

**“A lot of people didn't have a chance to support us  
because we never told them”**

**Stigma management, information poverty and HIV/AIDS  
information/help networks**

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Because of fears of stigmatization, people with HIV/AIDS (PHAs) may avoid health care and refuse illness-related information and support. However, HIV/AIDS-related information, especially that which is provided by other people, has also been shown to a vital resource for PHAs and their loved ones. This research examines the role of stigmatization in PHAs' and their friends/family members' efforts to establish personal networks for HIV/AIDS-related information and help ("information/help networks"). To investigate this question, I draw upon Goffman's (1963) stigma management theory and Chatman's (1996) theory of information poverty. Semi-structured, in-depth interviews were conducted with 114 PHAs, their friends/family members, health care and service providers in three rural regions of Canada. Results revealed that the majority of PHAs and friends/family members had relatively small networks for HIV/AIDS information/help. For many participants, the challenges of living with HIV/AIDS led to changes in their personal networks, and stigmatization playing a significant part in such changes. Participants developed information/help networks in a manner consistent with stigma management theory in their decisions to disclose selectively to others, to avoid the topic in conversation, to obtain information/help at a distance or to acquire information/help without disclosing their HIV status. However, in contrast to Chatman's theory, participants did not wholly avoid information from interpersonal sources nor believe that no one was available to help them. These findings suggest that information behaviour theory may need to evolve in order to account for the complexity of self-protective behaviour.

## **1.0 Background and Purpose**

It has long been observed that people may avoid seeking information if they believe that doing so will expose them to intolerable personal risks or costs. On a psychological level, people with serious illnesses may avoid health information so as to maintain hope or to control their overwhelming emotional distress (Lambert, Loiselle, & Macdonald, 2009; Lee, Hwang, Hawkins, & Pingree, 2008; Leydon, et al., 2000). And on a social level, people may also avoid seeking health-related information and help, especially from other people, if they believe that to do so might result in a loss of self-esteem (Harris & Dewdney, 1994) or negative material consequences (Chatman, 1992). Additionally, in cases where people are affected by stigmatized illnesses, such as HIV/AIDS, concerns about the social risk of information seeking may be particularly severe. For example, because of fears of stigmatization, people at risk of HIV infection may avoid or delay HIV testing (Chesney & Smith, 1999; Stall, et al., 1996) or steer clear of risk reduction information (Chesney & Smith, 1999). For these same reasons, people with HIV/AIDS (PHAs) may also avoid health care (Chesney & Smith, 1999; Green & Platt, 1997) and refuse illness-related information and support (Health Canada, 2000). And in close-knit communities, such as those commonly found in rural areas, such social stigmatization may be an exceptionally strong barrier to obtaining HIV-related aid (McKinney, 2002).

Despite the potential social risk or cost involved in seeking HIV/AIDS-related information, such information has been shown to a vital resource for people with HIV/AIDS (PHAs) and their loved ones (Health Canada, 2000; Hogan & Palmer, 2005; Huber & Cruz, 2000). Moreover, PHAs appear to rely heavily upon consultation with interpersonal sources, such as their personal physicians and other people with the disease, for HIV/AIDS-related information and help (Health Canada, 2000; Hogan & Palmer, 2005; Huber & Cruz, 2000; Sandstrom, 1996; Taylor, 2002). In this research, then, stigmatization does not appear to stand irretrievably in the way of PHAs and their loved ones' abilities to obtain HIV/AIDS-related information/help from other people. Such findings are thus in keeping with prior LIS research which documents diverse groups' use of social networks for gaining access to information (see, for example, Bishop, Tidline, Shoemaker, & Salela, 1999; Haythornthwaite, 1998; Hersberger, 2003; Huotari, 1999; Jeong, 2004).

