

Paper: Going Out on a LIM: The Role of Narrative on the Practices of Lay Information Mediarities

Abstract: Lay information mediaries (LIMs) are individuals who search on behalf or because of others. LIM practices are often guided by the LIMs' narrative regarding the individual or muse who inspired the search. How narratives influence LIMs as they provide informal caregiving to older adults and people with depression are analyzed.

Résumé:

1. Introduction

Caregiving has become an expected part of the life course for many Canadian families whether caring for an elderly parent, a family member with mental illness, or a chronically ill partner. The Canadian Caregiver Coalition (n.d.) estimates that between 4 to 5 million Canadians provide care and assistance to spouses, parents, children, and extended family members. In 2002, more than two million Canadian family and friend caregivers (one in five Canadians over the age of forty-five) reported assisting a senior because of the senior's long-term health condition (Cranswick & Dosman, 2008). Recent changes in patterns of care provisions for the elderly have included a "withdrawal of the formal system, and [an] increasing reliance on family care providers" (Hollander, Liu, & Chappell, 2009; Ward-Griffin & Marshall, 2003). Similarly, families are the largest group of caregivers for those with persistent and serious mental illness. According to Wrosch, Amir, and Gregory, caring for a relative with mental illness can be a greater physical, emotional, and financial burden than caregiving to dementia patients, and caregivers to people with a mental illness can experience high levels of stress, self-blame, substance abuse, and depressive symptoms themselves (2011).

Informal caregivers have been cited as a lay information mediary (LIM) group, serving as information gatekeepers for friends or family who have been conceptualized as the "muses" who inspire search behaviour (Abrahamson & Fisher, 2007; Family Caregiver Alliance, 2005; Fox, 2006). Lay information mediaries (LIMs), "those who seek information in a non-professional or informal capacity on behalf (or because) of others without necessarily being asked to do so, or engaging in follow-up," have received increasing notice in research, recognizing that people turn to one another to "help in fulfilling information needs" (Abrahamson & Fisher, 2007). Health information is increasingly being sought through an online platform, including social media (Fox & Jones, 2009; Kamel Boulos & Wheeler, 2007), as evidenced in a recent study by Pew Internet & American Life Project which found that "half of all online health inquiries are on behalf of someone other than the person typing in the search terms" (Fox & Jones, 2009).

One unexamined aspect of LIMB (lay information mediary behavior) is the role that narrative plays for LIMs who have formulated their own conceptualizations of the muse's context, health status, and information needs (often in relation to their own biographies and narratives) and the role of narrative (often biographical reconstruction) for the individuals or muses coping with changes in health status (Harden, 2005). Depression,

for example, is a disorder based upon narrative. Mental illness often threatens identity and sense of self when one's personal story is displaced by dominant illness narratives focussing on deficit and dysfunction (Kangas, 2001). One role of treatment, therefore, is to allow individuals to re-story their life in a more positive way which facilitates the reconstruction of a meaningful identity and sense of self (Carless & Douglas, 2008; Dowrick, 2004; Hermans, 2003; Kangas, 2001; Kirkpatrick, 2008; Rapport et al., 2010). Similarly, aging or dealing with chronic illness can threaten identity and sense of self as both muses and caregivers struggle to find meaning as they cope with changes in health and capabilities (Haggan, 1998; Langer, 2012). In this context, narrative plays an important role for both the individual coping with changes in health status and for LIMs searching for information on behalf of the muse.

This study responds to the call for further research on health information proxies (Morey, 2007) and further develops Abrahamson and Fisher's lay information mediary behaviour (LIMB) model. Specifically, this research project investigates: (1) how narratives inform the online and offline information practices of informal caregivers in their capacity as lay information mediaries; and, (2) how the information practices of these LIMs align with the LIMB model developed by Abrahamson and Fisher.

