Hepworth 2004).

Consequently, this paper aims to propose a model of information needs of informal carers that can be used to identify, understand, abstract, analyse and organise the actual everyday experiences and information needs of informal carers from their own perspective.

## Information Needs

Generally, researchers have identified many causes that give rise to information need such as: "seeking answers, uncertainty reduction, bridging gaps, solving problems, understanding (making sense), and stress and coping" (Case 2002). However, as is evident in the literature and everyday life, information need is more than that, because sometimes information itself increases the stress and uncertainty of individuals (Case 2002). For example, in some situations, individuals may not demand the information even if they need it. Therefore, understanding the difference between need and demand can assist in better defining information needs.

### Need and Demand

The American Heritage® Dictionary of the English Language (retrieved May 29, 2007) identifies many definitions for the term "need". Most of them focus on two major meanings *"a condition or situation in which something is required"* and *"necessity of or obligation to"*, which in turn implies two meanings i.e. the shortage or lacking and something imperative. Most scholars in the information behaviour field define and deal with the term "need" as lacking and very few define and deal with it as something necessary. On the other hand, there are various definitions of the term "demand". Most of them concentrate on two major meanings *"to ask for something"* and *"desire or willingness to"* (American Heritage® Dictionary of the English Language, retrieved May 29, 2007), which also implies two meanings i.e. the request for something and the desire or willingness to get or to do something. Many scholars in the information behaviour field define and deal with the term "demand" as *"a request made to an information system"* (Case 2002; p. 67) both informal and formal. Very few define and deal with it as a desire or willingness to get something.

In sum, the term "need" in this paper refers to anything necessary to do or satisfy something else depending on the context of such thing, and the term "demand" refers to an individual's willingness to get something which in turn may lead him/her to request that thing from an informal or formal information system.

### Information Needs: Lack and Necessity

Scholars have introduced many definitions for information need. For example; Krikelas (cited in Forsetlund & Bjørndal 2001; p. 2) defined an information need as *"the recognition of the existence of uncertainty"*. Case (2002; p. 5) defined information need as *"a recognition that your knowledge is inadequate to satisfy a goal that you have"*. Also Braun, Wiesman et al. (2007; p. 247) defined information need *"as an expression of missing information needed to perform a particular task"*. However all definitions concentrate on the recognition of the lack of information and the need of the information seeker to satisfy that shortage. This approach to information need assumes two things; (a) that information is already available and provided and (b) that the information seekers are responsible for recognising their lack of information and will subsequently demand that information. Conversely, scholars rarely focus in their definitions on the possibility that there is essential information that is not provided, not recognised and not demanded but that is still essential. This implies there is a body of information that is essential whether it is provided or not by providers, recognised or not, and demanded or not by end-users.

Wilson (1999; 1981) has highlighted the difficulty and the slow progress in defining and understanding information need and suggested that information seeking behavior should be studied instead of information need because the information seeking behaviour is a reflection of the information need. It can be argued that this statement somewhat ignored the fact that some people may engage in the information seeking behaviour even if they do not perceive or recognise the need for information. For example, a person may browse the Internet to get an idea on what information is available, which may later be of interest to him/her. The difficulty in defining information need seems to come from the separation between the two words "information" and "need". Defining the information need as one phrase and dealing with it as something essential and necessary may solve this difficulty. Every individual has essential information that results from the context that he/she acts in to survive and continue living in this world as well as to make his/her life easier and meaningful. However an individual

may recognise or not recognise his/her own information need and he/she may demand or not demand this information need. For example, the information need for a student exists whether the student demands it or not, and whether he/she recognises it or not.

Therefore, it can be suggested that information need may be grouped with other human needs or considered as the primary essential need for human beings because it raises awareness of the existence of other human needs and motivates the process of how and where to satisfy those human needs. For example, it can be argued that an individual will not know that he/she needs food until he/she thinks about that need by using information. In other words, information need is a primary need and not a secondary need as Wilson (1981) suggested, because it gives the individual information about all other human needs and the knowledge of how to satisfy those needs. Accordingly it can be assumed that information need exists and is necessary for the human being whether this information need is recognised or not recognised and demanded or not demanded by individuals in general and by informal carers in particular.

Consequently, if we deal with the term "information need" as two 'joint' words this implies that information is already available and information providers provide all information needed by individuals. However, this is contradictory with everyday life as there is a vast amount of information needed by individuals but still not available and not provided by information providers. In contrast, if the term "information need" is used as one phrase, this implies some of the information needs of people may not be available yet and providers should be aware of that and provide this information. Therefore, this paper defines information needs as any form of information that is essential to individuals as a result of the context that they act in. Information needs may also take any of the following forms: "factual data, advice, opinion, subjective data, channel of communication and physical entity" (Wilson 2000).

