“We have a lot of information to share with each other”: Understanding the Value of Peer-Based Health Information Exchange

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Abstract

Introduction. This study investigated whether rural people with HIV/AIDS (PHAs) exchanged information with their peers, and why they valued this process.

Method. In-depth interviews and personal social network solicitation were conducted with 34 rural-dwelling PHAs in Canada.

Analysis. Personal networks were analyzed statistically. Interview transcripts were coded using the constant comparison method. Data were analyzed with the aid of social comparison theory and the concept of ‘experiential information’.

Results. Most PHA participants were connected to at least one peer, and many had increased their contact with other PHAs after their diagnosis. PHAs valued peer-based information exchange for: the experiential information content that they shared; their practical and emotional uses of this information; and the positive feelings generated by interacting with peers.

Conclusions. Experiential similarity may predict interpersonal information seeking when people are under illness-related stress. Given its perceived value, peer-based health information exchange should be supported. Implications for information practice are discussed.

Introduction

Information seekers often begin a search for information by consulting other people. While this may be related to the ease with which one can consult others (Case 2002), certain people are more likely to be chosen as information sources than others. A person is more likely to choose a particular individual as an information source if he or she has greater access to resources than oneself (Johnson 2004) or if he or she is socially similar to oneself (Harris and Dewdney 1994). Socially similar people may be chosen as information sources partly because of opportunity; people who are similar to one another in terms of race, social class or geographic proximity are more likely to interact (McPherson, et al. 2001) and form friendships (Fehr 2008). With more interaction comes more information sharing. Moreover, socially similar people are more likely to have comparable life experiences, increasing the odds that they will understand one another’s social circumstances and hold similar values (Suitor, et al. 1995). Hence, information exchange among socially similar people may be driven by a combination of convenience, shared relevance and mutual understanding.
Yet, there are times when shared relevance and mutual understanding break down, such as when one’s life experiences depart from those of one’s close associates. Diagnosis with a serious illness can create such a circumstance, given that illness tends to be a stressful and disruptive life event (Livneh and Antonak 1997). In the case of illness, it appears that interpersonal sources of information are often chosen on the basis of greater access to resources; indeed, ill people rely heavily upon health information provided by health care providers, especially physicians (e.g., Hogan and Palmer 2005). At the same time, however, people undergoing stress often long for interaction and connection with people who share their experiences (Morgan, et al. 1997), or what I refer to as “peers.” Suitor (2000) argues that, in situations of personal crisis, experiential similarity may trump the usual demographic and geographic predictors of friendship formation. Ill people often want to share information with peers, as indicated by the fact that illness-related support group members cite information acquisition as a key benefit of their participation (e.g., Sandstrom 1996). Moreover, 37% of American adults have accessed user-generated health information on the web, primarily personal commentaries or experiences (Fox 2009). Thus, information exchange among ill peers appears to hold significant appeal. Yet we know little about which groups value this form of information exchange and why.

This paper investigates whether rural people with HIV/AIDS (PHAs) engaged in peer-based information exchange, and why they valued it. In-depth, semi-structured interviews were conducted with 34 PHAs in three rural regions of Canada. Findings reveal that most rural PHAs developed new relationships with PHA peers after they discovered their HIV status; these relationships were marked by valuable exchange of experiential information, such as practical disease management strategies and personal stories. Drawing from social comparison theory (Buunk and Gibbons 2007) and the sociology of illness (Julia 2003), I argue that rural PHAs valued this experiential information because it gave them unique informational content, which they used to interpret their experiences and to learn to live with the illness in a difficult environment. Additionally, dynamics of informational interactions with peers PHAs result in positive emotions. Information service models emphasizing capacity development should be emphasized to leverage the strengths of peer-based information exchange.

