

# **Making sense of evolving health information mediated by formal and informal information sources: Navigating uncertainty in everyday life**

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## **Introduction**

Much has been written about evidence-based practice and challenges encountered when translating knowledge into practice. Little attention, however, is paid to the changing, emergent and incomplete nature of evidence (Upshur, 2001), and to knowledge translation (KT) as an on-going process during which people interact with and integrate a wide range information sources. The dilemma presented by evolving evidence and KT is magnified for people making health decisions within an everyday life context. In this context individuals are commonly assimilating and responding to information mediated by a wide range of formal and informal sources. While there are studies which identify information sources consulted by various user groups, research exploring the experiences of individuals as they seek to make sense of uncertain and/or evolving health information mediated by diverse sources (e.g. health professionals, media and internet, and inter- and intra-personal sources) is limited.

In this study qualitative research methods are used to explore sense-making and information behaviors (IB) elicited by uncertain health information. An illustrative medical case in which medical evidence is explicitly evolving – health management during the menopause transition – provides context for this investigation. This case is particularly relevant for two reasons: (1) recent research 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). Furthermore, women are active information agents who gather, seek and store health information for themselves and others (Macias, Lewis, and Shankar 2004; Wathen and Harris 2006). Not only do women seek and use information from a complex array of formal and informal sources (Hoffmann, et al., 2005; MacLennan, Taylor, & Wilson, 2004), but they are increasingly engaged in health IB “either before, instead of, or unrelated to a visit to a doctor” (Warner & Procaccino, 2004, 714). Women are thus faced with integrating multiple sources and perspectives when managing personal health, a challenge which is heightened when health information is evolving.

## **Theoretical framework**

This exploratory research is based on a social constructionist approach which 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), and notions of meaning-making which incorporate an active, process-oriented view of IB (Dervin 1992). Social positioning theory (Davies & Harré, 1990) provides a lens for exploring dynamic aspects of information encounters, particularly interactions between women and formal information providers.

## **Research design and preliminary results**

This study reports analysis of data gathered through semi-structured interviews with a theoretical and purposive sample of 28 women who are engaged in information-gathering or decision-making related to hormone therapy and/or menopausal/postmenopausal health concerns. A purposive sample of 12 health professionals (including physicians, nurses, pharmacists, and alternative health practitioners) acting as information providers to women navigating the menopause transition was also interviewed. Participants were recruited from the community (e.g. physicians' offices, health food stores) and from a multidisciplinary 'menopause clinic' functioning within the public healthcare system and providing support to a cross-section of women. In order to yield rich descriptive data, two interview strategies were used with the first sample. (1) A semi-structured, narrative approach allowed women "scope to articulate their experiences in their own terms" (Petersen, 2006, 34). And (2) Johnson and Weller's (2002) 'in-the-moment' elicitation technique was used – women were presented with contrasting media articles in order to elicit reflection on conflicting media-mediated health information and its integration with information from other sources. For interviews with health professionals, the Promoting Action on Research Implementation in Health Services framework (Rycroft-Malone et al., 2002) provided a schema which facilitated insight into information sources, context, and the role of health professionals in facilitating KT (Genuis, 2008). Data were analyzed using NVivo software and an open-coding, grounded-theory approach.

Initial analysis of data draws attention to the complex information worlds which women inhabit, to strategies used to navigate and reconcile uncertain health information, and to information roles played by health professionals. Analysis also highlights the critical role of intra-personal information sources; the value which women place on learning within social contexts; the profound reach and influence of the internet, and the varying approaches which women and health professionals take to this medium; and deep ambivalence towards media-mediated health information.

## **Significance**

With increasing interest in the IB of "ordinary people in everyday life situations and health contexts" (Fisher & Julien, 2009, 317), this study makes an important contribution to Library and Information Science. Health professionals are most likely to involve women in shared decision-making in situations of uncertainty (Salkovskis and Rees 2004). Understanding women's experiences as they navigate evolving health information and integrate information from formal and informal sources is therefore critical for librarians and information professionals who seek to facilitate decision-making. Whereas librarians working in health fields have traditionally focused on delivering facts and research evidence, this study draws attention to the broad range of sources which inform women as they make decisions about personal health, and to the variety of roles librarians might take as they facilitate KT (Harvey et al., 2002; MacIntosh-Murray & Choo, 2005). Those working in both public and health sectors cannot ignore media and internet impact, the exploration of information sources which typically occurs prior to or in conjunction with health professional consultation, and the critical contribution of health information encountered within the context of everyday life. Librarians can facilitate decision-making in the context menopause and evolving health information by guiding women to high quality traditional and web resources

representing a range of approaches to this transition, and to less formal resources which facilitate information exchange and learning in social contexts – perhaps online discussion groups and community resources.

### **Contribution to conference topics**

This study contributes to two conference topics: user studies, and information and reference services. It explores how women make sense of and integrate uncertain health information mediated by diverse sources and encountered within the context of everyday life. In addition, it draws attention to the wide range of information sources which inform users and to the variety of roles available to librarians as they facilitate the translation of health knowledge into everyday use.

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