## Information Needs: Existence and Demand

In light of the above definitions for need and demand, it should also be noted that as derived from the literature, very few researchers have differentiated between information need and information demand. Most researchers equate information need with information demand. They do this by studying and focusing on the information seeking behaviour of individuals (e.g. Wilson 1999).

This paper argues that information need is different to either the information demand, the demand of information need or the demand of the available information because information need exists whether individuals demand it or not and whether information that fulfils this need is available or not. More details about these concepts can be found in Table 1.

Table 1: Summary of the concepts related to demand of information need

| Key Concept | Definition |
| --- | --- |
| Information need | Any form of information that is essential for an individual as a result of the context that he/she acts in. |
| Information demand | *"The request made to an information system"* (Case 2002; p. 67) to satisfy the lack of information. |
| Demand of information need | The availability of some characteristics in the information need context that make an individual has the willingness to get this essential information. |
| Demand of the available information | The actual request made by an individual for the available information that fulfils this essential information. |

Moreover, investigating information need is more comprehensive than investigating information demand, the demand of the information need or the demand of the available information. These are always less comprehensive than information need for many reasons:

- Individuals do not demand all the available information or all information needs (essential information) i.e. some types of information may increase their anxiety, which means they might want to avoid the information even when it is needed.
- Individuals do not have access to all the available information (Hjørland, retrieved March 30, 2007; Bernatowicz 1987) e.g. language (the book contains the needed information but is written in a different language) or to all information needs (essential information).
- The provision of information provided is often lesser than information needs (e.g. information providers are used to provide that kind of information which is commonly demanded by people).
- Individuals may not accept some forms or types or content of the available information.

Additionally, it should be noted that Hjørland (retrieved March 30, 2007) highlights the shortage of in-depth analysis and action to differentiate between information need and information demand.

Many scholars in the field of information behaviour have investigated and still investigate information demand instead of investigating information need. Therefore, they have not deeply examined the information need and have concentrated only on one pattern or mode of information behaviour namely, the information seeking behaviour (and consequently information searching and retrieving behaviour) rather than studying other patterns and modes of information behaviour which may result from in-depth analysis of the demand or non-demand of information need and not from the information demand. The field is full of research that ignores the nature and essence of the need and assumes it as something clear and understandable (Hjørland, retrieved March 30, 2007).

Acknowledging the difference between information need, information demand, demand of information need and demand of the available information may assist in studying and analysing the occurrence of the information needs, conceptualisation and abstraction of these needs and studying the different patterns and modes of information behaviour that result from each one of them. Therefore, it is important to note that the demand of information need may be considered as a consequence and a description of information need (Bernatowicz 1987); this means the information needs may be demanded or not demanded depending on the context of the information need itself and the individual circumstances, and the information demand and demand of the available information are a consequence of the demand of information need, as individual may decide to obtain this essential information after having the willingness to get it.

## Information Needs: Existence and Recognition

Furthermore, it can be argued that information need exists even if an individual is not aware of it or does not feel a lack of it. For example, information need of the student exists whether the student recognises its existence or not, recognises lack of this information or not and whether he/she recognises the availability of information that fulfils this need or not.

Hence, information need differs from either the recognition of lack of information, the recognition of information need or the recognition of available information. More details about these concepts can be found in Table 2:

Table 2: Summary of the concepts related to recognition of information need

| Key Concept | Definition |
|---|---|
| Information need | Any form of information that is essential for an individual as a result of the context that he/she acts in. |
| Recognition of lack of information | *"A recognition that your knowledge is inadequate to satisfy a goal that you have "* (Case 2002; p. 5) |
| Recognition of information need | The recognition of what this essential information is. |
| Recognition of available information | The essential information is available and the individual recognises its availability. |

Moreover, investigating information need is more comprehensive than either investigating the recognition of lack of information, the recognition of information need or the recognition of available information. These are always less comprehensive than information need for many reasons:

- Individuals do not recognise all the available information (Hjørland, retrieved March 30, 2007; Bernatowicz 1987).
- Individuals may not recognise all information needs (essential information). For example, a person performs a task, the information that essential to perform this task exists and may be available, but the person may not recognise this essential information or its availability.
- Lack of information is a consequence of information need because it is important to be aware of all essential information for an individual before deciding what information he/she may lack.

