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Modeling the information needs
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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 demand, unrecognised demand, recognised undemand, and unrecognised undemand. 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 (Stenberg 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 (Odiambo, 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

345

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