With such seemingly divergent findings, there is a need to clarify the dynamics of interpersonal HIV/AIDS-related information seeking and avoidance. To do so, this research locates such information behaviour within the literature on personal social networks, and how such networks develop and change. This is important because it is well known that personal networks are subject to change over time, particularly in the context of major life events and stressors (Bidart &

Lavenub, 2005; Leik & Chalkley, 1997; Wellman, Wong, Tindall, & Nazer, 1997). For example, a serious illness may precede reduction in the size and quality of one's personal networks over time (Bor, Miller, & Goldman, 1993; Miller, 2000; Turner, Hays, & Coates, 1993). However, adaptation to serious illnesses such as HIV/AIDS can also be a catalyst for a person to form new social network ties, particularly those with professional caregivers or with peers (Brashers, Haas, Neidig, & Rintamaki, 2002; Cohen & Lazarus, 1979; Moos & Holahan, 2007; Samson & Siam, 2008; Sandstrom, 1996). In fact, it has been argued that an ill person's establishment of such relationships is a crucial step in his or her psychosocial adaptation to illness (see, for example, Moos & Holahan, 2007; Samson & Siam, 2008)). Hence this research begins from the understanding that people living with HIV/AIDS and their loved ones may experience considerable change in their personal social networks over time, and that they may initiate at least some of this change in an effort to cope with their situations.

Based on review of prior research, then, it appears that people affected by HIV/AIDS may avoid interpersonally-provided HIV/AIDS information, or rely heavily upon it. Moreover, as they confront the disease, they may either lose members of their personal networks, or gain them. To address this apparent complexity, this research examines the role of stigmatization in PHAs' and their friends/family members' efforts to establish personal networks for HIV/AIDS-related information and help ("information/help networks" (1)). To investigate this research question, I draw upon the conceptual resources of two complementary micro-sociological theories: Goffman's (1963) stigma management theory and Chatman's (1996) theory of information poverty.

## **1.1 Stigma Management Theory**

Goffman (1963) defined stigma as "an attribute that is deeply discrediting" (p. 13) in the context of normative expectations about a person's identity. In Goffman's (1963) view, possession of a socially stigmatized attribute causes a person to be viewed as less than fully human. This leaves a stigmatized person with a 'spoiled' social identity, which isolates that person from both society and him or herself. Goffman (1963) suggests that, among other attributes, people may be stigmatized on the basis of their perceived conduct. Moreover, Goffman (1963) contends that intentional and explicit stigmatization tends to be directed at people who are stigmatized on these grounds, such as people with addictions or mental illness. Additionally, several scholars argued that HIV/AIDS related stigmatization can be viewed as a 'conduct stigma' because HIV infection is seen to be the result of voluntary, avoidable behaviours that are 'morally questionable', such as drug use, homosexuality or sexual promiscuity (Fife & Wright, 2000; Herek, 1999; Herek & Capitanio, 1999).

Consequently, rather than empathy or sympathy, PHAs may be subject to an angry, moralizing blame for their illness (Devine, Plant, & Harrison, 1999; Herek, 1999; Herek & Capitanio, 1999).

Goffman (1963) argues that when a person's stigmatized identity is not immediately known in a social interaction, she or he may be able to 'pass' as 'normal' (p. 42). Similarly, previous research has shown that many PHAs choose not to disclose their HIV status, or to do so selectively, as a result of stigmatization (see, for example, Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003). Goffman (1963) argues that passing involves use of techniques of 'information control', where the central issue is 'managing information' about one's stigma, "[t]o display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when and where." (p. 42). As a result, the world becomes 'divided up' between those who know and those who don't, and the places associated with each type of person (p. 66). In these cases, there may be "a large group to whom he tells nothing, and a small group to whom he tells all and upon whose help he then relies" (p. 95). Among those people who are likely to be 'told all', Goffman (1963) argues, are people who share their stigma, whom he terms 'the own', as well as 'the wise' (Goffman, 1963, p. 28), people whose 'special situation' makes them knowledgeable of, and sympathetic to, the experiences of stigmatized people. For instance, in the case of an illness, health care providers may be among 'the wise'. Additionally, Goffman (1963) argues that, along with being 'the wise', people close to stigmatized people may themselves be stigmatized, a phenomenon which he terms 'courtesy stigma' (p. 30).

Applied to the context of this research, Goffman's theory of stigma management suggests that participants may construct HIV/AIDS information/help networks through strategies that help them manage stigmatization in their relationships with others. Thus I examine the extent to which rural dwellers affected by HIV/AIDS engage in information control practices, and how this may relate to their formation of information/help networks.

