Health information behavior in families: supportive or irritating?

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ABSTRACT

We report preliminary results of a mixed methods study of relationships between family-based information behavior and social support in chronic illness. Twenty-four participants (12 people with HIV/AIDS (PHAs) and 12 people with diabetes) completed surveys, visualized their family-based social support networks, and participated in in-depth, qualitative interviews. Findings revealed that our sample of people with diabetes had significantly larger family support networks than did PHAs. These differences seem linked to greater interpersonal constraints in talking about HIV/AIDS in families. Yet, the two groups did not differ in terms of perceived social support (PSS), frequency of collaborative information behavior (CIB), or use of information obtained collaboratively. However, a surprising relationship between CIB and PSS emerged among diabetics but not PHAs: the greater the frequency of CIB with family members, the less supportive they were perceived to be. This seems rooted in the prevalence of attempted influence and interference by diabetics' family members. Nevertheless, among both PHAs and diabetics, a significant overlap existed between receipt of informational and emotional support. Indeed, information sharing and emotional support could be the same in interactions such as questions of concern, goal attainment, and caring forwards. This study is among the first to document differences in social support and CIB among people with different diseases, pointing to the merit of information services and systems differentiated by disease. The overlap between informational and emotional support suggests the value of organizing, presenting, or rating health information according to emotional valence. Demonstrating that CIB may have negative effects challenges information scientists to reconsider whether receipt of information is always positive. Health information behavior in families therefore appears more complex than has been previously shown.

INTRODUCTION

Chronic diseases—the leading cause of death in the United States—are prolonged illnesses that can be controlled but not cured (National Center for Chronic Disease Prevention and Health Promotion, 2009). The onset of chronic illness is a significant, negative life event that presents challenges across numerous areas of a person's life (Stanton, Revenson, & Tennen, 2007). Family members of chronically ill people frequently provide them with various forms of social support in responding to these challenges. Family members may help patients cope with the stress of their illness (Thoits, 1995), provide them with informal health care (Barrett, 2004), and seek out information for them about their illness and care. In fact, family-based support may be a driver of health information seeking on the Internet, since half of all health-related Internet searches are conducted on behalf of others (Fox, 2009).

The long-term physical and mental health of people with chronic diseases such as HIV/AIDS and diabetes can be critically influenced by the social support available to them, including within their families. Social support is defined as the "social resources" that a person perceives as available or that he or she actually receives from non-professionals in their lives (Gottlieb & Bergen, 2010). Among people with diabetes, social support has been associated with improved mental health (e.g., Harkness et al., 2010) and better health outcomes, such as lower mortality (e.g., Zhang, Norris, Gregg, & Beckles, 2007). Similarly, among people with HIV/AIDS (PHAs), social support has been associated with better mental health (e.g., Reich, Lounsbury, Zaid-Muhammad, & Rapkin, 2010) and slower disease progression (e.g., Leserman et al., 2000).

Although the health benefits of social support are well documented, stronger health benefits may relate to *perceptions* of social support, rather than actual receipt of that support. "Perceived support" has been defined as "…the individual's beliefs about the availability of varied types of support from network associates" (Gottlieb & Bergen, 2010, p. 512). In contrast, "enacted support" is defined as "reports about the types of support received" (Gottlieb & Bergen, 2010, p. 512). Perceptions of support tend to be weakly associated with enacted support (Gottlieb

& Bergen, 2010). Accordingly, we examine both perceived and enacted support within families in this research.

Informational support and the social contexts of illness
Health psychologists have long conceptualized information sharing as a key form of social support—what they call "informational support." Informational support includes interpersonal behaviors such as giving information, advice, suggestions, or directives to another person (Uchino, 2004). Informational support is believed to be one of three key forms of social support, along with emotional and tangible/material support (House & Kahn, 1985).

Despite its posited helpfulness, family members may find it difficult to provide their loved ones with informational support. One reason for this is that laypeople may have insufficient knowledge to provide specific information about health conditions and their management (Kadushin, 1999; Neuling & Winefield, 1988). Moreover, the ability of friends and family members to provide illness-related information to their loved ones may vary by disease—in part because of the differing social dynamics of different diseases.