Many scholars in the field of information seeking behaviour have investigated and still investigate the recognition of lack of information and the recognition of available information that fulfils this need instead of investigating information need. This paper proposes that it is also important to study the recognition and non-recognition of information need, for a more complete picture of the information need of individuals. This means the information need may be recognised or not recognised depending on the context of the information need itself and the individual circumstances. Further, the recognition of available information is a consequence of the recognition of information need because an individual only seeks for available information after recognising what this essential information is.

## 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"* (Beaver & Witham 2007; p. 17). However, informal carers have different identities depending on whether they are:

- Co-members of the official healthcare team, then the information for them become a prerequisite for delivering the healthcare services effectively (Morris & Thomas 2002), or
- Co-consumers with the persons whom they care for, then they have the right to receive their information needs like the persons whom they care for (Morris & Thomas 2002), or
- Intermediators or patient advocates for the persons whom they care for, then they need the information to help them to manage their health care and daily life (Morris & Thomas 2002), or
- Individuals in the community, 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.

Although research has highlighted the importance of identifying and supporting the informal carers in the community (Bulsara & Fynn 2006), informal carers have sometimes declined to identify their position (Harding & Higginson 2001), consequently there is no consensus on the term "informal carer" and some parties of informal carers prefer to identify themselves with the term "family member" (Richardson, Plant et al. in press) rather than "informal carer". Thus, whatever position or identity informal carers represent, it is evident that information is essential to them in order to do their role and tasks as carers more effectively (Morris & Thomas 2002). In addition, researchers and practitioners are increasingly paying more attention and recognition to the informal carers, and they have currently started to include and study the various aspects of informal carers.

## Information Needs of Informal Carers

Consequently, information needs of informal carers refer to the different types and forms of information that are essential to informal carers as a result of their role and tasks as carers in order to manage the caring services effectively without overwhelming their own lives. Therefore, informal carers not only need information to support the persons needing care, but also they need information to support themselves. In other words, this information facilitates the multifaceted care process and keeps it doable and agreeable as well as assists the commitment of informal carers toward caring without overwhelming their own lives. Additionally, the issues related to the information needs of informal carers in the literature can be summarized into five major themes:

### General Consensus on Information Needs of Informal Carers

There is not only a common agreement in the literature on the importance of information for informal carers, but also on the key topics of information needed by them (e.g. Krishnasamy, Wells & Wilkie 2007; Janda, Eakin et al. 2006; Cooper & Urquhart 2005; Salminen, Vire et al. 2004; Odhiambo, Harrison & Hepworth 2003; Morris & Thomas 2002; Collier, Pattison et al. 2001).

Literature shows that topics of information that informal carers need vary extremely from information related to the status of the person needing care (e.g. illness, disability, and elderly), to information related to the treatment or the caring itself, to information related to the coping strategies, to information related to everyday routine life and to information related to support their own lives (Richardson, Plant et al. In Press; Beaver & Witham 2007; Bulsara & Fynn 2006; Tilse et al. 2005; Lin & Tsao 2004; Odhiambo, Harrison & Hepworth 2003; Wong, Franssen et al. 2002). Although informal carers may have some information needs similar to those for the persons whom they care for, nevertheless, specific types of information needs of informal carers exist for them in order to be able to handle the caring process more effectively (Beaver & Witham 2007).

However, discussing of the occurrence and the arising of information needs of informal carers, the reasons for which they need information, and the abstraction and the classification of those information needs are still lacking in the literature.

### Information Provision for Informal Carers

Although it is clearly established in the literature that satisfying the information needs of informal carers can achieve many benefits i.e. managing the caring process successfully, coping with and explaining the status of the persons needing care to others, participating in the decisions that concern the persons needing care, supporting their roles in doing and to continue to do the caring services and maintaining their well-being and that of the persons needing care (Richardson, Plant et al. In Press; Hummelinck & Pollock 2006; Lowes, Lyne & Gregory 2004; Wong, Franssen et al. 2002; Collier, Pattison et al. 2001), research has proven that information needs of informal carers are not often acknowledged and as a consequence remain unmet (Hummelinck & Pollock 2006;

Kendall, Thompson & Couldridge 2004; Salminen, Vire et al. 2004; Odhiambo, Harrison & Hepworth 2003; Morris & Thomas 2002).

