Constructing “Sense” From Evolving Health Information: A Qualitative Investigation of Information Seeking and Sense Making Across Sources

Shelagh K. Genuis
Centre for Health Promotion Studies, School of Public Health, University of Alberta, 3-094 Edmonton Clinic Health Academy (ECHA), 11405 87 Avenue, University of Alberta, Edmonton, AB, Canada T6G 1C9. E-mail: genuis@ualberta.ca

Focusing on information behavior in a context where medical evidence is explicitly evolving (management of the menopause transition), this investigation explored how women interact with and make sense of uncertain health information mediated by formal and informal sources. Based on interviews with 28 information seekers and 12 health professionals (HPs), findings demonstrate that participants accessed and valued a wide range of information sources, moved fluidly between formal and informal sources, and trust was strengthened through interaction and referral between sources. Participants were motivated to seek information to prepare for formal encounters with HPs, evaluate and/or supplement information already gathered, establish that they were “normal,” understand and address the physical embodiment of their experiences, and prepare for future information needs. Findings revealed four strategies used to construct sense from health information mediated by the many information sources encountered and accessed on an everyday basis: women assumed analytic and experiential “postures”; they valued social contexts for learning and knowledge construction; information consistency was used as a heuristic representing accuracy and credibility; and an important feature of sense making was source complementarity. Implications for health information literacy and patient education are discussed.

Introduction

When the respected Journal of the American Medical Association published the news that the Women’s Health Initiative (WHI) study had been prematurely halted due to health concerns (Rossouw et al., 2002), the news reverberated through medical and consumer communities and was subsequently discussed and debated in hundreds of articles and editorials (Naughton, Jones, & Shumaker, 2005). Analysis of a stratified random sample of medical and consumer articles published before and after the release of WHI results raised questions about “how real people access, use, and interpret information about controversial or changing areas of medical practice” (Genuis, 2006, p. 983). These questions are widely relevant because, facilitated by rapid communication of research findings via the Internet and in the popular press, consumers are confronted on a regular basis with new and evolving medical evidence (Consumer Reports, 2006). Consider, for example, hopeful media coverage of a new cancer treatment (Woloshin, Schwartz, & Kramer, 2009), new findings and subsequent controversy about medical treatment for depressed children and adolescents (Bower, 2006), and contradictory media messages about the safety of fish consumption (Vardeman & Aldoory, 2008). In light of these and other findings and the fact that people access a wide range of information sources within the context of everyday health information seeking, this investigation was guided by the question: How do people respond to, make sense of, and use (or not use) uncertain and/or evolving health information mediated by formal and informal information sources? (Genuis, 2011).

Although scholars within Library and Information Science (LIS) “point toward feelings of uncertainty, ambiguity, or uneasiness as the root cause of information needs” (Case, 2007, p. 81), information behavior (IB) in
situations where information is explicitly emergent and provisional has received little attention. Dervin (1999) suggests that humans struggle with incomplete understanding of reality. Through a process of sense making, people engage in various IBs to bridge gaps in their understanding and achieve an end product that comprises knowledge, opinion, intuition, evaluation, and affective response (Dervin 1992). However, questions remain as to the strategies used to construct sense when information itself is uncertain. Because of this research gap within LIS, and because health care is an area in which evidence-based decision making is a key concern, study of health IB within the context of uncertainty is timely.

Focusing on IB in a situation where medical evidence is explicitly evolving—health management during the menopause transition—facilitated exploration of how women interact with, integrate, and construct sense from uncertain health information. To gain insight into specific strategies used to make sense of health information in this context, deeper understanding of women's experiences with and motivations for seeking menopause information is critical. The following research questions are therefore addressed in this article:

1. What are the experiences and motivations of women as they respond to, make sense of, and use uncertain and/or evolving information about hormone therapy (HT) and menopause?
2. What strategies do women use to construct and make sense of uncertain and/or evolving health information mediated by formal and informal information sources?

All aspects of the study received ethics approval from the Health Research Ethics Board (REB) and the Education, Extension, Augustana REB at the University of Alberta. Covenant Health Administrative Approval was also received for menopause clinic recruitment.

Literature Review

A Case Study for Exploring Evolving and Uncertain Health Information

Precipitated by the unexpected 2002 publication of the WHI (Rossouw et al., 2002) and its exhaustive coverage in the consumer and medical press (Genuis, 2006; Naughton et al., 2005), management of the menopause transition has undergone dramatic and rapid change in recent years. Peterson and colleagues (2004) note, “rarely has one study had the impact that the Women’s Health Initiative trial has had on the prescribing and use of HT” (p. 2010). Subsequent to the WHI, for example, the majority of physicians radically modified their clinical approach to management of this life transition, with menopausal prescription of HT declining significantly (Blumel et al., 2004; Buist et al., 2004; Hersh, Stefanick, & Stafford, 2004). This was accompanied by widespread uncertainty about menopause management among women (Barber, Margolis, Luepker, & Arnett, 2004; Rigby, Ma, & Stafford, 2007; Sawka et al., 2004).

While studies have focused on health IB in situations where there are complex information needs (Ariail, Watts, & Bowen, 2006; Burrows, Malley, Nettleton, & Watt, 2004; Cappiello, Cunningham, Tish Knobf, & Erdos, 2007; Neal & McKenzie, 2011), this study draws attention to a context in which both consumers and HPs are aware that health evidence is emergent, incomplete, and provisional (Upshur, 2001). Not only were standards of practice related to menopause management unexpectedly and dramatically rendered outdated by the WHI, but also uncertainty about translating these new findings into practice persists (Holloway, 2010; Wathen, 2006a). Furthermore, although practice guidelines suggest that HT for menopausal symptom relief is safe for up to five years (Pines, 2009), reputable sources contest the safety of these guidelines (Heiss et al., 2008; National Institutes of Health, 2008). Ongoing confusion about managing this life transition has resulted in the view that HPs are not meeting women’s needs for information and guidance (Ma, Drieling, & Stafford, 2006) and women are turning to other information sources, including the media and the Internet (Archer, 2007). Uncertainty in this context is, therefore, based not only on information complexity but also on the view that medical evidence represents “a transient moment in an indeterminate process of stabilization and destabilization” (Wood, Ferlie, & Fitzgerald, 1998, p. 1730).