## **1.2 Information Poverty Theory**

Like Goffman (1963), Chatman's (1996) information poverty theory attempts to describe and explain self-protective behaviours in the context of information and help seeking. Chatman (1996) posits that 'outsiders' may experience a state of 'information poverty' where "a person is unwilling or unable to solve a critical worry or

concern" (1996, p. 197). For Chatman (1996), people who are 'information poor' engage in self-protective behaviours in order to shield themselves from the unwanted intrusion of others, and because they do not trust that others can help them. Chatman (1996) argues that information poverty is only partially related to economic class, thus suggesting the theory's potential applicability to groups who are marginalized for non-economic reasons, such as people affected by HIV/AIDS. Indeed, Chatman's theory has subsequently been applied to research with disparate groups for whom social norms may play a powerful role in information behaviour, such as young people (Todd & Edwards, 2004).

For Chatman (1996), self-protective strategies associated with information poverty may include 'secrecy', or "a deliberate attempt not to inform others about one's true state of affairs" (p.199) and 'deception', "a deliberate attempt to act out a false social reality" (p.200-201). Clearly, these types of self-protective behaviour bear much resemblance to Goffman's (1963) model, since he states that information control strategies can involve both hiding and lying. However, Chatman (1996) sheds light on a prospect that Goffman does not discuss in detail "the possibility that stigmatized people may avoid information and help altogether, presumably such that they never form information/help networks. Because of this additional insight, I also use Chatman's (1996) information poverty theory to examine rural dwellers' HIV/AIDS information/help network formation behaviours. In so doing, I evaluate the match between study findings and both Goffman's (1963) and Chatman's (1996) theories.

## 2.0 Method

Semi-structured interviews were conducted with 34 PHAs and 28 of their friends/family members in three rural regions of Canada. Additionally, 52 of their health care and service providers (2) acted as key informants. This research was conducted in three rural Canadian regions with the understanding that because HIV/AIDS-related stigma may be more pronounced in rural areas (Heckman, Somlai, Kalichman, Franzoi, & Kelly, 1998; Reif, Golin, & Smith, 2005), dynamics of stigmatization might be more 'observable' in these settings. Interview participants in each region were recruited through collaborating organizations, as well as chain-referral procedures. Interviews lasted from one to three hours, and focused on participants' HIV/AIDS-related experiences, as well as eliciting their information/help networks through multiple 'name generator'-type questions which sought the names of actual or potentially helpful/informative people (van der Poel, 1993). Participants were given the option to be audio-recorded, or to have

the interviewer take handwritten notes only. Interview transcripts were created from these audio recordings and interview notes. Transcripts were analyzed thematically and compared to included theories using the constant comparison method (Glaser & Strauss, 1967). Categorization and open coding (Strauss & Corbin, 1998) of transcripts were conducted with NVivo qualitative analysis software. Personal network data gathered through interviews and chain-referral recruitment were also extracted and analyzed using SPSS statistical software. Ethical approval was obtained at The University of Western Ontario, the University of Victoria and Memorial University of Newfoundland.

### 3.0 Results

#### 3.1 Information/Help Networks of PHAs and their Friends/Family Members

The majority of PHAs and friends/family members had relatively small networks for HIV/AIDS information/help, with medians of eight and four network members, respectively (see Table 1) (3) . Although participants had been diagnosed for variable lengths of time (4), there was a very weak correlation between time since diagnosis and network size ( $r_s=0.12$ ;  $p=0.49$ ). Friends and family members of PHAs generally had smaller networks than PHAs themselves.

Table 1 - Size of HIV/AIDS Information/Help Networks		
Total Network Size	People with HIV/AIDS	Family Members/Friends
Mean (s.d)	13.65 (13.20)	5.79 (4.00)
Median	8.00	4.00
Minimum / Maximum	2.00 / 62.00	1.00 / 15.00

PHAs named health care and service providers as major players in their information/help networks, but friends and family members of PHAs relied to a lesser extent on formal caregivers than their loved one(s) with HIV/AIDS (see Table 2). Family members and close friends were the most frequently a part of friends/family members' networks, and were also significant components of PHAs' networks. Casual friends and acquaintances played a comparatively minor role in most PHAs' and friends/family members' information/help networks (see Table 2).