Moreover, some studies have highlighted the shortage and inequality in information provision for informal carers (e.g. Eriksson & Lauri 2000). In addition, the available information sources for informal carers are generally limited in their evidence-base and few informal carers utilise those sources (Cooper & Urquhart 2005). Furthermore, research has established that there are many factors influencing information provision for informal carers (Hummelinck & Pollock 2006; Patistea & Babatsikou 2003):

- Severity of the illness: informal carers of persons with an illness that required secondary health care received more information than informal carers of persons with an illness that required primary health care.
- Level of involvement in the caring process: informal carers of persons with an illness that required a high level of self-management and involvement seem to be offered more information than those of persons with other conditions which required a low level of involvement.
- Informal carers' experience: informal carers with a previous knowledge and experience of the illness of the persons they care for seem to receive more information that those who do not have previous knowledge and experience.

Although the above findings cover many aspects in the area of information provision, some issues are still lacking in the literature i.e. the benefits of satisfying the information needs of informal carers that related to their personal lives, and investigating the availability of other factors affecting the information provision.

## Variations in Information Needs of Informal Carers

A considerable amount of research has demonstrated that information needs of informal carers not only vary over the time and during the different phases of caring process, but also they vary according to the characteristics of informal carers themselves (Krishnasamy, Wells & Wilkie 2007; Hummelinck & Pollock 2006; Janda, Eakin et al. 2006; Salminen, Vire et al. 2004; Morris & Thomas 2002). Research shows that some characteristics of informal carers change their information needs i.e.:

- Gender: females need more health information than males (Eriksson&Lauri 2000).
- Education level: informal carers with lower educational level need more information than those with a higher educational level (Eriksson&Lauri 2000), contrary; some other studies (Salminen, Vire et al. 2004) found that informal carers with higher educational level need more information than those with a lower educational level.
- Occupation: informal carers in lower occupation need more information than those in a higher occupation (Collier, Pattison et al. 2001).

However, there is a need not only to investigate the different phases of caring over time but also to explore what information needs are required for specific phases and specific times. There is also a need to investigate other characteristics of informal carers that may influence their information needs such as their experience. In addition, whether the information needs of informal carers vary according to the characteristics of persons needing care and the formal carers as well is a rich area of research yet to be examined.

## Informal Carers Face Different Barriers to Recognise, Identify and Access Their Information Needs

Although it is evident in the literature that a number of barriers inhibit informal carers from meeting their information needs, most of this research explores the barriers of accessibility to information (during the information seeking process). This has yet to be extended to include other barriers that inhibit informal carers from recognising and identifying their information needs.

One of the main barriers is the healthcare policies which inhibit informal carers from gaining access to information because of the confidentiality, privacy and legal issues particularly in the developed countries which have started to adopt legislation that requires consent of the patients before providing information to their informal carers (Kendall, Thompson & Couldridge 2004; Morris & Thomas 2002). The relationship between informal carers and persons needing care is also an important barrier to access information (Morris & Thomas 2002). Moreover, many informal carers hardly express their information needs and they almost do not sense or know how to articulate those needs (Hummelinck & Pollock 2006) which highlights the importance of information illiteracy as another barrier.

**Information Needs of Certain Groups of Informal Carers and Persons Needing Care**

Recently, researchers have begun to address the information needs of informal carers more extensively. However, the studies tend to fall into two groups. The first group of studies tends to address the information needs of informal carers of persons needing care with specific illnesses or conditions such as; informal carers of patients with cancer (e.g. Beaver and Witham 2007), informal carers of elderly (e.g. Henz 2006) and informal carers of persons with disability (e.g. Stewart, Law et al. 2006). The second group of studies addresses the information needs of informal carers regardless of the illness or condition of the person needing care (e.g. McIlfatrick 2007). However, in both groups of studies, the informal carers tend to be limited to the parents and spouses.

Therefore, most of the available research rarely investigates the information needs of other groups of informal carers such as friends, children, and community volunteers. It is also still describing the information need itself rather than looking at the whole picture of the information needs process to understand it. In addition, it is lacking a comprehensive framework to conceptualise and abstract the information needs in order to predict them in future.

# Modeling the Information Needs of Informal Carers

Accordingly, identifying the information needs of informal carers and highlighting which of these needs informal carers recognise or do not recognise, and are willing or not willing to get or act on, is the first step to develop, provide and satisfy these needs effectively, which means keeping this process flexible and open to include the new information needs that may arise or change in future. This in turn emphasises the importance of predicting those information needs in order to meet the purpose of any information system for informal carers that should allow anticipating their own information needs over the time and during the different situations. However, the available studies describe the information needs of informal cares rather than predict them. So, modeling the information needs of informal carers may stand as a practical and real solution in order to embody the information needs of informal carers on an abstract level. This firstly involves categorising the information needs of informal carers and then abstracting those categorised information needs.