**Experiential Information**

People with serious, chronic illnesses face many challenges which go beyond biomedical questions of diagnosis, prognosis and treatment. Ill people may face: intense emotions; altered social relationships; changing roles and identities; pain or discomfort; and modified capabilities or lifestyles. In addition, they must learn to manage the illness and its treatment in the context of their lives. All of these issues might be summarized under the umbrella of “learning to live with” illness (Bury 1982), a range of concerns which are rarely addressed comprehensively by biomedical knowledge (Kivits 2004, Kutner, et al. 1999).

Borkman (1999, p. 228) defines “experiential information” as “wisdom and know-how gained through reflection upon personal lived experience.” Experiential information is thus characterized by a combination of practical strategies and personal stories which are based on the accumulation of articulated practical know-how (Mykhalovskiy, et al. 2004) and anecdotes (Taylor 2002). These practical strategies and personal stories are not strictly “lay knowledge.”
Rather, as Carey (2003) identified, experiential information may blend experience and appropriated biomedical information, created as patients attempt to make information meaningful. Experiential information may be developed and shared through discussion and facilitated by dense social networks in which people have similar experiences (Morgan 1986). Experiential information may assist ill people with navigating aspects of the illness experience that tend to be outside the purview of biomedicine, such as managing treatment and dealing with difficult social situations (Carey 2003, Hogan 2007, Mykhalovskiy, et al. 2004). Although previous research helpfully develops the concept of “experiential information,” scholars have yet to consider how the sharing of experiential information may be linked to the appeal of peer-based information exchange.

**Illness and social comparison**

Social comparison theory posits that people have a drive to evaluate their abilities, opinions and emotions, and that they do so by comparing themselves to others (Suls and Wheeler 2000). People are more driven to engage in social comparisons at times of uncertainty or threat, and at these times, they are most likely to compare themselves to others in similar situations. Social comparison activities include: 1) seeking information about what others experience, feel and think and 2) contact, and identification with, others (Helgeson and Mickelson 1995). Social comparison research shows that people under illness-related stress frequently compare themselves to their peers (Tennen, et al. 2000). Information about others may be obtained interpersonally through several interactive processes (Veinot 2009a) with PHAs often finding the physical appearance, personal narratives or actions of their peers to be informative (Taylor 2002). Thus, social comparison may be a psychological process underlying the use of peers’ personal stories as an information source.

An important insight of social comparison theory is that ill people want to have contact with experientially similar others in order to make comparisons (Buunk and Gibbons 2007). Motivations for engaging in social comparisons with similar others in times of stress include desires to: bond with others; improve oneself; feel better about oneself or circumstances; and reduce uncertainty about one’s situation (Helgeson and Mickelson 1995). To do so, people deliberately choose those to whom they compare themselves, selecting a person who is better or worse off than themselves – respectively termed “upward” and “downward” comparisons – depending on their needs in the moment (Buunk and Gibbons 2007). Ill people may use social comparison information in order to appraise their situations and assess their current reactions and coping abilities (Thoits, et al. 2000). And on an emotional level, social comparisons may help ill people to feel hope or inspire them to improve their situations (Thoits, et al. 2000), as well as provide needed emotional connection (Campbell, et al. 2004). Despite these insights, there has been little attempt to consider the implications of social comparison theory for human information behaviour (but see Harris and Dewdney 1994). Yet this framework may help to explain the motivation for and the use of information about others. The present research extends information behaviour research by considering the role of social comparison in PHAs’ perceptions of the value of peer-based information exchange.

**Method**
In-depth, semi-structured interviews were conducted with 34 rural-dwelling PHAs in three Canadian regions. PHAs were recruited through community-based organizations, clinical sites, public health units and chain-referrals (Erickson 1979). The interviews, which lasted from one to three hours, focused on the interviewees’ experiences with HIV/AIDS and their networks for information and help. Personal network solicitation took place during the interviews; these network data were then used for chain-referral recruitment.