Women and Health Information Behavior

Women’s health is not only a major area of study within health fields, women’s health IB has been identified as a developing area of study within LIS (Case, 2007). Research demonstrates that women are active information agents who gather, seek, and store health information for both themselves and others and who interact with an array of information sources (for example, Macias, Lewis, & Shankar, 2004; Wathen & Harris, 2006). Women are increasingly engaged in health IBs “either before, instead of, or unrelated to a visit to a doctor” (Warner & Procaccino, 2004, p. 714). Moreover, valued sources of health information include not only HPs and health organizations but also informal sources such as books or magazines, the Internet, and interpersonal relationships (for example, Suter et al., 2007; Warner & Procaccino, 2004; Wyatt, Henwood, Hart, & Smith, 2005). Although figures within individual studies vary, primary sources of information about menopause, the WHI, and HT include physicians, the media, friends and family, and the Internet (Castelo-Branco et al., 2006; Ekstrom, 2005; MacLennan, Taylor, & Wilson, 2004; Theroux, 2005).

Although some scholars suggest that people are seeking health information from informal sources because physician-provided information is not meeting patients’ information needs (Hoffmann, Lindh-Astrand, Ahlner, Hammar, & Kjellgren, 2005; Macias et al., 2004), other
factors also contribute to women’s reliance on informally mediated health information. Online information seeking has been transforming traditional models of health communication (Fox, 2005), with women identified as one of the groups most likely to access online health information (Fox, 2005; Madden & Fox, 2006). Mass media have also had a dramatic influence on decision making for women experiencing the menopause transition (Archer, 2007). Furthermore, sociocultural influences, such as the focus on individual responsibility for physical well-being and health-related decisions (Cangelosi & Markham, 1994), play an important role in IBs and knowledge construction (Spink & Cole, 2006). Women now commonly include aspects of nutrition, fitness, family relationships, and more within the parameters of health and wellness (Fox, 2005; Macias et al., 2004; Wathen & Harris, 2006) with the inevitable result that health information is drawn from a greater range of sources.

With the rapid communication of new health information in public forums, women’s use of informal information sources, and the emphasis on shared decision making in health fields (American Medical Association [AMA], n.d.; Canadian Medical Association [CMA], 2010; Légaré & Brouillette, 2009; Salkovskis & Rees, 2004), nuanced understanding of how women interact with and make sense of uncertain health information derived from both formal and informal sources is critical.

Research Methods

Qualitative methods, which accept “people’s knowledge, views, understandings, interpretations, experiences, and interactions” as meaningful properties of the reality being researched (Mason, 2002, p. 63), were used to explore how women experienced and made sense of changing health information mediated by formal and informal sources. Semistructured interviews were conducted with a sample of women involved in IBs related to the menopause transition, and with a smaller sample of health providers acting as information providers for this population of women. The study focused on women’s experiences, IBs, and knowledge construction. Interviews with HPs focused on themes emerging from interviews with the primary participants and HPs’ perceptions of their roles as information providers. Selection of populations and sampling was theoretically informed.

Definitions

The following definitions informed this study:

- The menopause transition refers to the stage of life which incorporates perimenopause, menopause and, for those women who continue to experience menopause symptoms, postmenopause. Because investigation focused on women’s experiences and perceptions, women who self-identified as seeking information related to this life transition were included in the study.

- Because the term of hormone replacement therapy (HRT) represents the view that postmenopausal women suffer from a deficiency disease that requires remediation (Worcester & Whatley, 1992), this article uses the neutral term, hormone therapy (HT). This term has come into widespread use since the 2002 publication of the WHI results and is applied to a range of menopausal treatment regimens using exogenous hormones.

- In this article, formal information sources include HPs, medical or professional associations, and established medical institutions or consumer health associations. Informal sources include personal contacts, the media, lay publications, and online sources. It should be noted that women also accessed hybrid sources (Warner & Procaccino, 2004). The Internet, for example, provided access to both formal (e.g., the Mayo Clinic Web site) and informal (e.g., interactive discussion lists) sources.

- Finally, the term participants is used to refer to the primary study sample (women navigating the menopause transition). HP participants are identified as HP(s) or HP participant(s).

Theoretical Framework

Based on a social constructionist approach and notions of meaning making that incorporate an active, process-oriented view of IB (Dervin, 1992), this study identified “general sense-making practices on the basis of which people orientate themselves in their everyday and working lives” (Talja, Keso, & Pietilainen, 1999, p. 761). Interviews with participants were viewed as “reality-constructing, meaning-making occasions” where meaning was “actively and communicatively assembled in the interview encounter” (Holstein & Gubrium, 1995, p. 4). Additional theory was incorporated during analysis to facilitate exploration and contextualize emerging themes. Although not the focus of this article, social positioning theory (Davies & Harré, 1990) facilitated exploration of the dynamic aspects of information encounters (Genuis, in press).

Context

The study was conducted in Canada, where there is publicly funded health care. Although this might suggest greater participant access to formal health information, comparisons between Canadians and insured Americans indicate that these populations are equally likely to report unmet health needs (Blendon et al., 2004), with cost being a barrier in the United States and wait times for care being a primary barrier in Canada (Canadian Institute for Health Information, 2006).

Sampling

Sample 1: Women. Twenty-eight women who had been or were engaged in information gathering and/or decision making related to menopause management were interviewed. The goal of sampling was to gather rich
qualitative data from women with varying approaches to menopause management. Sampling was purposive: recruitment occurred in the community (n = 18) and at a hospital-based, publicly funded menopause clinic (n = 10). Participants also volunteered and/or were invited to give the investigator’s name to other interested parties. Participants lived in one Canadian province. Final sample size was guided by theoretical saturation and sufficiency: participants reflected a reasonable range of approaches that might be found within the targeted population “so that others outside the sample might have a chance to connect to the experiences of those in it” (Seidel, 1998, pp. 47–48).