Given the information above and as demonstrated from the above literature summary, the information needs of informal carers can initially be categorised into the following main groups:

- Information needs related to the persons needing care.
- Information needs related to the informal carers themselves.
- Information needs related to the relationships between informal carers and persons needing care.
- Information needs related to the relationships between informal carers and formal carers (other healthcare system parties).

**The Proposed Model of Information Needs of Informal Carers**

Moreover and as derived from the in-depth exploration of the general literature of information needs and behaviour, the above four main groups of information needs of informal carers can be represented, conceptualised and abstracted on four more abstract levels:

(a) Recognised demanded information needs {explicit information needs or the actual user of information as suggested by Wilson (1999) and Bernatowicz (1987) respectively}. This can be defined as any form of information that is essential to informal carers as a result of their role as carers; both that informal carers recognise and that they have the willingness to get.

(b) Unrecognised demanded information needs {implicit information needs or the actual user of information as suggested by Wilson (1999) and Bernatowicz (1987) respectively}. This can be defined as any form of information that is essential to informal carers as a result of their role as carers; that informal carers do not recognise but they have the willingness to get.

(c) Recognised undemanded information needs {the potential user of information as suggested by Bernatowicz (1987)}. This can be defined as any form of information that is essential to informal carers as a result of their role as carers; that informal carers recognise but they have not the willingness to get.

(d) Unrecognised undemanded information needs. This can be defined as any form of information that is essential to informal carers as a result of their role as carers; that informal carers neither recognise nor have the willingness to get.

More clarification about the categorisation and abstraction of the information needs of informal carers is shown in Figure 1:
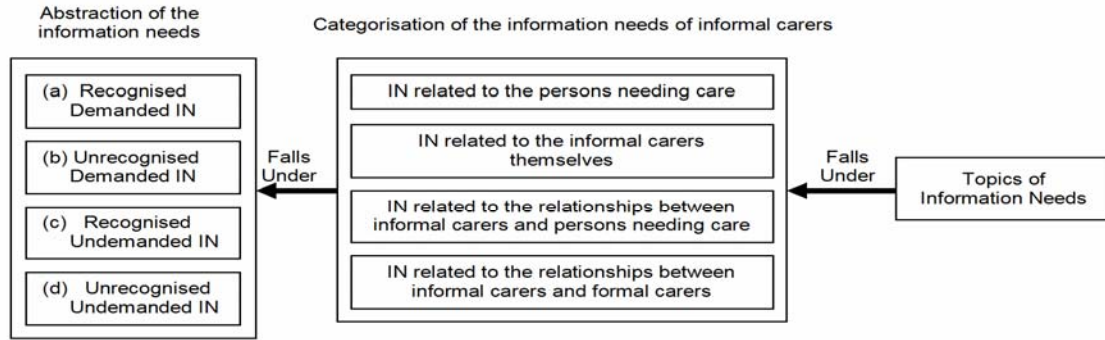
Figure 1: The proposed model of information needs (IN*) of informal carers

* IN refers to information needs

In addition, the final abstraction of information needs of informal carers can be represented by a matrix as shown in Figure 2:
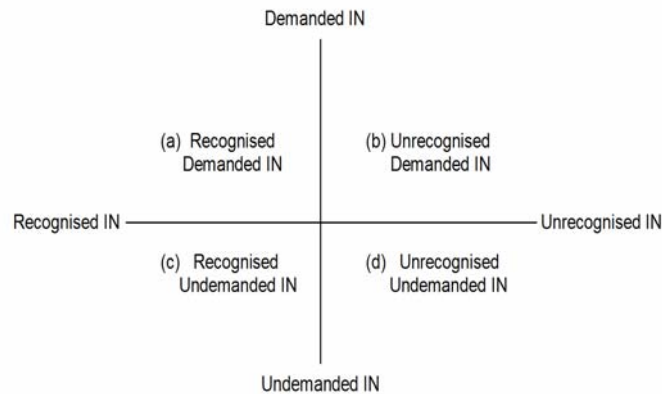


Figure 2: The proposed abstraction of information needs (IN*)

* IN refers to information needs

Furthermore, we can highlight the following points which are related to the above proposed model:

i.     Demanded information needs may be explained and measured by the availability of different characteristics or indicators: i.e. {*stress/coping, time pressure, importance, the penalty incurred by acting in the absence of full information, the availability of information sources, availability of money, and the costs of using these sources* (Godbold 2006; Wilson 1999; Leckie, Pettigrew & Sylvain 1996)}.