Diseases vary by prevalence in different groups. For example, they tend to cluster in certain communities and families based on factors such as genetics or common living conditions. For members of high-prevalence families or communities, such clustering may increase one's experience with a given disease, resulting in acquisition of greater disease-related knowledge (Matsagianis, 2008; Warren-Findlow & Prohaska, 2008). Additionally, stigmatizing attitudes towards a given illness may be related to both silence and lower knowledge levels about it in a community, thus affecting one's ability to acquire information about a health condition without seeking it out (Veinot & Harris, 2011). People with stigmatized conditions such as HIV/AIDS may disclose their illness selectively, further limiting the number of people in their families or communities from whom they might receive informational support (Veinot, 2010). This would also reduce the ability of others to learn from the patient's experience of the disease.

Consequently, people with different diseases may have varying experiences of informational support from members of their families, depending on the prevalence and stigmatization of their particular condition. Yet, previous research has rarely compared the informational support experiences of people whose illnesses differ according to such factors. Therefore, we compared the informational support perceived and received by people with diabetes and HIV/AIDS. These two diseases were chosen as the focus of this research because they offer significant contrasts along the aforementioned social dimensions. Diabetes is more prevalent in the United States than HIV/AIDS: 25.8 million Americans have diabetes, whereas 1.1 million have HIV/AIDS (Centers for Disease Control and Prevention, 2010, 2011). Furthermore, unlike HIV/AIDS, diabetes has

genetic origins (Jin & Patti, 2009), thereby facilitating its clustering within families. Additionally, HIV/AIDS is one of the most severely stigmatized illnesses (Kaplan, Scheyett, & Golin, 2005) and thus is arguably more stigmatized than diabetes. Therefore, we compared levels of perceived and enacted social support, including informational support, in a sample of diabetics and PHAs. Based on these differences in prevalence and stigmatization, we hypothesized that:

H1: People with diabetes will have significantly larger family-based networks for enacted social support, including larger family networks for informational support.

H2: People with diabetes will report significantly more perceived social support (PSS) from their family members than PHAs.

Informational and emotional support
Informational support and emotional support are generally conceptualized as distinct (Harlow & Cantor, 1995). However, they often occur together in interactions and can be difficult to separate (Berkman & Glass, 2000). There may be a strong association between receipt of informational and emotional support in close relationships (Dunkel-Schetter, Folkman, & Lazarus, 1987; Schaefer, Coyne, & Lazarus, 1981). Schaefer (1981) also argues that receiving information can be experienced as emotionally supportive because it can "signal caring" (p. 386).

Although previous research has questioned the distinction between informational and emotional support, it has not considered whether the relationship between them differs across diseases with different social implications. For example, information sharing about a stigmatized illness might be perceived to communicate interpersonal acceptance of PHAs and may, therefore, be perceived as emotionally supportive. Nevertheless, research suggests that health information is an important resource for both PHAs (Hogan & Palmer, 2005) and people with diabetes (Wagner, Baker, Bundorf, & Singer, 2004). Receiving information from other people also provides emotional benefits to ill people, regardless of illness, including helping them maintain hope (Salander, 2002), keep a positive morale (Schaefer et al., 1981), and reduce illness-related stress (Wortman & Dunkel-Schetter, 1987). Accordingly, we hypothesized that:

H3: Among both diabetics and PHAs, enacted informational support from family members will be significantly and positively associated with their receipt of emotional support from these relatives.

From "informational support" to "collaborative information behavior"
While health psychologists have studied informational support in some depth, their focus has remained on what information science researchers would call "information sharing." Consequently, they have rarely addressed the full range of collaborative information behaviors that may be present in interactions. In contrast, information science

researchers have defined "collaborative information behavior" (CIB) as "an activity where two or more actors communicate to identify information for accomplishing a task or solving a problem" (Talja & Hansen, 2006, p. 114). Talja and Hansen (2006) and Hertzum (2008) further argue that CIB includes both collaborative information seeking to acquire new information and sharing of information that has already been acquired.

We extend the previous literature by documenting the frequency of CIB's full range (i.e., both acquisition and sharing) in families and comparing its frequency among PHAs and diabetics. Because diabetes is heritable, we hypothesized that people with this disease would be more likely to have family members who shared their illness, thus leading to more CIB. So, we hypothesized that:

H4: People with diabetes will report significantly more CIB with their family members than PHAs.