The audio-recorded interviews were transcribed and interview data were categorized and coded using NVivo software. A constant comparison analytical approach (Glaser and Strauss 1967) was used to categorize emergent data and assess the fit between study data and concepts of experiential information and social comparison. Personal network data were analyzed statistically to determine network composition. Ethical approval for the study was obtained at The University of Western Ontario, the University of Victoria and Memorial University of Newfoundland. Interviews were conducted from May 2005 to August 2006.

Research Questions

1. To what extent do rural PHAs exchange HIV/AIDS-related information with other PHAs?
2. Do rural PHAs value information exchange with their peers, and if so, why?

Findings

Participant Demographics and Networks

Roughly equal proportions of males and females participated in interviews (see Table 1). Most participants were between the ages of 30 and 49 and white/European descent. Approximately 40% identified as gay, lesbian or bisexual.

<table>
<thead>
<tr>
<th>Table 1 – Demographics of PHA Interview Participants</th>
<th>BC / Kootenay Region</th>
<th>NL / Rural Newfoundland</th>
<th>ON / Huron-Perth</th>
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<td>18</td>
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<tr>
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<td>5</td>
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<td>4</td>
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<tr>
<td>Unknown</td>
<td>1</td>
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The majority of PHAs had relatively small networks for HIV/AIDS information/help, with a median of eight network members (Table 2). While not discussed in depth here, PHAs’ networks emphasized formal caregivers, family members and close friends; networks contained very few casual friends or acquaintances. Most participants had at least one PHA peer in their networks (Table 2).

<table>
<thead>
<tr>
<th>Total Network Size</th>
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<tr>
<td>Mean (s.d)</td>
<td>13.65 (13.20)</td>
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<td>Median</td>
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<tr>
<th>Network Composition</th>
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<tr>
<td>Number of Ties with other PHAs</td>
<td></td>
</tr>
<tr>
<td>Mean (s.d)</td>
<td>3.64 (7.17)</td>
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<tr>
<td>Median</td>
<td>1.00</td>
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</table>

Table 2 – Characteristics of PHAs’ HIV/AIDS Information/Help Networks

**Experiencing HIV/AIDS in rural Canada**

Rural PHA participants lived in sparsely-populated regions, most with a low HIV prevalence. Many PHAs felt that members of their communities thought that HIV/AIDS did not exist locally, resulting in a lack of ownership and silence about the disease, as this PHA explained, “It’s rarely talked about. Rarely. Just, you know, living up here I don’t, I don’t even hardly hear anybody hardly talking about it...” At the same time, as documented elsewhere (Veinot 2009b), rural PHAs confronted stigmatizing attitudes and behaviour locally. PHAs’ experiences of stigmatization were often internalized, leading to feelings of humiliation and shame. As this PHA described through tears, “I’ve experienced a lot of humiliation, discrimination, with being HIV positive.” Or, as this PHA explained, “I’m still trying to find my own self worth for being loved and touched...it’s like a dirty disease.” As a result of such experiences, many PHAs chose to conceal their HIV status in their local communities; this made it more difficult for PHAs to find one another.

Additionally, the majority of PHAs experienced the disease itself as highly distressing, with diagnosis linked to fear about their future health and lifespan. Moreover, PHAs often found living with their disease personally demanding — from fatigue and physical symptoms, to the emotional strain of stigmatization, to the financial costs of travel for health care. PHAs also felt isolated when the people close to them did not fully understand or empathize with their experiences. As such, many PHAs faced significant challenges, and meaningful community support was not always forthcoming.

**Connecting with peers**

Anchored in the demands of rural living with HIV/AIDS in Canada, many PHAs felt that they needed the particular support of peers. Or, as this PHA said, “I’d like to meet a person who got what I got...” Four PHAs felt this need, but had PHA spouses, making it possible to obtain such support at home. However, HIV-positive sexual partners were not always sources of support:

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1 One region had a higher HIV prevalence due to a serious outbreak of HIV which took place in the 1980s.
there were nine cases where a PHA acquired HIV from a sexual partner with who they were not on good terms, and two PHAs had lost partners to AIDS. And while eight gay male participants were acquainted with other (often urban) PHAs at the time of their diagnosis, they felt isolated in rural areas and wished for more contact with other PHAs. Accordingly, many PHAs felt, at some point, that they did not have sufficiently supportive ties with other PHAs, and in some cases, had not known any other PHAs at all.