Interviewed women ranged from 43 to 72 years of age, with the majority (n = 19) being between 45 and 60 (see Table 1). Menopause status was based on self-report (see Table 2). Three participants had immigrated to North America from other continents, and, based on census data, participants were better educated than average (E-Stat, 2006).

Sample 2: Health professionals. To strengthen findings derived from theoretically informed population selection and sampling, data from primary interviews (women experiencing the menopause transition) were triangulated with data gathered from interviews with a smaller sample (n = 12) of HPs (Creswell, 1998). These latter interviews illuminated and confirmed themes arising from interviews with women. HPs were recruited from two hospital-based menopause clinics, through personal contacts and by referral. Interviewed HPs included members of the North American Menopause Society, who were certified menopause practitioners (North American Menopause Society, 2011), practitioners focused on providing care for this population of women, and HPs with diverse practices that included women in this life transition. The sample was purposive: both community and clinic practitioners, as well as a range of disciplines, were represented (see Table 3).

### Interview Approaches

All participants took part in one, audio-recorded interview that took place in a mutually agreeable location that was amenable to recording (participants’ homes, places of work, or public spaces). General strategies such as neutral agreement, asking for additional information, summarizing, and paraphrasing were used to encourage dialogue and clarification (Schensul, Schensul, & LeCompte, 1999). Interviews are viewed as sites for social construction and meaning making (Holstein & Gubrium, 1995). Within 24 hours of each interview, field notes were recorded. (Author may be contacted for interview guides.)

### Interviews with women.

Interviews with women lasted 40 to 80 minutes (mean, approximately 60 minutes). Two interview strategies were used to yield rich descriptive data. A semistructured, narrative approach was primarily used, giving participants “scope to articulate their experiences in their own terms” (Petersen, 2006, p. 34) and facilitating constructive processes as participants related and explained their experiences (Becker, 1997; Petersen, 2006). “In the moment” elicitation (Johnson & Weller, 2002) was then used to elicit women’s emotive responses to and tacit understanding of contrasting media-mediated health information. Chosen on the basis of national readership data (Canadian Media Directors’ Council, 2007–2008) and with attention to readers’ age and gender, three articles containing contrasting information about Vitamin D and midlife women (CBC, 2007a, 2007b, 2008) were sequentially presented to participants. Discussion focused on how women made sense of the articles and integrated media-sourced health information with other sources of health information.

### Table 1. Age of women participants (n = 28).

<table>
<thead>
<tr>
<th>Age range</th>
<th>Number of women</th>
</tr>
</thead>
<tbody>
<tr>
<td>40–44 years</td>
<td>2</td>
</tr>
<tr>
<td>45–49 years</td>
<td>6</td>
</tr>
<tr>
<td>50–54 years</td>
<td>7</td>
</tr>
<tr>
<td>55–59 years</td>
<td>6</td>
</tr>
<tr>
<td>60–64 years</td>
<td>4</td>
</tr>
<tr>
<td>65–69 years</td>
<td>2</td>
</tr>
<tr>
<td>70–74 years</td>
<td>1</td>
</tr>
</tbody>
</table>

### Table 2. Self-reported menopause status.

<table>
<thead>
<tr>
<th>Self-reported menopause status</th>
<th>Number of women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Post-menopause</td>
<td>17</td>
</tr>
<tr>
<td>Perimenopause</td>
<td>8</td>
</tr>
<tr>
<td>Premenopause</td>
<td>1*</td>
</tr>
<tr>
<td>Unsure</td>
<td>2†</td>
</tr>
</tbody>
</table>

*During preinterview e-mails this participant identified as entering menopause and described seeking menopause information; her interview narrative suggested that she was likely premenopause.

†Two participants stated that they were “unsure” of menopause status because of HT’s impact on menses.

### Table 3. Health professional participants (n = 12): Summary of demographics.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Discipline</th>
<th>Employment</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 – female</td>
<td>4 – Family physicians</td>
<td>5 – Community</td>
</tr>
<tr>
<td>2 – male</td>
<td>2 – Dieticians</td>
<td>5 – Menopause clinic</td>
</tr>
<tr>
<td>2 – Nurses</td>
<td>1 – Academic/community</td>
<td></td>
</tr>
<tr>
<td>2 – Pharmacists</td>
<td>1 – Retired</td>
<td></td>
</tr>
<tr>
<td>1 – Alternative health practitioner</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 – Specialist physician</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Data Analysis

Interviews were transcribed verbatim and NVivo 8 software facilitated data organization and identification of emerging themes and coding. Analysis incorporated directed content analysis guided by theory (Hsieh & Shannon, 2005) and grounded theory’s constant-comparative method, interactive close reading, and examination of texts for conformity and variation from emerging themes (Glaser & Strauss, 1967). Descriptive, interpretive and discursive approaches to data analysis were utilized and theoretical perspectives from a range of disciplines were used to illuminate and develop themes emerging from analysis.

Analytic rigor was enhanced by a robust sample size (Kvale, 1996; Miles & Huberman, 1994) and triangulation, which served to “corroborate, elaborate or illuminate the research in question” (Marshall & Rossman, 2006, p. 202). Three forms of triangulation were incorporated: triangulation of interview approaches (narrative and elicitation) allowed in-depth exploration of women’s experiences and sense making; data source triangulation (women and HPs) facilitated confirmation and augmentation of themes; and theory triangulation (Patton, 1990) illuminated analysis. Measures were also taken to strengthen credibility: identification and exploration of negative instances; debriefing with experts in the field and peers; and careful documentation at all stages of the research process.