Previous qualitative research has shown that CIB in the context of HIV/AIDS may be regarded as supportive (Veinot, 2009). However, we know little about the magnitude or potential statistical significance of this relationship. Thus, we extend prior research by statistically testing the following hypothesis:

H5: Among both diabetics and PHAs, CIB will be positively and significantly associated with PSS.

Information use and social support
With its sole focus on informational support, previous social support research has also largely ignored patterns of information use. However, the usefulness of information obtained collaboratively with family members might also vary by disease, based on the knowledge levels and disease-related experiences of these family members. Because of the higher prevalence of diabetes, we hypothesized that:

H6: People with diabetes will report significantly more use of information obtained collaboratively with their family members than PHAs.

Additionally, actual use of information obtained collaboratively might affect the extent to which its acquisition is viewed as supportive. For example, information that one uses to care for oneself or to maintain hope may be perceived as more supportive than information that is not used. Similarly, information that cannot be used because it is repetitive or irrelevant to one's situation may be perceived as less supportive. Previous research, however, has not considered whether information use may be related to perceptions of social support. Hence, we tested the following hypothesis:

H7: Among both diabetics and PHAs, use of information obtained collaboratively will be positively and significantly related to PSS.

Explaining relationships between variables
We also sought to explore the reasons for observed relationships between variables. Consequently, we posed the following research question when observed statistical relationships were significant:

RQ1. Why do study variables have these relationships?

METHODS
We report preliminary results from a longitudinal, mixed methods study of the role of information in family-based coping, care, and support in relation to chronic illnesses. Results presented here are from time 1 data collection conducted with the first 24 recruits. Quantitative survey data were initially used to examine statistical relationships between variables. Next, concurrently gathered qualitative interview data were used to explore potential reasons for statistically significant relationships between variables.

Participants
We recruited 12 diabetics and 12 PHAs from health clinics and community-based, disease-specific agencies in a Midwestern state. Clinic participants were approached consecutively in the clinic before or after their medical appointments, based on staff-determined eligibility. Due to the goals of this research, potential participants were screened based on their willingness to discuss their family relationships and to recruit members of their families into the study. In recognition of the diversity of family forms in the US (Coleman & Ganong, 2004), participants were asked to define their families for themselves, resulting in the inclusion of diverse people such as current and former spouses/partners; parents and children; siblings; aunts and uncles; cousins; stepfamily members; in-laws; and close friends (or "chosen family," Weston, 1991).

Because African Americans and Latinos experience disproportionate burdens of both HIV/AIDS and diabetes (Centers for Disease Control and Prevention, 2010, 2011), clinic recruitment times were selected in consultation with staff so as to provide the greatest possible racial diversity among participants, as well as representation of men and women. Community-based agencies recruited their clients, with effort focused on ensuring racial and gender diversity.

Procedures
Each recruit participated in a three-part meeting lasting between one and two-and-a-half hours in total. First, participants completed a paper survey that gathered data regarding patient demographics, PSS, and information behavior. Second, participants completed an in-depth, semi-structured interview (Johnson, 2002) about their family's experiences of managing HIV/AIDS or diabetes. Third, participants visualized their family support networks using procedures developed by Marin and Hampton (2007) to reduce response burden.

Variables
We measured *perceived social support (PSS)* using questions from the "family" factor of the Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet, & Farley, 1988), as well as four new questions about disease-specific support (Cronbach's alpha = .92). The questions included items such as "My family really tries to

help me," and "I can talk about my problems with my family." Agreement with these statements was measured on a five-point Likert scale. *Enacted social support* was measured by support network size, including sub-networks for information, emotional support, or tangible aid.

Based on previous qualitative research (e.g., Veinot, 2009, 2010), we created a 13-item Likert-scale-based measure of frequency of *collaborative information behavior (CIB)* in the past four months. Examples of questions included, "A family member gave me [HIV/AIDS or diabetes] information without me asking for it," and "I looked on the Internet with a family member." The collaborative information behavior frequency scale had good internal reliability (Cronbach's alpha = .90). Similarly, drawing from previous research (Fox, 2009), we created a 16-item *information use* scale to measure the frequency with which participants used information that they had obtained collaboratively in the past four months. The scale included items such as using information to "Feel more in control of my [HIV/AIDS or diabetes]," and "Make [HIV/AIDS or diabetes]-related treatment or self-care decisions." This scale also had good internal reliability (Cronbach's alpha = .94).

