

Constructing sense from uncertain and evolving health information

Abstract: This qualitative study explored individuals' everyday life experiences as they interacted with and integrated uncertain health information mediated by formal and informal sources. Findings demonstrate that knowledge translation is a multifaceted, ongoing process of social construction. The study has implications for health literacy and shared decision-making.

Résumé : Cette étude qualitative explore les expériences individuelles quotidiennes dans une option d'interaction et d'intégration de renseignements médicaux incertains provenant de sources formelles et informelles. Les résultats démontrent que le transfert de connaissances est un processus de construction sociale continu à multiple facettes. L'étude a des répercussions sur la littératie en santé et la décision par consensus.

1. Introduction

While evidence-based practice and the associated challenge of knowledge translation (KT) has garnered much attention in health fields, attention has not been directed to the provisional, emergent and incomplete nature of health information (Upshur 2001) and to KT as an on-going process of social construction. The challenge of evolving health information is magnified within everyday life contexts. In these places and spaces individuals are navigating information mediated by both formal and information sources. The published literature identifies some of the information sources consulted by users (*cf.* Harris and Wathen 2007; Warner and Procaccino 2004); however, research which explores the experiences of individuals as they interact with and integrate health information mediated by diverse sources (e.g. health professionals, the media and internet, and inter- and intrapersonal sources) is limited. This study explores the experiences of women as they make sense of and use (or do not use) uncertain and/or evolving health information. It furthermore investigates the ways in which formal and informal sources facilitate response to uncertain health information and how women construct and make sense of this information. A medical case in which evidence is explicitly evolving – health management during the menopause transition – facilitates exploration of the diverse factors which influence health information use and the management of personal health. This exploratory study is informed by the view that health information is not something that is *implemented* with linearity of cause (research evidence) and effect (evidence-based health behaviours), but rather it is *translated* into practice through a constructed process that is based on 'factual' and experiential knowledge as well as on reflection, context, and inter- and intra-personal influences.

2. Brief consideration of the literature

Women are active information agents who gather, seek and store health information for both themselves and others (*cf.* Macias, Lewis, & Shankar, 2004; Wathen & Harris, 2006). Increasingly engaged in health IB within the context of everyday life and "either before, instead of, or unrelated to a visit to a doctor" (Warner & Procaccino, 2004, 714),

women seek and utilize information from a complex array of formal and informal sources (*cf.* Castelo-Branco et al., 2006; MacLennan, Taylor, & Wilson, 2004). They are thus faced with the challenge of integrating multiple sources and perspectives when managing personal health, a challenge which is heightened when health information is evolving.

The medical case that provides context for this study (health management during the menopause transition) is particularly relevant for two reasons: (1) recent research has had a significant impact on women's health care in this area and has resulted in significant change and ongoing ambiguity related to menopause management (Peterson et al. 2004; Wathen, 2006); and, (2) knowledge of medical uncertainty in this area is widespread due to exhaustive documentation in the medical and consumer press (Archer 2007; Genuis 2006). With patient preference and shared decision making becoming a central issue for health professionals (Salkovskis and Rees, 2004), increased understanding of how people experience and make sense of evolving health information will significantly advance understanding of patient perspective and help information professionals and health librarians as they facilitate KT for women navigating this life transition.

3. Theoretical framework

Based on a social constructionist approach and notions of meaning-making which incorporate an active, process-oriented view of IB (Dervin 1992), this study seeks to identify "general sense-making practices on the basis of which people orientate themselves in their everyday and working lives" (Talja, Keso, & Pietilainen, 1999, 761). Social positioning theory (Davies & Harré, 1990) provides a lens for exploring the dynamic aspects of information encounters, particularly the multiple 'storylines' that are used both unintentionally and intentionally to construct identity within social interactions and interactions between women and formal information providers (Julien and Given 2002). Furthermore, the Promoting Action on Research Implementation in Health Services (PARIHS) framework (Rycroft-Malone et al., 2002) is used as a heuristic for exploring the interplay between evidence, context and facilitation.