Table 2 - Composition of HIV/AIDS Information/Help Networks		
	People with HIV/AIDS	Family Members/Friends
Health Care Providers in Networks (Median)	3.00	0.00
Service Providers in Networks (Median)	1.00	0.00
Family Members in Networks (Median)	1.00	1.00
Close Friends in Networks (Median)	2.00	0.50
Casual Friends/Acquaintances (Median)	0.00	0.00

### 3.2 Stigma and HIV/AIDS Information/Help Networks

For many participants, an HIV/AIDS diagnosis was a significant challenge that shifted their expectations for the future, drew them into intense emotions, and often changed their sense of themselves and what they wanted out of life. With such significant challenges often came shifts in their relationships with others. In some cases, PHAs noted that dealing with their diagnosis brought them closer to people in their lives; in others, existing ties were strained or ruptured. And for some, revised life experiences and emotional upheaval caused them to form new relationships. Additionally, stigmatization often played a role in this network change.

Study participants often faced the sting of other people's stigmatizing attitudes and actions towards them. Indeed, some PHAs and family members felt that living in a rural area increased the extent of the stigma that they faced, particularly due to a lack of personal exposure to PHAs in the general population. Some participants believed that this lack of exposure increased others' fear of catching HIV/AIDS in a myriad of impossible ways. In addition to community members' irrational fears of contagion, some participants felt confronted by moralistic judgments about sexual behaviour and HIV transmission, in a manner consistent with Goffman's concept of 'conduct stigma' (Goffman, 1963). These moralistic judgments particularly aligned with negative cultural attitudes about women and gay men. As this PHA said, she felt that others thought, "'being HIV-positive and female' must be a slut." In keeping with Goffman's (1963) idea of a 'courtesy stigma', some family members of PHAs (5) also felt stigmatized, and some PHAs were terrified of bringing shame on their family.

In general, disclosure of one's HIV/AIDS-related experiences was a key choice in the formation of HIV/AIDS information/help networks. Yet, because of the stigma surrounding HIV/AIDS in their local communities, risks of judgment and rejection

loomed large in many PHAs' and their loved ones' disclosure decisions. Thus, while some PHAs and friends/family members were open about their HIV-related experiences to everyone in their lives, many hid their experiences in order to protect themselves or loved ones from possible judgment or loss of status. Thus many participants attempted to control information about their illness, by not 'letting on' (Goffman, 1963, p. 42). Such attempts also typified Chatman's (1996) concept of secrecy as a form of self-protectiveness. As a result of these self-protective strategies, people dealing with the disease often acquired information/help from far fewer people than they actually knew. This could leave them with few sources of aid, unable to turn to others, and at its most extreme, painfully alone to deal with major crises in their lives, as this family member of a PHA said,

"a lot of people didn't have a chance to really support us because we never told them. And you certainly can't give support if you don't know — we carried that pain ourselves, but we weren't willing to share with anybody"

However, use of these self-protective strategies, and others which I describe below, varied based on the relational context in question. Thus PHAs and their friends/family members behaved differently in close relationships than in those with acquaintances, and differently yet again in ties formal caregivers. Accordingly, I discuss the ways in which stigmatization affected PHAs' and friends/family members' formation of ties with these different categories of people.

### **3.2.1 Ties with Casual Friends and Acquaintances**

Self- and family-protectiveness often led to non-disclosure to casual friends and acquaintances, whom participants implicitly trusted less than their loved ones. Indeed, as shown in Table 2, few participants relied upon casual friends of acquaintances as sources of HIV/AIDS-related information/help. For example, this rural health care provider explained how her clients wanted to keep their HIV status private beyond a few trusted people,

"They've chosen to have some select individuals that they would share their status with — [t]hey worry about how the community is going to perceive them and [have], a lot of anxieties around that."

Thus PHAs and their friends/family members commonly engaged in secrecy



(Chatman, 1996) or information control (Goffman, 1963) in relation to casual friends and acquaintances. For PHAs, these decisions were generally made possible because they were well enough to conceal visible signs of their illness. However, the physical appearance of some ill PHAs sparked questions from acquaintances or casual friends. In response, and supporting Chatman's (1996) concept of deception, some denied their condition when asked about it by such people, as this PHAs admitted with some regret, "Nobody know what I got. I tell them I got cancer."

Hence although some PHAs engaged in such deception to conceal their true situations, this was more often the case in relationships with casual friends and acquaintances.