Data analysis
For survey data, we compiled descriptive statistics and then conducted *t*-tests and a Mann-Whitney *U* test to examine differences in study variables among people with diabetes and HIV/AIDS. Pearson product-moment coefficients and chi-square tests of independence were used to examine bivariate associations between study variables. These statistical calculations were completed using SPSS statistical software.

Qualitative interviews were audio-taped and transcribed to facilitate analysis. To further investigate statistically significant relationships, we categorized and open coded (Strauss & Corbin, 1998) interviews for examples of 1) choices affecting participants' support network size; 2) statements concerning the relationship between information behavior and emotional support; and 3) family-based CIB. We then compiled a profile of each participant using these coded data in order to understand each case in depth. Following this, we coded participant profiles selectively (Strauss & Corbin, 1998) to generate explanations for statistically significant relationships. In so doing, we sought common themes across participants for whom statistical relationships (direction, magnitude) were similar. We also quantitized our qualitative data to identify frequencies of themes among participants. Qualitative analysis was conducted with NVivo qualitative data analysis software.

RESULTS

Participant demographics
Of the 24 participants, 19 (79%) were male and 16 were white (66%) (see Table 1). Of the white participants, two identified their ethnicity as either Hispanic or Arab. Twenty participants (83%) had some form of education beyond high

school. The majority (63%) were unemployed, retired, or disabled. The mean age of diabetics was 62.42, while it was 47.17 among PHAs—a difference that was statistically significant ($t(22)=2.88$, $p<.01$). The mean number of years since diagnosis was 16.53 for people with diabetes and 15.12 for PHAs; this difference was not statistically significant ($t(22)=.35$, $p=.35$).

	Diabetes	HIV	Total
Gender			
Male	8	11	19
Female	4	1	5
Race			
Black	4	3	7
White	8	8	16
Other	1	1	2
Ethnicity			
Hispanic or Arab	1	1	2
Education			
Less than high school	0	2	2
High school graduate or equivalent	2	0	2
Beyond high school	10	10	20
Primary employment status			
Employed	4	3	7
Student	0	2	2
Unemployed	2	5	7
Retired or Disabled	6	2	8

Table 1. Participant demographics

Nine HIV/AIDS patients (75%) and three diabetes patients (25%) had a history of mental health issues (most commonly depression) and/or substance abuse. A chi-square test of independence showed that diagnosis was dependent on mental health and/or substance abuse problems (χ^2 (1, N=24) = 6.00, $p < .05$, $phi = .50$).

Ten of twelve (83%) of the participants with diabetes rated their physical health as good to excellent, as did 100% of PHAs. A chi-square test of independence indicated that diagnosis was independent of self-rated health (χ^2 (3, N=24) = 4.22, $p = .239$, $phi = .42$).

A larger proportion of diabetics had at least one other person in their family with their illness (8/12 = 67%) than the PHAs (2/12 = 17%). A chi-square test of independence showed that diagnosis and having a family member with the same disease were dependent upon one another (χ^2 (1, N=24) = 8.71, $p < .01$, $phi = .60$).

Differences in social support by disease

As Table 2 shows, the mean family support network size for people with diabetes was 9.75 people, whereas it was 5.50 people for PHAs. In support of hypothesis 1, this difference was statistically significant ($t(22)=2.43$, $p=.024$). People with diabetes also reported receiving informational support from a larger number of network members ($M = 3.17$ vs. 1.58), but this difference was only marginally significant ($t(22)=1.85$, $p=.078$).

People with diabetes had higher mean PSS scores than PHAs ($M = 4.25$ vs. 3.97). However, in opposition to hypothesis 2, this difference was not statistically significant ($t(22)=.97$, $p=.34$).