4. Research methods

This paper examines the ways in which formal and informal information sources facilitate women's responses to uncertain health information, the experiences of women as they respond to, interact with, and use (or do not use) changing information, and how women construct uncertain health information as they make sense of and use health information encountered within everyday life contexts. The study reports analyses of data gathered from semi-structured qualitative interviews with a sample of (1) 28 women who were engaged in IB related to the management of menopause, and (2) 12 health professionals (HPs) (including physicians, nurses, pharmacists, dieticians, and alternative health practitioners) acting as information providers for women navigating this life transition. Recruitment occurred in the community (e.g. physicians' offices, health food stores) as well as at a multidisciplinary, publicly funded menopause clinic. Two interview strategies were used during interviews with women. A semi-structured and narrative approach was taken in order to allow participants "scope to articulate their experiences in their own terms" (Petersen, 2006, 34) and to facilitate participants' constructive processes as they related, interpreted and drew together their information seeking and health related experiences (Becker, 1997; Petersen, 2006). Second, Johnson

and Weller's (2002) 'in the moment' elicitation technique was used in order to elicit response and reflection about evolving health information encountered in the popular press. Semi-structured interviews with HPs provided insight into themes emerging from interviews with women and the roles HPs play in facilitating the translation of knowledge into practice within the lives of women. Data were analyzed using NVivo software and an open-coding, grounded-theory approach.

5. Results

Data analyses drew attention to the complex information worlds women inhabit, their ready engagement with information sources, their focus on independent information seeking and interpretation, the pervasive influence of the internet, the critical role played by intrapersonal information sources, and the facilitating roles which women valued when gathering information from HPs. Analyses also highlighted the influence of the 'symptom experience' on women's IB, women's desire to align personal experience with perceived 'normal' experiences, and the increased feelings of personal responsibility which were engendered by actual or perceived upheavals in conventional medical knowledge. Finally, data demonstrate that women's construction of menopause-related information was influenced by their construction of evidence as research, as material object, as negotiated belief, and as lived experience. Source complementarity (Dutta-Bergman 2004) played an important role as women navigated uncertain health information; and social contexts were critical to learning and knowledge construction. Findings raise new considerations related to KT as an ongoing process of social construction which takes place within everyday life contexts.

6. Implications and significance

With increasing interest in the IB of "ordinary people in everyday life situations and health contexts" (Fisher & Julien, 2009, 317) and increasing focus on KT within health fields, this study contributes both theoretically and practically to knowledge in Library and Information Science and health care fields. While strong theoretical underpinning is important for all scholarly research, this study brings attention to the contribution of theory triangulation for exploratory research. This study demonstrates, for example, that whereas human information behaviour theory provided a foundation for investigation of information sources and IB, positioning theory brought focus to women's roles in decision making and to sociocultural influences, and the PARIHS framework facilitated exploration of KT as a multifaceted, constructed process which is shaped not only by information itself, but by women's contexts and the ways in which knowledge is presented.

Two primary implications for practice also emerge from this study. First, findings suggest that current approaches to health literacy do not incorporate the complex, everyday life worlds which women inhabit and the ways in which information "is actually used and made valuable in people's lives" (Souden et al. 2010). Health literacy education should move beyond an emphasis on 'good' vs. 'bad' information sources and instead teach generic assessment skills, including helping women to understand that different forms of knowledge (or *evidence*) are valuable for different information needs. Second, data analyses demonstrate that women's views of shared decision-making (SDM) are nuanced: they explicitly positioned themselves as autonomous information seekers and decision-makers, yet they valued input from HPs. Findings suggest that particularly in areas where health information is uncertain, SDM models should

encompass two-way information sharing and consideration of knowledge and treatment options which may be introduced not only by HPs, but also by women. While HPs may not always be in agreement with women's decisions, acknowledging the emergent nature of biomedical knowledge will allow acceptance of provisional decisions based on women's current contexts and will leave the door open for further collaboration and ongoing revision of decisions as new research findings emerge.

7. Relationship to conference theme

This study directly contributes to the conference theme, *Exploring Interactions of People, Places and Information* by exploring the “spaces and places in which informing is enacted” (e.g. homes, work and social environments, and interactions with HPs) and investigating the experiences of women inhabiting these spaces as they accomplish the ‘work’ of constructing and using emergent health information about the menopause life transition.

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