

Information behavior of religious parents of chronically ill children / Devorah Feldman

Abstract

The number of children living with chronic illnesses is increasing (Van Cleave et al., 2010) while the burden of care and management of the illness is mainly imposed upon parents, who must familiarize themselves with various aspects of medical care. Such burden typically co-occurs with multiple other roles parents fulfill. Most importantly, parents hold a unique position as intermediaries between the professional and therapeutic staff and the chronically-ill child. Prior studies mainly focused on two topics; parental experiences and the parents' information behavior. This current study offers a unique perspective by integrating three aspects. : First, it examines parents' experience within the context of information behavior. Second, it explores the information behavior of religious parents. Finally, it emphasizes the role of information in their lives as parents of ill children. The goal of the study was to understand these experiences as perceived by parents' with a religious worldview by conducting an in-depth analysis of the way they perceive, structure, and use information. The study utilized a qualitative phenomenological analysis of semistructured in-depth interviews and participants included 18 religious parents of chronically ill children.

The first part of the study discusses various aspects of **parents' information behavior** and focuses on information needs, information avoidance, construction of meaning, and information processing. From the parents' narrative it appears that information meets two **types of needs**: The first is a practical need that is reflected in decision-making, treatment, and illness management. The second is an emotional need to control and reduce uncertainty. Despite the need for information the narratives also reveal mechanisms of avoidance. The research identified two **patterns of avoidance**: the first is conscious and derives from a desire to maintain an optimistic outlook and to channel emotional resources towards coping with daily life. The other is not conscious and stems from the need for escape or denial. Such behaviors are interpreted within the framework of theories on stress and coping. Finally, the current findings indicate the central role **information processing** plays in information behavior during which parents go through the stages of identifying a need,

information gathering, processing and structuring within the framework of existing knowledge. The research identifies two types of knowledge, experimental and verbal, which represents different stages of the search process. The first occurs before the need is identified and the second follows that stage. These two stages are differentiated from each other by the way individuals acquire and process knowledge. The second chapter examines parents' **worldview** within the framework of Chatman's Normative Behavior theory and Dervin's (1976, 1992, 2003) Sense Making theory and presents the different ways it's reflected in their information behavior: The first, **role perception**, reveals several roles they have fulfilled as parents of ill children: Care giver, expert, advocator, facilitator and interpreter. Parent's perception of their role evolved with time and affected their information need, search, sharing, and use. The second, **illness perception**, describes the ways in which parents' perceive the illness. Parents chose a positive approach towards the illness that have shaped the way they shared and presented information about the illness to the ill child, family and community, as well as their perception of the future. The third, **faith based approach** is reflected in their attitude towards information and its value for religious parents. The analysis points towards a complicated perception of the faith based individual since information is part of a belief system based on a balance between faith in G-D and human endeavor (*hishtadlut*). Perception of human endeavor, the degree of responsibility bestowed upon the individual, defines the attitude towards information and affects information need, information search, and information use as well as the degree of involvement in the treatment. The meaning of information is not consistent among religious parents, and their perception of information is often not absolute since they experience information as having limited influence due to their faith in GD. The fourth aspect, **perception of small world**, the interviewees experience points to an existence of a small world, but mostly this perception didn't stem from the interviewees themselves but rather from their surroundings. This perception was expressed by the fear of sharing, encouragement of secrecy, prejudice and an attempt to keep the social norms of a small world even under extreme circumstances. The contribution of the current study relates to the identification and discovery of several elements of information behavior:

- a. **Context** – information behavior should be examined within the context of its expression, and as part of a wider context of the individual's life.

- b. **Information's value** - the importance the individual's places on information shapes the way he consumes information, structures its meaning and uses it. Research in the field should examine the role of information in people's lives.
- c. **Information processing** is a central stage in information behavior and this process begins before the need exists. Furthermore, the identification of this need is an outcome of the initial stage of this process.
- d. The **worldviews** and value system of the individual, which dictates his conduct including the use of information, is multilayered. The research field of health information behavior could examine role perception, value perception, illness perception, and the cultural environment of the individual.

This understanding is vital for advancing theoretical understanding and research in the field, as well as practical implementation in assisting parents of chronically ill children.

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