	Diabetes	HIV	Both
Total support network size (mean)	9.75	5.50	7.63
Informational support network size (mean)	3.17	1.58	2.38

Table 2. Size of enacted family support networks

Explaining differences in support network size

One potential explanation for the significantly greater number of support network members among diabetics versus PHAs was previously described. Specifically, diabetics were significantly more likely to have other people with their disease in their families than PHAs. Interview data revealed that people with diabetes in the same family frequently shared emotional and informational support with one another, often learning from one another about diabetes management and potential complications of the disease. As this diabetic woman explained, she shared her experience of eye-related complications with her relative as they engaged in joint information seeking:

"...the loss of sight in my right eye...that's because of the diabetes... we were talking because she's having some eye problems now...we were...looking up different things ...so that hopefully she won't develop the same thing."

Another potential explanation is found in differing family relationship dynamics. As Table 3 shows, people with diabetes had larger numbers of "other immediate family" and "other people" (primarily in-laws) in their support networks. A Mann-Whitney *U* test revealed significantly more diabetes patients than HIV/AIDS patients had immediate family ties ($U = 30.50$, $z = -2.43$, $p < 0.05$) and ties of type "Other" ($U = 33.00$, $z = -2.33$, $p < 0.05$). Hence, the lesser involvement of biological family members and in-laws may contribute to PHAs' smaller support networks.

Next, we examined interview data to determine whether PHAs' relationships with biological family members and/or in-laws were different from those of people with diabetes. Analyses revealed that more PHAs than diabetics reported significant *interpersonal constraints* in speaking with their family members about their disease (9/12 (75%) of PHAs vs. 1/12 (8%) of diabetics). One constraint concerns

different disclosure patterns. While only one diabetic patient said that she did not tell a specific relative about her illness, four PHAs chose not to tell one or more relatives. Participants provided several reasons for their decisions to avoid disclosing their HIV status to family members, including not wanting to worry them and their stigmatizing attitudes towards HIV/AIDS and/or gay people. As this PHA explained,

"...none of my blood family knows. I...prefer to keep it that way...because when I came out to my mom, one of the big things that she was concerned about was that I would get HIV. And I really don't want to put her through that."

	Diabetes		HIV	
	n	%	*n*	%
Spouse/partner	8	67	6	50
Other immediate family	12	100	7	58
Other extended family	3	25	1	8
Friend	7	58	8	67
Other	10	83	5	42

Table 3. Number of participants naming this type of person as a member of their support network

Constraints also arose from troubled family relationships, marked by painful histories or family members' negative reactions to participants' illness. For example, three PHAs were currently estranged from biological family members who knew of their HIV status. This PHA described HIV-related humiliation by his brother:

"...I have been, like, the punching bag and the point of jokes... in their home, I was the easy target to lambast..."

Additionally, two PHAs indicated that their family members knew about their disease, but never spoke of it:

"...he knows I have HIV. He never asked me about it ...I think he's disappointed..."

"...I don't talk about it to them, or what's going on with it."

These experiences of estranged family relationships and disease-related silence were not reported by diabetic participants. In contrast, people with diabetes were more likely to report unwanted involvement of their family members in their health, as described below.

A final potential reason for the significant difference in network size may be the aforementioned higher rate of mental health and/or substance abuse problems among PHAs. Such problems might affect relationships with both family members and close friends. Thus, while one diabetic patient (a veteran) said that he limited his social contacts because of post-traumatic stress disorder (PTSD), three PHAs said that they had done so for mental health or addiction-related reasons. In particular, PHAs who were recovering from substance abuse cut themselves off from

others whom they thought might undermine their recovery. For example, this PHA said that his circle of friends is, *"Very slight, a few people in recovery now...."*

The information-emotional support relationship
For hypothesis 3, we examined the relationship between enacted informational support and enacted emotional support for *each individual* in the patient's social network. That is, we examined whether a person who provides informational support is more likely to provide emotional support (or vice versa). In support of hypothesis 3, a chi-square test for independence (with Yates Continuity Correction) indicated a significant association for both diabetes, χ^2 (1, N=117) = 25.42, $p < .001$, $phi = .48$, and HIV/AIDS, χ^2 (1, N=66) = 12.20, $p < .001$, $phi = .47$. Hence, the magnitude of the association between informational and emotional support was roughly equivalent among people with either disease.

