

Modeling the Information Needs of Informal Carers

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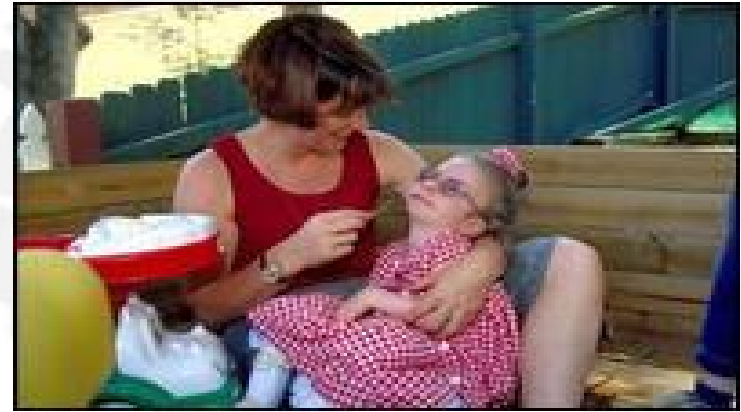


Modeling the Information Needs of Informal Carers

Presentation Outline

- ✓ **Goals**
- ✓ **Literature Background**
- ✓ **Critical Analysis of the Literature**
- ✓ **Gaps in the Literature**
- ✓ **Model Development**
- ✓ **The Proposed Model**
- ✓ **Contribution**
- ✓ **Future Research**





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Goal

To develop a **Framework** or **Model** of information needs of informal carers that can be used to identify, understand, abstract, analyse and organise the actual information needs of informal carers from their perspective.



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Literature Background

- Health Information Systems
 - Are increasingly being developed and deployed to target patients or persons needing care (*Haux 2006*).
 - Help the patients to manage their own health and enhance the abilities of their relatives (informal carers) to care for them (*Tang, Ash et al. 2006*).
 - Most of these systems have failed to achieve the required level of acceptance (*Bergman, Plsek, and Saunders 2006*).
 - Rarely consider information needs of informal carers.
 - Information needs of informal carers should be included in designing any information system that targets the patients or persons needing care.
 - Support the persons whom they care for.
 - Support themselves.
 - Carry out their tasks more effectively as carers without overwhelming their own lives.



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Literature Background: Information needs in general

- Define information needs as the recognition of lack of information (*e.g. Case 2002*).
- Assume information is provided and available.
- Assume people are responsible for recognising their lack of information and subsequently demand that information.
- Equate information need with information demand (*e.g. Odhiambo, Harrison and Hepworth 2003*).
- Study information needs indirectly through analysing information behaviour.
- Lack a systematic comprehensive understanding (frameworks or models) (*Marcella, Baxter and Moore 2002*).



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Literature Background: Information needs of informal carers

The issues related to information needs of informal carers can be summarized into five major themes:

- General consensus on information needs of informal carers.
- Information provision for informal carers.
- Variations in information needs of informal carers.
- Informal carers face a number of barriers to recognise, identify and access their information needs.
- Information needs of certain groups of informal carers and persons needing care.



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Gaps in the Literature

- Shortage of in-depth analysis of information needs.
- Lack of research that conceptualises the information needs of informal carers (frameworks and models).
- Shortage in research that addresses those needs from the perspective of information systems in the health care system.

Comprehensive understanding of information needs helps:

- Identify and predict what types of information informal carers need.
- Take these needs into consideration when designing information systems that target those carers.
- Evaluate how well these needs are provided and fulfilled.



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Model Development

Any type and form of information that is essential to individuals as a result of the context that they act in.

- Information need exists.
- The recognition and demand of information needs are a consequence and description of the existing information needs.
- People may recognise or not recognise and demand or not demand their information needs.
- The recognition and demand of information needs depend on the context of the information needs and the individuals circumstances.
- Lack is a consequence of the information needs.
- Some of the information that people need may not be available yet.



Any type 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

Any type 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

Any type 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

Any type of information that is essential to informal carers as a result of their role as carers; that informal carers recognise and that they have not the willingness to get

Abstraction Groups of IN**

Recognised Demanded	Unrecognised Demanded
Recognised Undemanded	Unrecognised Undemanded

Falls Under



* (Beaver and Witham 2007)

** IN refers to Information Needs

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Theoretical Contribution

- Develops a framework that can be used to identify, understand, abstract, analyse and organise the actual everyday information needs of informal carers from their own perspective.
- Can be utilized to propose a number of assumptions about the various patterns of information behaviour and the information sources and channels that informal carers engage in.



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Practical Contribution

- Can be used as an evaluation framework that helps information systems developers and providers to:
 - ✓ Identify the various topics of information needs that fall under each of the four main groups.
 - ✓ Evaluate their provision of information.
 - ✓ Take actions to provide the missing information.
 - ✓ Encourage and enable informal carers to meet their information needs.



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Future Research

- ❑ Examine the proposed theoretical model among a small sample of informal carers to identify and understand their actual information needs from their point of view.
- ❑ Identify what topics of information needs fall under each of the four abstraction groups and to confirm or modify the proposed theoretical model based on the findings.
- ❑ Extend the proposed model to include the various patterns of information behaviour and the information sources and channels that informal carers engage in and make a request for and test it empirically.



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Thank You



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