Participants’ insufficient or minimal acquaintanceship with other PHAs led 25 participants to form at least one new information network tie with a PHA peer. Additionally, four PHAs developed new ties with peers in which they gave information without receiving it themselves. So, 29 of 34 participants’ increased their contact with peers after their HIV diagnosis. How did they accomplish this in regions where it was difficult to meet peers? As outlined elsewhere, rural PHAs primarily met peers who lived close to them with assistance from others — primarily AIDS service organizations or other people in their networks (Veinot 2010). Additionally, some rural PHAs met geographically dispersed peers via the Internet. As might be expected, PHAs who formed new personal network ties with peers valued this contact; indeed, many PHAs marveled at how much information PHAs could share, and how helpful this was.

“…the people…that I’ve met who are infected have so much to share.”

“…we’re all PHAs and we have a lot of information to share with each other…which is really good…”

In these comments and others, PHAs expressed a clear consensus that peer-based information exchange was valuable to them. Why was this so?

The value of peer-based information/help exchange

PHAs faced a monumental challenge: how to live with the disease as well and as long as possible. But this was not something that people could usually learn from their formal caregivers; rather, it was other PHAs who possessed this knowledge, “…she showed me that you can live with HIV…” As I describe below, PHAs valued peer-based information exchange for: the content of experiential information they obtained, the uses to which PHAs put this information, and the information exchange interactions themselves.

“They all have answers”: the content of experiential information

From one another, PHAs learned practical strategies for dealing with HIV/AIDS. This included the emotional and spiritual issues arising from the disease. For example, PHAs shared ways of handling their emotions and thinking about their experiences. As this PHA explained, he learned from “people’s outlook on [having HIV] and how they deal with it.” Discussions included ideas about when and how to disclose one’s HIV status, and to whom. PHAs also shared tips and strategies for self-care, including ideas about healthy living. As this PHA said, “…you have to get rid of stress, quit your job — those who stayed working died.” Complementary therapies and nutrition also figured highly in PHAs’ articulated strategies for staying healthy. For example, this PHA shared information with peers about “…different vitamins and things like that I’ve
taken...things that I think help...”. Additionally, PHAs shared strategies for managing HIV drug side effects. For instance, this PHA explained that speaking to a peer helped her figure out what to do about her peripheral neuropathy: “...soak your feet in cold water, not hot...[it] was like, ‘oh, this works’”.

One form of practical knowledge that was locally unique concerned how to obtain needed supports. This was critical because rural PHAs lived in communities in which it is difficult to acquire needed care, treatment and support. Local health care providers often lacked up-to-date knowledge regarding HIV, and some did not accept HIV patients. As a result, rural PHAs discussed the names of providers who were considered knowledgeable about or receptive to caring for PHAs. Moreover, because rural communities were densely knit and characterized by multiple, overlapping relationships, it was difficult to obtain services confidentially. To deal with this, PHAs compared the confidentiality practices of providers and discussed methods for obtaining HIV treatment privately. Additionally, PHAs recognized that there was an art to obtaining needed resources, from making a successful disability claim to obtaining financial aid for health care-related travel. As such, PHAs shared approaches to securing resources, as this person explained: “...he’ll guide me to where I get connected...like, where I can get like a gas rebate...”

PHAs’ also shared personal stories about their respective experiences with HIV and its treatment. In part, this involved making biomedical information personally meaningful by linking biomedical concepts, such as medication side effects and blood counts, to real-life, embodied experience. Some of this conversation related to discussion of which medication regimens each person was taking, the current success of one’s treatment or drug side effects. The narrative detail that PHAs applied to treatment issues appeared to make complex information more real to them.