Explaining the information-emotional support connection
Interview data suggest that the significant overlap between network members' provision of informational and emotional support may relate to the positive emotional valence of information sharing in some interactions. One such interaction might be called the *question of concern*, involving both interpersonal information sharing about an illness and feelings of being emotionally supported. As this diabetic patient noted,

"...in our circle...of friends...I'm the only one with diabetes...they want to learn just so they can know what to look out for ... and then emotionally, they ask me, 'Well... you been feeling all right with, how's the diabetes been treating you? Have you been maintaining your levels?'"

Notably, when people who knew of their illness did not pose *questions of concern*, participants viewed them as emotionally unsupportive—a painful experience noted by several PHAs. Another informative-emotionally supportive type of interaction involved aid for patients who were attempting to change their lifestyles. In particular, patients appreciated it when their family members helped them with personal health *goal attainment*. For example, this diabetic got information from his family members to help him avoid going on insulin, which also made him feel cared for:

"...it's not only helpful because of the information, but it's helpful because of the support that I'm getting from them. It's like stroking my ego..." (laughs)

Additionally, the act of sharing or forwarding unsolicited illness-related information was often seen as caring, particularly among PHAs. *Caring forwards*, often related to HIV treatment, were widely appreciated—even though this information could rarely be put to use due to poor quality or personal irrelevance. For example, this PHA said, although his father sent him information that he took "with a grain of salt," it was emotionally significant for him.

"...I thought, 'Yeah, my dad really does love me enough that he's looking at all of these alternative therapies.'"

Or as this PHA explained, his chosen family members sent him information about medical advances in HIV treatment in order to *"...give me hope. And I know that's what they're trying to do."* Again, this was something he appreciated even though he could not use the information.

Similarly, PHAs also felt supported when family members watched television programs with HIV/AIDS-related content along with them. For instance, this PHA said that when she and her husband watched a show together, *"...it...makes me feel like somebody else cared."*

However, two PHAs did not like it when family members sent unsolicited information about the disease, using descriptors such as "pushy" to describe their behavior. Their complaints revolved around the frequency of information sharing. As this PHA complained, her sister's forwards had the unwanted effect of *"...like every other day or every day, reminding me about my HIV/AIDS."*

Nevertheless, in the context of the aforementioned *interpersonal constraints* in communicating about HIV/AIDS, intermittent *caring forwards* appeared to be a powerful communication of acceptance and consideration.

Collaborative information behavior
We examined our fourth hypothesis: people with diabetes would report significantly more CIB with their family members than people with HIV/AIDS. Despite the fact that people with diabetes had higher mean CIB scores than people with HIV/AIDS ($M = 1.04$ vs. .89), this difference was not statistically significant ($t(22)=.43$, $p=.67$). Hypothesis 4 was, therefore, unsupported.

Following this, in order to test hypothesis 5, the relationship between CIB and PSS was investigated using Pearson product-moment coefficient. For diabetes patients, a negative correlation existed between the two variables, $r=-.59$, $N=12$, $p<.05$. For HIV/AIDS patients, there was a positive correlation between the two variables, although this relationship was marginally significant, $r=.58$, $N=12$, $p=.05$. Accordingly, hypothesis 5 was not supported. However, the unanticipated negative relationship warranted explanation.

Explaining the CIB-PSS relationship
Qualitative interview data revealed that people with diabetes and HIV/AIDS had different experiences of family support. People with diabetes reported considerably more negative information-sharing experiences—usually related to *attempted influence*. Specifically, eight of twelve diabetic participants (67%) described incidents in which family members used diabetes information to question or challenge their food choices. Such incidents were often described as unwelcome, invasive, or irritating. For example, this man said that his sister reacted to his food choices as follows:

"...first thing she screams is, 'How's your diabetes? Have you taken your medication?'... every once in a while it's a little too much caring, and it can get really irritating."

In these exchanges, people with diabetes often felt criticized. As one diabetic woman explained, she had learned to *"accept their criticism."* These interactions also manifested power struggles between relatives in which diabetic patients felt that their autonomy was not respected. As this male diabetic patient said, his wife

"...holler[s] at me if I pick up a donut ... I don't like to be told what to do... if she tells me 'no,' I'll eat two of them."