Unfortunately, supporting PHAs' lack of trust in such acquaintances or casual friends, some PHA participants had negative experiences with such people that confirmed their worries. In a few extreme cases, PHAs became grist for the rumour mill in their small communities when people spread the news of their illness to large numbers of others. PHAs who had this experience felt immensely betrayed and vulnerable, as this participant said,

"There really isn't much personally that can happen now [everyone] knows thanks to this individual and it just made me feel like I was walking around naked"

Some PHAs were even publicly humiliated in their home communities, such as one PHA who recently became the focus of a controversy at her workplace because customers perceived her illness to be a threat to their safety. In another case, young people had called a PHAs' house to threaten him with comments like, "we know you've got AIDS and we're going to get ya!". Perhaps due to extremity of possible reactions, even those who had not had such directly negative experiences were afraid of becoming the target of such behaviour.

Participants' choices to hide their HIV-related experiences were thus most commonly directed at acquaintances and casual friends. In personal information/help network terms, this resulted in what Goffman (1963) referred to as the creation of a large group of people in one's life who were unaware of one's HIV status, and thus unable to provide any form of aid. Consequently, the

most powerful impact of stigmatization on potential information/help-giving ties with casual friends or acquaintances appeared to be defensive exclusion of such people from the opportunity to play a role.

### **3.2.2 Ties with Family Members and Close Friends**

Generally, participants' information/help networks contained a larger proportion of close friends and family members than casual friends/acquaintances (see Table 2), people who Goffman (1963) would call 'the wise' because of their 'special situation' of close social proximity to HIV/AIDS. Thus rural dwellers affected by HIV/AIDS, especially family members of PHAs, often regarded their family members and close friends as central sources of HIV/AIDS-related help and information.

However, even with respect to family members and close friends, stigmatization played a role. For example, some PHAs and friends/family members chose to avoid or delay telling specific individuals because they felt that their attitudes, values or personalities predisposed them towards being judgmental or inconsiderate. Thus they engaged in information control (Goffman, 1963) or secrecy (Chatman, 1996) in relation to these individuals. For example, this family member who didn't want to tell his siblings because,

"I really don't have any faith in their ability to deal with it, or understand it — they wouldn't be able to deal with it in the way that I would need them to deal with it."

Another PHA said that she told some of her siblings, but didn't tell others because of their tendencies to be 'very judgmental'. Yet another PHA decided never to tell a specific relative because of a negative comment he made in passing about AIDS. Similarly, in a different family, certain relatives' prejudicial values meant that they never learned of their daughter's disease,

"They're very old school — it's just, 'hell and damnation', so. And it's like people deserve to get it. "Well you must have done something to deserve it", which is very close-minded. They really are. And, just derogatory statements, especially in my family, about it being a homosexual thing, they've got this big thing about, they're very homophobic:

Moreover, when PHAs and their family members actually did decide to tell their family members and close friends about their experience, they often thought carefully about who needed to know - and even then, disclosure was often tinged with dread and doubt. Relatedly, experiences of HIV status disclosure occurred in the context of relationships with their own history and climate, such that these experiences were highly conditioned by what came before. Hence as Charmaz (1991) observed, PHAs worried to a greater degree about disclosure in the context of relationships that had a history of difficulty or strain, relationships that they felt were less able to accommodate the weight of the information, as this PHA said,

"my mother — her and I had a rocky childhood relationship — we have worked very hard to develop a really close relationship — my fear is fear that that would change"

Additionally, even after PHAs had disclosed their HIV status, some noted that they rarely, if ever, spoke about the disease with their families or close friends. At times, this made it difficult to access information/help from these ties, since both PHAs and their families chose not to raise the issue. For example, this PHA felt that there was an unspoken agreement that his disease should only be mentioned in emergencies,

"my family's a little bit, how do I put it without sounding negative? They know and I'm sure if it ever came down to something that I really need or support or whatever they'll be there, but other than that, it's never discussed".

Thus while many rural dwellers affected by HIV/AIDS had supportive ties with their loved ones, stigma played a role in circumventing the flow of information/help in many of these relationships. This occurred when participants chose to conceal their experiences from selected people, particularly relationships that were already fraught with tension or judgement. Additionally, some PHAs found that their relationships were characterized by constraints in relation to talking about their illness, thus standing in the way of possibilities for routine information/help exchange.