“Holy God, there’s hope!”: uses of experiential information

By and large, PHAs felt that the information they obtained from one another was helpful. This speaks to the role of information use in valuing peer-based information exchange. Experiential information which focused on practical strategies, such as how to manage drug side effects, gave PHAs ideas that they applied to their own self-care through trial and error. Moreover, if they were successful, these activities were incorporated into ongoing health management routines. PHAs also connected to services that they learned about from each other and interacted with them in ways suggested by peers.

Additionally, in keeping with social comparison theory, PHAs also used the personal stories of other PHAs to interpret their own situations. This form of information use was emotional in nature, as evidenced by the fact that PHAs generally thought about the experiences of other PHAs in ways that made them feel good about their personal situation; they did so whether the other person was better or worse off than him or her. For instance, in an example of upward comparison, several newly diagnosed PHAs took the experiences of long-term HIV survivors as evidence that they could live longer than they initially thought. Hence, identification with long-term survivors allowed them to feel hope.
“He’s had AIDS for many years and he’s gone through a lot...he’s been through the treatments...I guess that there is hope, that’s what I learned from him.”

“...he looked at me and he said, ‘I’ve been diagnosed 15 years ago’, and I thought that long! ...so it was like holy, God, there’s hope!”

When engaging in downward comparisons, PHAs took careful note of the health of PHA peers who they believed were sicker than them or more plagued by symptoms. In these cases, PHAs concluded that they were fortunate to be in relatively good health. “It’s like I don’t have the disease...I don’t get nearly anything that my friends all seem to suffer from.” Additionally, while undergoing demanding but medically necessary treatments, PHAs used their peers’ experiences to conclude that their negative drug side effects were comparatively minor.

“...[I have a] ...little bit of lipodystrophy here...but I’ve had friends that look like a human skull you know, walking around so compared to them I’m very fortunate.”

PHAs also marshaled the experiences of their peers to feel good about their ways of responding to the disease. For example, this PHA felt that talking to peers confirmed the wisdom of his self-care strategies. He said “...how you’re dealing with it in relation to other people... that helps...bolster[s] what you’re doing is right...” Accordingly, PHAs often used experiential information to make social comparisons which led to maintaining a positive viewpoint as they faced the challenges of the disease.

“I thrive from helping other people”: informing interactions and positive emotions

The interactions in which peer-based information exchange occurred were often emotionally positive experiences. PHAs felt that their peers truly understood their challenges, which resulted in deep feelings of connection. Connections were felt when engaging in mundane activities such as joking around, as well as profound activities such as discussing personal struggles. As an example of the latter, this PHA explained,

“...we talk about the anxiety of waiting for [blood test results] to come back or what the numbers mean, or how often you...have to go to the Clinic, those kinds of things that only somebody else that’s positive would know.”

PHAs felt that this kind of connection was an important antidote to the lack of understanding which their HIV-negative family members and friends could display. Additionally, rural PHAs felt that being with peers allowed them to relax and have a needed reprieve from the stigmatization that they experienced. As one PHA explained, when she is with her peers, “I know I’m not being judged.”

In addition to the support they received, PHAs also tried to give help to one another by sharing information. Through volunteer roles as “buddies” or “mentors” at AIDS service organizations or simply through responding to others in need, PHAs gave of themselves in information exchanging interactions. Acts of helping gave PHAs a sense of reward.
“...it’s nice knowing that I’m helping somebody... they can phone [me] up and say ‘I’m having trouble with this,’...So I thrive from helping other people.”

Similarly, this PHA described sharing information with peers on the Internet as uplifting.

“...they want someone to talk to and you get chatting, and you pass on information to them, and so that can be very helpful but also emotionally and spiritually lifting for them and for me...”