Study Limitations

Findings are limited by the study context and populations sampled; however, ongoing uncertainty about menopause management suggests that this context was, for women and HPs, representative of evolving health information. Limitations are associated with sampling. Participation may have had greater appeal for women experiencing health challenges and for those self-identifying as information seekers. HPs self-identifying as information providers may have been more likely to participate. Chosen methods pose limitations: Meaning was constructed from personal narratives and selected elicitation articles may have specifically shaped participants’ responses. Finally, as noted earlier, research was conducted in a setting where health care is funded, which may limit generalizability in contexts where individuals are without or have limited health care coverage.

Results and Discussion

Women’s Experiences in Response to Uncertain and Evolving Health Information

Women participating in this qualitative study engaged in a range of IBs as they explored concerns about health and wellness during the menopause transition. Data analyses demonstrate that, for these participants, information seeking was strongly associated with the experience of uncertainty. This was demonstrated by active information seeking, which incorporated a variety of formal and informal information sources and which was motivated by a range of factors and circumstances.

Uncertainty and information behaviors. Uncertainty about menopause as a life stage and about menopause management in the absence of definitive research evidence was integral to women’s IB. In response to uncertainties related to initial experiences attributed to this life transition, 13 of the interviewed women immediately engaged in autonomous information seeking, “I really started reading up on it a lot” (Sue; pseudonyms used throughout); 10 consulted HPs, “I went straight to my doctor” (Thea); and three sought information from interpersonal contacts, “First of all I listened to what my sisters had went through” (Dana). Twenty-six of the interviewed women consulted an HP at some point as they sought to make sense of their menopause experience. All of the women noted that the Internet was an important source of health and menopause-related information. “Lived experience” was also critical to interviewed women. This was demonstrated not only by interaction with personal contacts, but also by information gathered via other mediums. Jill, for example, searched online for factual information about menopause, but she also noted: “Then I went and scrolled down into some of the comments of the people that lived through that. And to me, that’s a big source right there too. Talk to people that lived through that.”

Not all of the interviewed women were familiar with the WHI but all were aware that the evidence base in this area of clinical care is evolving and contested. Anita, who sought specific information about HT risk, exemplified the frustration experienced as a result of the uncertain evidence base: “Problem is that the doctors never know. Most of the time they have no idea.” Largely based on the view that HPs could not offer definitive information about managing this life transition, all of the interviewed women described information gathering that incorporated multiple sources. Paula, for example, respected and liked her physician, but she explained that if he wanted to prescribe a medication, she would first seek information independently (via the Internet, library, and interpersonal sources) before making a decision about recommended treatments. And Roslyn described consultation with many sources as she searched for menopause information:
noncrisis health management. Twenty-six of the 28 women experienced over a period of years, and generally involves the fact that menopause is common to all women, is usually life disrupting, their IBs were likely influenced by the fact that menopause experiences varied from relatively unremarkable HPs.

These examples demonstrate that participants used multiple resources, moved fluidly between sources, and did not explicitly differentiate between formal and informal information.

Women’s perception of sources as mutually enhancing was supported by the value participants placed on direct or indirect referral between sources. The following examples are representative: Lisa related that she tended to read books recommended by trusted Web sites, and Vicky emphasized the importance of health resources recommended by trusted interpersonal contacts. Furthermore, 11 of the interviewed women noted that HPs pointed them to supplemental health information. This was particularly valued not only because it augmented HP-patient information exchange, but also because women perceived that information referral demonstrated that HPs recognized the uncertain nature of menopause information and were open to information from other sources. Nicole was not alone in expressing increased trust in her physician because of this HP’s use of supplementary sources: “She provided actual print information. . . . So, I thought, ‘Okay. This is somebody I relate to, this is somebody I have respect for. I think I want to head in this direction, at least right now.’ ”

All of the interviewed HPs acknowledged the uncertainty associated with menopause management. HP Connie’s comments were representative: “I think one of the main things we try and get across to women is that hormone therapy isn’t—it’s not a recipe.” Although only some of the interviewed HPs shared secondary information sources with women (e.g., HPs working in menopause clinics provided prepared consumer health resource lists), most acknowledged the value of referring women to supplementary information, particularly to reputable online resources. HP participants working in the community, however, felt less prepared for this activity. HPs Wanda and Clare, for example, cited their own knowledge deficit when explaining why they avoided referral to Internet sources. This lack of engagement as information providers may represent a lost opportunity: HP referral to supplemental information sources is not only contingent on trust (Brown, Carroll, Boon, & Marmoreo, 2002), but data from this study suggest that it may play a role in building trusting relationships between women and HPs.

It is important to note that although women’s menopause experiences varied from relatively unremarkable to life disrupting, their IBs were likely influenced by the fact that menopause is common to all women, is usually experienced over a period of years, and generally involves noncrisis health management. Twenty-six of the 28 women spoke of gathering information for a period of time in excess of one year. For the two exceptions, one reported discussing menopause-related issues at one medical appointment after which other life circumstances assumed priority. In the second case, the participant actively investigated formal and informal resources; however, she determined that she was not yet in this life transition and therefore suspended information gathering.

Motivation for information seeking. Women’s IBs were motivated by a range of factors and circumstances. Participants sought information in preparation for formal encounters with HPs, and they explored additional sources to evaluate and/or supplement information they had already gathered. Women were also motivated to seek information to establish that they were “normal,” and to understand and address the physical embodiment of menopause, particularly the symptom experience. Finally, they gathered information for potential future use (see Table 4).