### **3.2.3 Ties with Health Care and Service Providers**

As has been described previously, rural PHAs' information/help networks emphasized health care and service providers — also people who Goffman (1963) would call 'the wise'. Many PHAs valued their ties with such formal caregivers because of their expertise, as well as their helpful and kind ways of interacting with them. However, participants' accounts also emphasized that they relied upon professionals to a significant extent because they were bound by formal confidentiality codes that made HIV-related disclosure feel safer. Indeed, when participants were unwilling or unable to turn to lay people in their lives for HIV/AIDS information/help, they often relied extensively or even exclusively upon formal caregivers for this aid. For example, a small number of participants had never disclosed their HIV status to anyone other than their health care providers, such as a PHA who said that she "never told a soul" or this PHA, who had never told anyone other than his medical caregivers,

I: What makes you not tell anyone but your medical people?

R: I don't see any upsides to that. I see lots of downsides, but no positive. To me, medical health is a private, personal thing. Medical history is a private thing. I'm not sure I would want others to know'circumstances change or relationships change, and people might tell someone who's not as sympathetic."

Nevertheless, some participants felt that densely-knit relationships between residents of their rural communities made it difficult for them to use local services confidentially. As a result, they developed information/help networks in circuitous ways. One circuitous approach involved the use of HIV/AIDS-related services in distant locations, while allowing other needs to be met at home. As a result, providers observed that their rural dwelling clients endured considerable inconvenience, and occasionally risked their safety, to avoid obtaining services locally,

"People from [rural area] will use our local pharmacies in [city name] and will drive in through flippin' snowstorms to get their meds because they don't want their local pharmacy to know. Because they say "I know that they're supposed to be confidential, but I know that Aunt Susie's whatever", just the familiarity and closeness"

Additionally, although the majority of PHAs disclosed their HIV status to their

providers, some PHAs gained information/help from providers without disclosing their HIV status at all; such behaviours were reminiscent of Goffman's concept of information control as well as Chatman's (1996) concepts of secrecy and deception. For example, service providers mentioned that they had clients who would only use anonymous services, such as toll-free telephone information lines or the Internet. Some PHA participants also said that when they saw health professionals whose therapies posed no risk of HIV transmission, such as chiropractors, they did not mention their illness because they did not trust that it would remain confidential. In extreme cases, physicians even struggled with how to provide treatment to PHA patients whose true identities were unknown to them,

"we've had several situations where people have wanted to be anonymous to the point where they will dream up a name and you know, 'call me Mike' and then you find out a month later that when they finally trust you what their real name is. One chap was very, very difficult — finally he did come out with his name but we didn't even have [a health plan number] for him at one point. And I would write his initials on the prescription and he would write in his name after he left and go to a pharmacy"

As well, PHAs who were very concerned stigmatization sought information/help through intermediaries. For example, this PHA connected with her local AIDS organization through a friend so as to avoid being identified, he said, "look it, nobody even needs to know your last name and if you don't want to talk to them, then I will be the go-between between you and her."

Thus fears about stigmatization appeared to be related to PHAs decisions to develop HIV/AIDS information/help networks that emphasized health care and service providers. However, fears about stigma and confidentiality also caused some to distrust local providers, leading them to acquire services from formal caregivers using self-protective strategies that they hoped would preserve their privacy, such as obtaining help at a distance, obtaining information/help anonymously or without disclosing ones illness, and seeking aid through intermediaries.

## **4.0 Discussion**

Consistent with Goffmans (1963) stigma management theory, fear of being stigmatized permeated many PHAs and family members HIV disclosure decisions, and hence the ways in which they formed networks. Specifically, they displayed behaviours that resembled Goffmans (1963) concept of information control and Chatmans (1996) concepts of secrecy and deception. Despite their use of protective strategies, however, participants in the present study did not think that there was no one available to help them – the first proposition in Chatman's (1996) model. This is because even when they chose to conceal their experiences with HIV/AIDS from virtually everyone in their private lives, all PHA participants, as well as many family members/friends, had ties with formal caregivers to whom they turned for HIV/AIDS-related information/help (see Table 1 for minimum network sizes). Thus, rather than being unable or unwilling to resolve a critical need as per Chatman, participants' lives became, as Goffman (1963) posited, 'divided up' between people who did not know the nature of participants' true struggles, and the smaller group of people upon whom they relied for aid (p.95). And as Goffman's (1963) posited, there appeared to be a special role for 'the wise', people who could be trusted because of their social or professional proximity to the disease. Additionally, rather than the wholesale avoidance of interpersonally-provided information/help described by Chatman's (1996) theory, participants displayed a range of self-protective behaviours, most of which did not completely cut them off from aid. Thus rather than having no networks at all, selective disclosure decisions helped to produce personal HIV/AIDS information/help networks that were relatively small, weighted towards formal caregivers, and largely devoid of ties to casual friends and acquaintances. Notably, these findings regarding casual friends and acquaintances stand in contrast to Granovetter's (1973) strength of weak ties theory, which suggests that 'weak ties' in social networks will be important sources of new information.