PHAs who gave information to others also had positive feelings related to experiencing a sense of mission, a helpful distraction from dwelling on one’s own problems and from having their expertise recognized by others.

**Discussion and Conclusion**

A significant finding of this research was that the majority of PHA participants developed information network ties with PHA peers, and they did so despite the challenges of a rural Canadian environment. This finding has resonance with social psychological research, which has demonstrated that people are attracted to experientially similar others when they are under stress, and that this may become more important than social similarity when forming new relationships (Suitor and Pillemer 2000). This was the case among rural PHAs, who formed ties with peers across boundaries of sexual orientation, race/ethnicity and differing social circles. Consequently, this research suggests that our conception of social similarity as a predictor of information seeking may need to expand in order to reflect the dynamics of illness-related stress.

This study also illustrates that PHAs placed significant value on the exchange of information with their peers; moreover, it extends previous research by showing that PHAs valued peer-based information exchange in part because of the experiential information that was available through these ties. In addition, this study reinforced previous research regarding the content of experiential information — namely, that it is comprised of accrued practical wisdom and personal stories (e.g., Borkman 1999, Mykhalovskiy, et al. 2004, Taylor 2002). As well, this experiential knowledge was characterized by appropriation of biomedical expertise as a form of meaning construction (Carey 2003). However, this research also documents a form of experiential information borne of the specificity of the rural HIV context – how to successfully obtain knowledgeable and confidential services. This research, therefore, highlights ways in which the content of the experiential knowledge may vary by setting. As such, the experiential knowledge described in this paper is firmly grounded in the Canadian rural context, but with broader theoretical implications.

This research also illustrates uses of experiential knowledge that have otherwise been identified, such as application of practical strategies to managing treatment (Hogan 2007). However, the present research augments previous analyses by documenting the dynamics of social comparison in information use. Social comparisons consistently allowed PHAs to feel good about their situations and themselves. Hence, social comparison theory helped to explain PHAs’ perceptions that peer-based information exchange was valuable, while describing an important form of their...
use of this information. This study points to the value of future application of social comparison theory to information behaviour research.

A further contribution of this research is that it documents that peer-based information exchange was an emotionally rewarding and positive experience for PHAs. PHAs were rewarded because they felt that their peers connected with them more deeply than others did. Likewise, social support researchers have observed that people with similar problems may provide one another with greater empathy than do others (Ussher, et al. 2006). Moreover, in the face of stigmatization, PHAs found interactions with one another to be especially comforting. This is in concordance with research showing that spending time with people who share one’s stigma is linked to positive self-esteem (Frable, et al. 1998). PHAs also felt good when they gave information to others. The fact that giving was a positive experience is unsurprising. The benefits of helping others include greater happiness, life satisfaction and health (Post 2005).

Peer-based health information exchange fills an informational gap in the lives of rural PHAs, while making them feel good. But is there a downside? Concern has been expressed, for example, about the quality of peer-based health information on the Internet (Kelly, et al. 2002), and HIV/AIDS-related misinformation is often shared in rural Canada (Harris, et al. 2008). Patients may also misunderstand meaning as they appropriate experiential information, or they may over-generalize as they interpret personal stories. While these concerns hold some validity, PHAs’ reasons for valuing peer-based information exchange suggest that there is a need to further develop information services which build on its strengths, while minimizing potential quality lapses. A current library and information science (LIS) model – information literacy skills training – offers one way forward. In particular, it is notable that some information literacy programs also engage peers as educators or trainers (e.g., Warner et al., 2005). However, this service approach might be extended to more fully address the range of benefits enjoyed by participants in this study. To do so, LIS can draw from public health service models that train and support lay people to provide peer-based information (e.g., Eng and Parker 2002, Heisler 2010). Accordingly, peer-based information exchange provides an opportunity to move health information services more fully from a focus on enforcing quality to one of building capacity.

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References