<table>
<thead>
<tr>
<th>TABLE 4. Motivation for information seeking.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>In preparation for encounters with health professionals</strong></td>
</tr>
<tr>
<td>- “It always worked for me, first of all, looking for information. . . . Books. The Internet. So before I meet with the doctor I already know or have an idea about the things that are happening.” (Anita)</td>
</tr>
<tr>
<td>- “Unless I’m in a great deal of pain, I don’t want to go to a doctor first. I’d rather do my own reading so I get a little bit educated, or talk to some other people.” (Faye)</td>
</tr>
<tr>
<td><strong>To evaluate, confirm, and/or supplement previously acquired information</strong></td>
</tr>
<tr>
<td>- “I was looking first for a confirmation of what [the doctor] had said. Expansion of the information because she hadn’t given me or I hadn’t taken in thoroughly the information. Because I kind of went away and said, ‘What about this?’ You know, and, ‘Why is this?’ ” (Christy)</td>
</tr>
<tr>
<td>- “That was the end of the appointment. And I was sort of standing there. Okay, so at that point I went to the computer to look up [the diagnosis] to see what that was.” (Roslyn)</td>
</tr>
<tr>
<td><strong>To normalize experience</strong></td>
</tr>
<tr>
<td>- “I guess I look up on the Internet to see if, ‘Oh yeah, it seems like that’s normal for most people my age to go through something like this.” (Laura)</td>
</tr>
<tr>
<td>- “I found I’d be talking to women, you know, peers, friends, relatives [asking them], ‘Does this seem normal?’ ” (Dale)</td>
</tr>
<tr>
<td><strong>To understand physical embodiment of this life transition</strong></td>
</tr>
<tr>
<td>- “So I went to the library and looked [menopause] up and got whatever articles I could from the library and read [them] over. And decided that I was having menopause symptoms, and what I needed to do was ask my doctor to do the hormone testing thing so that he could see whether or not—what my body was producing. And that would tell him that I was having menopause symptoms.” (Murriel)</td>
</tr>
<tr>
<td>- “I feel that I was driven in trying to solve those symptoms, for sure. [My symptoms] were really taking over my whole enjoyment factor in life.” (Thea)</td>
</tr>
<tr>
<td><strong>To prepare for potential future information need</strong></td>
</tr>
<tr>
<td>- “I read everything that I can on everything [related to health]. . . . I guess I file it. I file it in my mind.” (Dana)</td>
</tr>
<tr>
<td>- “When I see information in the Journal [newspaper] or the paper, I sort of scan it and it sits somewhere.” (Naomi)</td>
</tr>
</tbody>
</table>
Although 13 of the participants specifically stated that they gathered health information to prepare for formal encounters with HPs (primarily physicians), narratives indicated that most interviewed women gathered information prior to seeing an HP. Many participants went to HPs only after exhausting personal information-finding capabilities or when access to a specific medical service was desired (e.g., hormone level assessment). Interviews with HPs confirmed this motivation. HPs, however, were likely to position themselves as interpreters of the health information women derived from other sources.

HP Denise commented, “They’ll come in with an array of information and not know sometimes how to interpret it or what to do with it.” HP Francis’s comments exemplified the view that HPs are arbiters of health information: “[Women] talk and they argue and they say ‘Well, can you find something else for me? Are you sure that this is the best way?’ . . . . I’d say to myself, ‘Why [is] the patient coming to see me if she already made up her mind that she is not going to listen to my advice?’” Francis’s frustration with women’s questions about presented treatment options was, perhaps, grounded in notions of shared decision making, which are found in the medical literature: Information and treatment options are communicated to patients by HPs, who then help patients understand the presented options and make treatment choices (Légaré & Brouillette, 2009). This contrasts with the perspective expressed by the majority of interviewed women who positioned themselves as independent and self-directed information seekers and decision makers with respect to menopause management (Genuis, in press).

While all of the interviewed women consulted more than one source for menopause information, 22 specifically noted that they looked for health information to evaluate and supplement previously acquired information. Women’s familiarity with menopause management uncertainty contributed to their motivation to seek supplemental information. Participants not only confirmed and supplemented HP-provided information in other sources, they also sought information within their households (Moen & Brennan, 2005), women used for managing and physically storing health information.” HP Francis’s comments indicated that most interviewed women gathered information to prepare for formal patient-HP relationships. Furthermore, interviews with HPs confirmed this association. HP Amy observed, “For the most part [women seen at the clinic have] been struggling with their symptoms for a while, so they’ve often looked for information.”

Finally, similar to the “just in case” strategy that women used for managing and physically storing health information within their households (Moen & Brennan, 2005), women were motivated to collect and mentally “file” health information to prepare for potential future need. This theme emerged from interviews with nine women and was supported by HP interviews. HP Sonya related:

That’s the other thing that’s amazing with health information and women, they’ll read something and I think they rip it out and put it somewhere. Or a phone number or something. And then months later they’ll say, “Oh, I read that article.” And they’ll follow up with it . . . . Or, even if we do an interview in the [newspaper], you’ll get calls even a year later saying, “I saw that in the paper.” Although information gathering has been noted as a means of improving self-efficacy prior to encounters with HPs (Wathen, 2006b), the nuanced purposes that emerged from the current data empowered participants as primary stakeholders in their health and wellness. Macias and colleagues (2004) observed that access to online health information gave women greater control over their health and contributed to a changing balance in women’s relationships with HPs. Although this may threaten traditional authority structures within health care, increasing focus on patient-centered care and shared decision making (AMA, n.d.; CMA, 2010) suggests that patient information gathering should be viewed as a positive contribution to patient-HP relationships. Furthermore, participants’ strong motivation to gather information and their appreciation for HPs who point them to secondary information sources suggest an opportunity for HPs. By making high-quality, personally relevant information available to women, HPs will facilitate individual responsibility...
for health and well-being and will foster positive HP-patient relationships.

**Constructing “Sense” From Formal and Informal Health Information**

Although women consulted many sources as they responded to uncertainties associated with menopause and menopause management, they did not view sources in isolation from one another. Rather, they constructed knowledge by integrating health information gathered from the wide range of sources that they encountered and sought. Monica’s approach was typical: “I’d go to various places. I’d go to the Internet, I suppose. I would ask around. Talk to my doctor. And then, you know, pull [the information] together. I wouldn’t go to just one source.” This draws attention to the second research question: *What strategies do women use to construct and make sense of uncertain and/or evolving health information mediated by formal and informal information sources?*

Findings suggest that upheavals in conventional medical knowledge increased women’s feelings of responsibility not only for information seeking and decision making, but also for making sense of uncertain and potentially conflicting menopause information. While the notion of sense making is frequently a “given” within IB research, results provide textured understanding of how participants constructed sense from informally mediated and formally mediated health information. Analysis revealed that women assumed analytic and/or experiential “postures,” sought social contexts for learning and knowledge construction, used information consistency as a heuristic for trustworthiness, and viewed information sources as complementary.