Because of the roles that health care and service providers played in participants' networks, it appears that the availability of such confidential services was a key factor in participants' acquisition of HIV/AIDS information/help despite their use of self-protective behaviours. Thus a potential explanation for the difference between Chatman's theory and the information behaviours of rural study participants might be found in national health policy differences. Chatman's research was conducted entirely in the United States, a country that lacks a national system for paying for health care (Jonas, 2003). In contrast, Canada has a nationally-funded health care system that guarantees citizens access to the services of physicians and hospitals based on need, rather than ability to pay (Canada. Department of Justice, 1985). Hence, although she did not report details on their health insurance status, Chatman's socio-economically marginalized study participants may have lacked access to health care providers - whereas no participants in this research were in this situation. Lack of health insurance, where it exists, might

have a powerful impact on an individual's perceptions regarding the availability of information/help. To help illuminate these issues, future consumer health information behaviour research may profit from attention to participants' access to services such as health care.

Findings from this research suggest that people with stigmatized illnesses may engage in a variety of self-protective strategies, resonating with scholarship that has challenged the idea that health information seeking is not an 'all or nothing phenomenon' (Loiselle, Lambert, & Dubois, 2006, p. 375). For instance, ill people tend to be selective in regard to the information sources that they use (Loiselle, Lambert, & Cooke, 2006; Williamson & Manaszewicz, 2002). These findings further suggest that theoretical frameworks regarding information behaviour may need to evolve in order to account for the complexity of self-protective behaviour. Additionally, these findings suggest that health information practice might benefit from a focus on stigma reduction as a strategy for improving access to HIV/AIDS information within communities.

## **5.0 Conclusion**

Experiences with HIV/AIDS-related stigma profoundly affected the ways in which rural PHAs and their family members formed, and interacted with, networks that provided them with HIV/AIDS-related information and help. Participants developed information/help networks in a manner consistent with Goffman's (1963) stigma management theory in their decisions to disclose selectively to others, to avoid the topic in conversation, to obtain information/help at a distance or to acquire information/help without disclosing their HIV status. However, in contrast to Chatman's (1996) theory, participants did not wholly avoid information from interpersonal sources nor believe that no one was available to help them. These findings suggest a need to further elucidate the complexity of interpersonal health information seeking and avoidance, particularly in the face of differential health service access and painful social consequences.

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## Footnotes

<sup>1</sup> The concept of 'information/help networks' was used in recognition of information behaviour research which has shown that information seekers may define 'information' as anything that 'helps' them (Dervin, 1992; Dervin & Fraser, 1985; Harris & Dewdney, 1994).

<sup>2</sup> Health care and service provider participants occupied formal caregiving roles vis-à-vis rural dwelling PHAs and friends/family members. These provider participants included: physicians; nurses; health social workers and psychologists; AIDS organization support workers; addictions workers; housing and income support workers; alternative health care providers; and individual members of several other health professions and community service sectors.

<sup>3</sup> Table 1 shows that mean network sizes were biased by outliers. Median network sizes were less affected by outliers, however. Thus median values are discussed in greater depth herein.

<sup>4</sup> At the time of the interviews, 5 PHA participants (15%) had been diagnosed for 2 years or less; 10 (29%) participants had been diagnosed for 3-9 years; 9 participants had been diagnosed for 10-14 years; and 10 (29%) had been diagnosed for 15 or more years.

<sup>5</sup> Friends of PHAs reported feelings of stigmatization less commonly than PHAs' family members.