2. Theoretical frameworks

Abrahamson and Fisher's (2007) general LIMB model provides the theoretical framework used to evaluate LIM practices. The general model for LIMB arose from their research that indicated that lay information mediary behaviours are "sufficiently related to be conceptualized as one broad type of information seeker" (Abrahamson & Fisher, 2007). The participants within the model include LIMs (e.g. informal caregivers) who seek information on behalf of or because of a muse (e.g. older adults or people with depression). Cognitive, affective, physical and social contextual factors are also established for LIMs and muses. Baker and Manbeck (2002) report that health information is of particular use in investigating LIMBs owing to uncertainties and apprehension associated with illness and wellness. Moreover, Abrahamson and Fisher (2007) call for "further research [that] examines more deeply why and how lay information mediaries search." This project capitalizes on these identified research gaps by examining the role narrative plays in LIM behaviors and by examining whether Abrahamson and Fisher's general LIMB model is relevant to a specific LIM group: informal caregivers who search for online health information regarding the older adult in their care or informal caregivers searching online newsgroups for information about depression.

3. Methodology

The data for this study were collected from two different settings: online newsgroups and telephone interviews. Two different groups of informal caregivers were sampled: those caring for an older adult and those who care about someone with depression. The online data came from the postings and messages placed on three online newsgroups in which depression and treatments for depression were discussed. Newsgroups were selected according to their longevity, large number of subscribers, high degree of activity, and relevant subject matter. Over 10,000 messages that met the study criteria (i.e., that

received more than one response, were relevant, and were not spam or advertisements), were purposively sampled via keyword searching for instances of queries made by LIMs on behalf of a muse.

Additional data was collected via telephone semi-structured interviews with five (5) participants from across Canada in October and November 2011, who self-identified as informal caregivers of an older adult. Participants were recruited from electronic posters distributed via different online caregiver communities as well as via snowball sampling. All participants were female with an age range of 35-65. Interview data were transcribed. Both the newsgroup messages and the interview transcriptions were coded using open coding which allowed for the range of potential meanings, properties and dimensions contained within participants' words to be developed (Strauss & Corbin, 1998). Data were then analyzed using constant comparison method as developed by Glaser and Strauss (1965).

4. Results

From the data gathered, information seeking, searching, and use proved to be both complex and personalized processes. Participants' searches are internally motivated, self-initiated, and occur only in the presence of a catalyst. The data show that participants use both personal and professional experiences to shape and guide their searching processes, and that LIMs often choose to store information found without sharing it with the muse. Wanting to be informed, or seeking support, caregivers identified the information need and then proceeded to search for personal interest, to supplement their own understanding, or to receive emotional support from others. Most commonly, caregivers turned to online health information in order to "seek to understand" different facets of the well-being of the muses they care for.

Within their unique information seeking processes, the LIMs studied often crafted a narrative about the muse as a means to make sense of how and where to search for relevant information and support. Then, information was gathered, considered, or incorporated into the narrative constructions of the LIM. This information could challenge or strengthen the LIMs' narrative constructions regarding the identity, biography, or health status of the muse.

These results are in partial support of the LIMB model. The lack of support for all seven LIMB characteristics provides evidence for the complexity of informal caregivers' LIMBs, suggesting that informal caregivers may require their own, unique set of LIMB characteristics, that take into account the importance of informal caregivers' narratives in information seeking behaviours.

5. Conclusion

The relatively rapid aging of the Canadian population and the increasingly complex mental health treatment landscape combined with a looming informal caregiver shortage (Gonyea, 2009) brings about complicated information delivery challenges and

opportunities for informal caregivers, the people they care for, and for information professionals.

The information behaviours of LIMs are complex and personalized, and shaped by past experiences. Information seeking behaviours were motivated by a desire to better understand the muse's health and by a sense of responsibility to the muse and their family. While LIMs used an array of internal and external sources to guide information seeking, searching, and evaluating information, the construction and reconstruction of narratives about the muse proved to be a strong contextual factor in LIM practices. In addition, an amended LIMB model, with a greater focus on LIMs and how they construct and reconstruct the illness narrative of the muse, may be necessary for informal caregivers in order to improve information services to these specific information seekers and users.

6. References

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