**Analytic and experiential “postures.”** Interviewed women made sense of uncertain health information by adopting analytic and/or experiential approaches to menopause information. This finding builds on the notion of two interacting modes of information processing (Epstein, 1994). The psychological notion of mental processing, however, does not incorporate comprehensive understanding of IB as illuminated in LIS (Case, 2007; Fisher & Julien, 2009; Wilson, 2000). Within the context of this exploration, therefore, the term *posture* (“a stance, an attitude”; “OED Online,” 2010) is used as it more accurately describes participants’ conscious and unconscious approaches and dispositions as they made sense of health information.

Analytic posture was demonstrated by the following: women focused on finding logical connections as they explored and gathered health information, they described actions which were based on conscious considerations and linking of information from different sources, and they used different forms of evidence to justify information use (or nonuse). These characteristics, described in part by Slovic et al. (2004) were exemplified by Camille and Sylvia who made connections between different kinds of information and then inductively extrapolated to manage their menopause symptoms (see Table 5).

Women from this sample also adopted experiential postures, which incorporated intuition and affect. This posture is oriented toward “more rapid processing” (Slovic et al., 2004, p. 313) and was demonstrated by women who drew attention to information that made sense according to their physical experiences and/or intrapersonal health knowledge (see Table 5). Ten of the interviewed women, for example, used words and phrases, such as “intuition,” “my gut,” “instinct,” and “inner spirit,” which, upon closer questioning, identified an intrapersonal and experientially based knowledge source. For this sample of women, an experiential posture frequently served as a filter for information from other sources, thus influencing knowledge construction and decision making.

Assumed postures were neither static nor mutually exclusive; both approaches facilitated sense making. This was exemplified by Christy, who assumed analytic and experiential postures during the course of her interview.

| TABLE 5. ‘Postures’: Approach and disposition when constructing sense. |
|-----------------------------|-------------------------------|
| **Analytic posture: Illustrations** |
| **Camille:** What I would do is build up a sleep debt after about three nights and then I’d take a sleeping pill. Because I didn’t want to be doing that every night, right? So that’s what I would do, if I went on without a good sleep for two, three nights, a third night I’d take a pill. **Interviewer:** Did someone tell you to do that or did you . . . **Camille:** No. That’s just what I thought. I mean, because I realize that if I take a pill every night then I’m [going to] need one to get to sleep. So I would just kind of accrue this debt and then, poof. **Interviewer:** Then how did you decide to do that? **Camille:** I don’t know. I just did. I just thought about it and thought, Well, that’s the part that makes the most sense. And my doctor said be careful to not – or he said, “Try not to take this more than two or three times a week.” I mean, I had a friend who was taking two a night. Every night. So, and I don’t like to take a lot of medication. “On the Internet, I looked up gallbladders and hormone replacement therapy and what I did find is that hormone replacement therapy concentrates the bile. And I was not eating a lot of fat. So I thought, I’m going to start eating a tablespoon of peanut butter every morning and see what happens. Sure enough, I haven’t had any of those symptoms again. Soon as I forget, it comes back.” (Sylvia) **Experiential posture: Illustrations** |
| “Menopause’s going to be what I experience, not from what I read from a book. . . . I’m not even going to give my mind a chance to even excuse certain behavior [because of] what I read.” (Jill) **Interviewer:** “I think that’s probably one of the reasons I just turned off on the HRT stuff. There was just So. Much. Stuff. And, I was, as I said, satisfied with where I was going, with where my body was going.” (Nicole) **Interviewer:** “It’s hard to explain [how I make sense of menopause information]. My gut feeling; I listen to that. My instinct; I listen to that.” (Lisa) |
with each posture facilitating information integration. When seeking to verify information heard from a friend, for example, Christy adopted an analytic stance. She conducted an online search and found both “old wives’ tales” and citations to the medical literature. In light of her own knowledge, Christy then assessed the gathered information and established a rational basis for adopting the information mediated by her interpersonal contact. When this participant encountered information about the WHI, however, she became concerned about what she was physically “feeling.” In this instance, Christy assumed an experiential posture and, without further information seeking or medical investigation, concluded that HT was causing undesired physical consequences.

Examination of analytic and experiential postures contributes to understanding of health IB and sense making. It also has relevance for patient education. Consumer health resources have been “designed, almost exclusively, to evoke analytic processing” (Hibbard & Peters, 2003, p. 428). This study, however, illuminates the sense making functions of both analytic and experiential postures, thus highlighting the importance of health information and communication that provokes both cognitive and experiential response (Dunlop, Wakefield, & Kashima, 2010).

Social contexts. A second and prominent theme that emerged from the interviews was that social contexts play an important role for women as they construct sense from information about this life transition. At the same time as acknowledging a need for biomedical knowledge, interviewed women viewed research-based evidence as only one part of decision making (this is also recognized in the literature; for example, McCormack et al., 2002; Rycroft-Malone et al., 2002). Perhaps because of the universal nature of this life transition for women and existing uncertainty about the evidence base for menopause management, interactive contexts were viewed as empowering opportunities which facilitated sense making, integration of formal and informal information, and effective management of personal health. For these participants, useable knowledge was, at least in part, “a communicative construct which [was] produced in a social context” (Tuominen & Savolainen, 1997, p. 89).

Interviewed women found interactive contexts in a variety of ways with the most apparent (noted by all interviewed women except one) being that created by interpersonal information sharing. Naomi’s comments were representative:

> We do talk about [menopause] at work, and we do have those conversations, and people have come up with different solutions and other people have tried them. Or they recommend one product over another product and I think that that is very, very helpful for everybody. . . . Sometimes you have to talk quite a bit about it before you can wrap your head around certain things.