ii.    Undemanded information needs may be explained and measured by the availability of different characteristics or indicators: i.e. {*the involved risk, stress/coping, unavailability of time, unimportance, unavailability of information sources, do not know how to seek/search usefully, and unavailability of money* (Godbold 2006; Wilson 1999; Leckie, Pettigrew & Sylvain 1996)}

iii.   The vast amount of information behaviour research including the information behaviour of informal carers has concentrated on the first and second abstraction groups of information needs (namely, recognised demanded and unrecognised demanded) of the informal carers by studying the actual user of information. Moreover, it has rarely explored the third abstraction group of informal carers (namely, recognised undemanded), in other words, the potential user of information.

iv.   The fourth abstraction group of informal carers (namely, unrecognised undemanded) has not been explored yet.

v.    Furthermore, it can be argued that studying the third and fourth abstraction groups of informal carers is very important, as one of the main roles of information providers is to identify all information that is essential for informal carers whether this information is currently recognised and demanded or unrecognised and undemanded, because the characteristics of this information (unrecognised and undemanded) might change in the future and the informal carers may become aware of and have the

willingness to get it. So as to be aware of not providing the informal carers with information that they do not demand, which means not to overload them with vast amount of information that they do not have the willingness to get and consequently they may not use and that sometimes may increase their anxiety.

vi.   So far little is known about the motivations of informal carers in seeking or not seeking and using or not using the needed information (Wilson 1981). The above proposed model could shed light on this issue by identifying and characterising the information needs topics that fall under each of the four groups and the pattern or mode of information behaviour and information source that suits of each group, so we can understand why some informal carers who need specific information seek and act to satisfy that information and other informal carers who have the same information needs do not seek or act to satisfy that specific information. This issue is a very promising area in research which is yet to be explored.

vii.  Figure 2 suggests that information needs emerge in four different abstraction groups and every group has its patterns/modes of information behaviour and information sources/channels.

## Conclusion: Future Research and Contribution

As theoretical systematic knowledge on the information needs of informal carers is hardly available, this paper initially proposes a categorisation for the information needs of informal carers. The formulation of a model of information needs of informal carers may offer a solution for predicting these needs and including any new information need that emerges in future. Drawing upon the previous available research on information needs in general and information needs of informal carers in particular, this paper proposes a conceptual model of the information needs of informal carers. The conceptual model illustrates four abstraction groups of information needs of informal carers i.e. recognised demanded, unrecognised demanded, recognised undemanded, and unrecognised undemanded.

The paper highlights the difference between information and information need and suggests that information need may be considered as a primary human need along with other human needs. It also sheds some light on both the difference between the recognition of information need and the existence of information need as well as the difference between demand of information need and existence of information need and concludes that the information need exists whether individuals in general and informal carers in particular recognise or do not recognise and demand or do not demand it. This paper also provides an in-depth understanding of the information needs of informal carers and how these needs can be conceptualized in a practical manner which will help to summarize and organise the topics of information needs of informal carers. This in turn will help developers and providers to develop and deploy information systems that fulfil all those needs.

This proposed theoretical model is the basic fundamental step for further investigations in the field of information systems and information and library sciences. Therefore, future research will focus on testing the proposed theoretical model among a small sample of informal carers to identify and understand the actual information needs of informal carers from their point of view, also to identify what topics of information needs fall under each of the four abstraction groups and the reasons for which they need this information as well as to confirm or modify the proposed theoretical model based on the findings. Another area for future research which is related to the previous one will utilise both the findings and the tested model in order to develop a survey which will be used to validate this model empirically with a large sample of informal carers.

Additionally, the proposed theoretical model can be utilized to propose a number of assumptions about the various patterns/modes of information behaviour and the information sources and channels that informal carers engage in and make a request for, to meet, hold or ignore their information needs by assuming that each abstraction group of information needs has its pattern(s) or mode(s) of information behaviour and its source(s) and channel(s) of information system as well. Moreover, this model helps to explain why two individuals or informal carers who have the same information needs and circumstances engage in different information behaviours and make a request from different information sources and channels.

Furthermore, the proposed theoretical model can be used as an evaluation framework that helps information providers to identify the various topics of information needs that fall under each of the four abstraction groups and to assess the provision of information as well as to take actions to provide the missing information and support informal carers to get this information.

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