Perhaps partly because HIV/AIDS is managed less through behaviors like diet and exercise than is diabetes, PHAs did not describe such experiences of *attempted influence*.

Three diabetic participants (25%) also described unwanted *interference* from their family members in their relationships with physicians or others. With regard to the former, diabetes patients described annoyance at situations in which a loved one told their physician about symptoms that they did not want shared or requested follow-up that they did not want to have. As this diabetic man explained,

"She brings up things about my health care that concern her that don't concern me...at times it feels interfering."

Such *interference* was not described by most PHAs. Instead, as mentioned previously, PHAs described more *interpersonal constraints* in relation to family involvement in their management of HIV/AIDS.

Information use

To test hypothesis 6, we examined whether people with diabetes reported significantly more use of information obtained collaboratively with their family than people with HIV/AIDS. Although diabetics scored higher on this scale ($M = 1.93$ vs. 1.65), this difference was not statistically significant ($t(22)=.59$, $p=.56$).

We examined our seventh hypothesis, which posited that information use scores would be positively associated with PSS. This hypothesis was not supported, since there was no significant correlation between the two variables for diabetes ($r=-.23$, $N=12$, $p=.47$) and a marginally significant relationship for HIV/AIDS ($r=.54$, $N=12$, $p=.07$).

DISCUSSION

This paper reports preliminary results of a mixed methods study of relationships between family-based information behavior and social support in relation to two chronic illnesses. Our initial findings revealed that people with diabetes had significantly larger family support networks than their PHA counterparts. These differences appeared to be related to greater *interpersonal constraints* in talking about HIV in families. Despite this, these two groups did not differ in terms of PSS and frequency of CIB or use of information obtained collaboratively. However, preliminary findings revealed a surprising relationship between CIB and PSS among diabetics, but not among PHAs. Specifically, in this sample, the greater the frequency of CIB with family members, the less supportive they were perceived to be. This unexpected finding seems rooted in the prevalence of

experiences of *attempted influence* and *interference* among diabetics. Nevertheless, among both PHAs and diabetics, a significant overlap existed between receipt of informational and emotional support from individual network members. This may be linked to several types of interactions in which information sharing and emotional support overlapped: *questions of concern*, help in *goal attainment*, and *caring forwards*.

This study is among the first to systematically examine differences in social support and CIB among people with different diseases. In drawing explicit comparisons between similarly recruited people with diabetes and HIV/AIDS, this study highlights factors that may exert influences on health information behavior within families. Specifically, this study suggests that lower disease prevalence and higher stigma may be linked to greater interpersonal constraints in talking about a disease, as well as smaller support networks. However, there were no significant differences in participants' perceptions of family support or in the amount of CIB in which they engaged, suggesting that while their networks are smaller, PHAs do have network members who provide them with needed support. These findings warrant further investigation with a larger sample in order to determine their generalizability.

These preliminary findings suggest the value of providing information systems and services explicitly targeted at both chronically ill people and their loved ones. However, findings also suggest the potential merit of differentiated strategies based on the social dynamics of diseases. Such an approach, while common in health-consumer-driven non-profit organizations, is less common in general information services, such as libraries or broad health websites. Specifically, these results suggest that for less prevalent, more stigmatized diseases, there may be a need for greater outreach to connect to patients and their families. There may also be a need for efforts to promote wider dialogue and improved attitudes about such diseases, including among family members who may not know of their loved one's illness. Additionally, information systems and services might focus on expanding the social support networks of people with stigmatized illnesses to reduce the potential burden of support on their small networks. In contrast, the ubiquity of information about less stigmatized, more prevalent diseases might necessitate efforts to increase the information literacy and management skills of people with diabetes and their families, rather than promoting information sharing in the first place.