Social contexts were also experienced within online environments and, notably, via the media. Anita, for example, was one of seven participants who explicitly valued the learning that occurred between television show host Oprah and her audience. This participant highlighted what she learned about menopause from this celebrity: “You’re not alone. You’re not crazy. You can get help if you want. You have different options.” HP Sonya also noted the influence of mediated social contexts: “I think this whole sort of interest in bioidenticals is Oprah. One woman talking to another woman. Even though it’s an audience of 30 million or whatever.” Participants’ reflections suggest that interaction within social contexts constituted more than information transfer; the process of interaction itself “construct[ed] and produce[d]” knowledge (Tuominen & Savolainen, 1997, p. 92).

An unexpected finding was that 19 of the interviewed women expressed explicit appreciation for learning and constructing knowledge in social contexts. Eleven of these women specifically identified a preference for the learning that occurs in formally or informally organized groups. (Only one interviewed woman belonged to such a group.) When Paula, for example, was asked to envision an ideal way for women in this life transition to learn about health, she responded:

> Women’s health center . . . a place that women could share. Like, maybe there are menopause support groups. I don’t know, ‘cause I never went to one, but by women sharing with each other and having that common thread . . . knowing that you’re not alone. Whether it’s menopause, cholesterol, or whatever it may be. I seriously believe that it’s important for women to share that information.

Information consistency. Information consistency was used as a heuristic that represented information accuracy and credibility. In other words, participants not only were motivated to seek information that allowed them to evaluate and supplement previously acquired information but also constructed knowledge by comparing and compiling information across sources. Just as parallel evidence found in similar, but not identical, studies improves the “strength” of evidence (Howick, Glasziou, & Aronson, 2009), women viewed parallel information as enhancing the “strength” of a given conclusion or course of action. While data analysis suggests that this heuristic was intrinsic to most participants’ sense making, Muriel was representative of the 10 women who explicitly drew on this heuristic. She explained that she evaluated and made sense of health information based on “cumulative information.”

This heuristic was highlighted by those noting multiple occurrences of similar information within a single type of source and by those who looked for similar information across sources (see Table 6). Use was particularly prominent among women seeking online health information. It was, however, also used by participants making sense of information from interpersonal sources and those integrating information from formal and informal sources. At the same time as information consistency suggested information sufficiency and was therefore viewed as a reasonable
TABLE 6. Information consistency as a heuristic for accuracy and credibility.

<table>
<thead>
<tr>
<th>Multiple instances of similar information within a source</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I will look at a variety of sites. So I will look at – you know university based sites, or Mayo clinic sites, things such as that. And look at them with a great deal of care and try and see if all of them are in agreement. Because sometimes they aren’t. Sometimes their information is somewhat different. Or sometimes it’s the same information but there’s a slight twist in the interpretation.” (Nicole)</td>
</tr>
<tr>
<td>“There’s two verifications right there [confirmation from two people that an over-the-counter product provided symptom relief] and I’m the third because I did it and it worked. That’s pretty good. Pretty – then I can trust that.” (Lisa)</td>
</tr>
<tr>
<td>Similar information across sources</td>
</tr>
<tr>
<td>“I go to the library, I look at self-help books. I go to [name removed] Bookstore, I get lay people books as well as Mayo Clinic or professional journal articles. And I talk to friends. And then I figure out where things are overlapping and what makes sense. . . . [I] read really broadly until I figure out, until I started to see overlaps of information. And then I can start saying, ‘Okay, here’s the reliable stuff and here’s just the stuff that everybody’s saying.’” (Faye)</td>
</tr>
<tr>
<td>“I try and definitely cover more than one source so I can compare information as well. One might contradict another; [then I] try and find another to see what they say.” (Dale)</td>
</tr>
</tbody>
</table>

basis for decision making, information inconsistency proved to be an impetus for ongoing information seeking. Interviewed HPs confirmed that consistency facilitated information use and decision making. HP Amy observed:

What we have found on many occasions is that it’s helpful for the patient to hear a message from more than one [HP], and that it takes hearing it from more than one person before [women] kind of, you know, decide, “Oh, okay, here’s what’s happening and it probably would be beneficial.”

Furthermore, this theme is supported in the literature. Brashers (2001) notes that although information reduces uncertainty, “correct” information is not required, only perceptions of coherence. In addition, Lankes (2008), in an exploration of online information seekers’ understanding of credibility, highlights a shift from traditional “authority”-based credibility to a “reliability” approach where cohesion and consistency is sought among sources. For interviewed women, source consistency was a prominent heuristic that facilitated the construction of uncertain health information as credible, and thus as a basis for information use.

Source complementarity. Health information sources are frequently conceptualized as being in competition for the limited time or allegiance of the information seeker/patient. Interviewed women, however, tended to seek and monitor menopause information across media. This suggests that a predominant feature of participants’ IB was complementarity, not competition or displacement. This construct, first elucidated as media complementarity theory (Dutta-Bergman, 2004), suggests that enduring interest in a specific subject area motivates IBs across media, with diverse sources fulfilling individuals’ information needs in complementary ways. Data from the current study suggest that complementarity theory offers nuanced and unique insight into the sense making of participants.

Complementarity was demonstrated in a number of ways: interviewed women moved fluidly between a range of sources; they valued sources which directly or indirectly pointed to other information sources; participants described seamless integration of online and offline information seeking; and they viewed media-mediated health information as a valuable awareness tool and “springboard” for information seeking via other mediums. Given the novel application of this theory, a specific illustration of complementarity as demonstrated in this study follows.