This study also found that participants with both HIV/AIDS and diabetes tended to receive emotional and informational support from the same people, which is in accordance with previous research showing strong associations between receipt of informational and emotional support in close relationships (Dunkel-Schetter et al., 1987; Schaefer et al., 1981). This may be because family relationships are often perceived as emotionally close, since close relationships often involve provision of more forms of support than do

more distant relationships (Gottlieb & Bergen, 2010). Additionally, as described in the introduction, emotional and informational support may occur simultaneously in interactions. However, the present research showed that informational and emotional support may, in fact, be the same thing in certain types of interactions, such as *questions of concern*, *goal attainment*, and *caring forwards*. In these interactions, information provision was as much about expressing or receiving interpersonal care as it was about cognitive content. Accordingly, as noted by Harris and Dewdney (1994), information that was of poor quality or irrelevant was still appreciated. Yet, the relational significance of information sharing is rarely acknowledged in the design and delivery of information systems and services. To better support family members in sharing information in caring interactions, information might be helpfully organized, presented, or rated according to emotional valence. For example, tagging or rating systems could highlight relationally significant dimensions such as "hopefulness" or "empowerment." Additionally, human information intermediaries could assess potential relational uses of health information and thus connect people with information that is relevant in terms of both content and relational context.

The emotional significance of CIB in intimate relationships underscores our surprising finding regarding the negative relationship between CIB and PSS. The discovery that *attempted influence* and *interference* are possible explanations does, however, find some resonance in the health psychology literature. Briefly, researchers have shown that attempts at informational support within families can backfire, resulting in negative feelings or interactions. For example, women with diabetes have reported that their family members may misunderstand the information that they need and deliver it in unhelpful ways (Carter-Edwards, Skelly, Cagle, & Appel, 2004). Additionally, as we demonstrated, information sharing in families may be aligned with behaviors intended to exert health-related social control upon another person—"interpersonal interactions that involve influence, regulation, and constraint of health practices" (Lewis & Butterfield, 2007, p. 299). Health-related social control, common in close relationships, may involve discussing health information, as well as its repetition through encouragements, suggestions, directives, warnings, requests, or reminders (Tucker & Mueller, 2000). While potentially improving health-related behaviors, health-related social control has been linked with emotional distress, depression, lowered self-esteem, and relationship strain (e.g., Fekete, Geaghan, & Druley, 2009; Stephens et al., 2009). Our results thus find support in prior research about the potentially negative psychosocial effects of attempts to use information to influence loved ones' health behavior—in this case, largely around eating.

Demonstrating that CIB may have negative effects challenges information science researchers to reconsider whether receipt of information is always positive. Indeed, "information" is typically perceived as good and helpful, as evidenced by the body of information science research that conceptualizes information as a type of "help" (Dervin, 1992; Harris & Dewdney, 1994) or "resource" (McCreadie & Rice, 1999). In contrast, our research suggests that information acquisition and sharing in families can also irritate and demoralize people. This suggests the merit of replacing the assumption of information's helpfulness with a less prescriptive understanding of information and its consequences. An interactional view of information behavior, rooted in sociology's interactionist paradigm, offers an alternative that more aptly reflects the preliminary findings reported here. An interactional approach defines information as a "shared meaning" that is constituted in human action and interaction (Veinot & Williams, 2011). In this view, the significance of information behavior emerges from its relational and interactional context. Understanding this might allow providers of information systems and services to examine potential unintended effects of programs and to take steps to ameliorate them. For example, family members and friends of chronically ill people could be coached or trained in skills for providing information to their loved ones with an emphasis on offering it in a helpful, non-judgmental way.

Several limitations of this study should be noted. First, this study involved a small, non-randomly selected sample of only 24 participants, and thus results of this study cannot be generalized to a wider population. Second, the small sample size means that we did not possess sufficient statistical power to conduct multivariate statistical tests, notably multivariate regressions. As this study proceeds, we aim to enlarge our sample to permit use of such multivariate statistical techniques, thus allowing us to control for demographic factors like age. And finally, because this paper is based on cross-sectional data, it is impossible to determine historical precedence of events. Our future research, in adopting a longitudinal design, will aim to address this limitation.

CONCLUSION

We examined the connections between family-based information behavior and social support among people with diabetes and HIV/AIDS. We found that for both groups, informational and emotional support overlapped by source and that provision of information could actually be a form of emotional support. We also demonstrated differences between the two groups, notably with regard to support network size and the relationship between CIB and PSS. We generated several themes that explained these findings focused on stigmatization and health-related social control. These findings revealed that health information behavior in families is more complicated than has been previously shown. More study is needed of when and why such behavior may be experienced as helpful or irritating.

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