Most interviewed HPs expressed concerns about the competing influence of media-sourced health information, with three quarters specifically noting the influence of Oprah. Women’s reactions to Oprah’s discussions of menopause management (Kosova, 2009), however, provide a compelling illustration of complementarity. While HP Gail positioned the North American Menopause Society and Oprah as conflicting information sources, Sue and Camille explicitly valued information from both Oprah and a menopause clinic guided by North American Menopause Society standards. Camille, furthermore, highlighted a relationship between Oprah’s television show and interpersonal information gathering among women: “It kind of opened up the dialogue and stuff. Because we’d say, ‘Oh, did you see that Oprah?’” HP Amy provided support for complementarity between the Oprah show and other information sources: “I guess the good thing is that it does get the conversations started, you know. Like certainly more women are coming forward and looking for help.”

Complementarity was further illuminated by a HP working in a menopause clinic:

I can’t believe the influx of calls we’ve had from that Oprah show. I really can’t. We’ve over 200 women waiting to see us now . . . whereas before our wait list, before the Oprah show, . . . we were down to about, you know, maybe 40 or 50 at our peak times of people waiting. Now we have over 200 women waiting to be seen.

While interviewed HPs were unenthusiastic about Oprah as a purveyor of health information, these observations clearly illustrated complementarity: Many women who gathered health information from Oprah were also motivated to seek information about menopause from formal sources. Findings from this study are both supported by and extend previous considerations of complementarity. First established as a feature of news consumption across traditional and new media (Dutta-Bergman, 2004), complementarity has been established between modes of interpersonal crisis communication (Dutta-Bergman, 2006), and between mass media and visits to HPs (Tian & Robinson, 2008).
Implications

The current emphasis on patient-centered care and shared decision making (AMA, n.d.; CMA, 2010) has brought focus to the critical role of patient education and health information literacy. While research and practice have primarily focused on facilitating consumer/patient use of empirically derived authoritative resources, this study draws attention to women’s perspectives and demonstrates that it was the interaction between and integration of both formal and informal health information which met participants’ information needs and enabled sense making. This is a challenging proposition as health and information professionals tend to be leery of informal health information, particularly experiential knowledge, knowledge constructed in social contexts, and media-provided or Internet-mediated information.

Findings suggest that this dilemma can be addressed. Deeper understanding of what motivates information seeking and the strategies women employ when making sense of uncertain health information will allow researchers and professionals to develop effective patient education practices that incorporate the range of sources that women actually use when making decisions about health management. Instead of ignoring or vilifying nontraditional sources, discussion of health information derived from all sources should be encouraged to better understand consumers’ contexts and needs, illuminate the ways in which different sources address the diverse needs of individuals, and facilitate sense making.

This study also illustrates the ways in which theory can illuminate understanding of complex, real-world situations. Although the notion of sense making is well established within LIS, analysis of interview data provided nuanced insight into the different strategies participants used as they constructed knowledge. Use of theoretical perspectives drawn from other disciplines validated and extended research findings by rooting themes in previous research and demonstrating “theoretical elaboration in new contexts” (Vardeman & Aldorry, 2008, p. 286).

Future Research Directions

Health information is not only inherently provisional and emergent, but there is always a measure of uncertainty as population-based findings are applied within individual contexts. This study, an exploration of how one population experienced and made sense of uncertain health information, represents a first step in the investigation of health information as a provisional construct and sense making in the context of evolving health information. Future research should engage with the notion of health information as emergent and provisional and explore how other populations respond to and construct knowledge from uncertain health information. Exploration of how HPs themselves experience, make sense of, and then communicate provisional and evolving health information will also make an important contribution to the study of IB and patient-HP communication.

Furthermore, despite the acceptance of sense making as an intrinsic component of IB, greater understanding of the specific strategies people use as they bridge information gaps will contribute to a nuanced understanding of sense making. Four sense-making strategies emerged from this qualitative study. These constructs hold promise for illuminating further the multifaceted information worlds that women inhabit. Investigation of these constructs in other populations will add both theoretically and practically to understanding of health-related IB. Exploration of how patient education and health information literacy instruction can be informed by participants’ sense-making strategies is also warranted.

Conclusion

With the rapid communication of health knowledge via the Internet and media, consumers are being informed on a regular basis of new and changing medical evidence and reliance on both formal and informal information sources has become an everyday reality. Information needs are deeply contextual and to understand health IB, researchers and professionals need to understand how people engage with evolving health information, the specific needs which motivate information seeking, and the strategies people use to make sense of the vast amount of formal and informal health information incidentally encountered and deliberated sought.

This study focused on women’s experiences and sense making when navigating evolving and uncertain menopause information. Interviews with HPs were used to triangulate and confirm emerging themes. Findings demonstrated that women were motivated to seek information to (a) prepare for formal encounters with HPs; (b) evaluate, confirm, and/or supplement information they had already gathered; (c) establish that their experiences with this life transition were “normal”; (d) understand and address the physical embodiment of menopause, particularly the symptom experience; and (e) prepare for potential future information needs. Because women did not perceive that HPs could offer definitive information about managing this life transition, interviewed women felt responsible for not only seeking but also making sense of encountered and gathered information.

Analysis of interview data revealed four primary strategies that women utilized to construct sense from uncertain and evolving health information: (a) women assumed...
analytic and experiential “postures” as they assessed and integrated information from different sources; (b) they explicitly valued social contexts for learning and knowledge construction; (c) information consistency was used as a heuristic which represented information accuracy and served as a basis for information use; and (d) whereas HPs tended to view formal and informal information as competing influences, findings provide support for complementarity theory—women viewed formal and informal information sources as mutually enhancing. Although each of these strategies add “texture” to the notion of sense making, they all demonstrate that, in the context of evolving and uncertain health information, it was the synergistic interaction between both formal and informal information sources which met women’s information needs and enabled knowledge construction.

Acknowledgments

Sincere gratitude to Dr. Heidi Julien and Dr. Brenda Cameron for their valuable guidance and encouragement, to the women and health professionals who so generously shared their thoughts and experiences, and to funders, including the Social Sciences and Humanities Research Council of Canada and the Medical Library Association. Thanks are also due to the anonymous reviewers who provided helpful suggestions for improving this article.

References


